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Mosaics, Ambiguity and Quest:  
Constructing Stories of Spirituality with  
People with Expressive Aphasia

by

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## Abstract

Despite the current emphasis on person centred, holistic care in health, the concept of spirituality has been discussed very little in the field of speech and language therapy (SLT). The nursing spirituality literature has proliferated in the last twenty years but, by contrast, very few SLT studies exist which mention the spiritual needs of patients with communication problems and how they express them.

Individuals experiencing severe, life-changing events, such as a stroke, may need to engage with and discuss their spiritual needs, in order to make sense of what has happened to them. The aim of this study was to discover what it is like to express spiritual issues when one has an acquired communication impairment (aphasia). I also wanted to discover what it is like to be a healthcare professional working with people with communication impairment expressing their spirituality.

I used a phenomenological approach in order to interview eight people with aphasia about their spirituality. Participants with aphasia used a variety of strategies to express these ideas, which included employing non-verbal communication techniques, such as gesture, writing key words, intonation and artefacts. I also interviewed five members of the multidisciplinary stroke team (MDT) about what it is like to work holistically with people with aphasia.

Each interview resulted in a participant story. People with aphasia talked about religious themes, such as visions and prayer, but also non-religious life meaning-makers, such as gardening and art. MDT members discussed themes such as spirituality as part of their remit and giving the patient time to communicate. The stories were then explored through the interpretive lens of some concepts propounded by Merleau-Ponty (2002), namely ambiguity, lived body, language and thought, and wonder. Frank's illness narratives (chaos, restitution and quest) were also considered in order to analyse the participants' stroke journey in relation to expressing spirituality.

People with aphasia can and do discuss their spiritual concerns, particularly when they are entering a quest phase of their illness narrative. They employ many non-verbal mosaics in order to convey spiritual issues, and are helped by the listener employing a phenomenological attitude of openness and attentiveness. Healthcare professionals expressed their willingness to listen to their patients' spiritual stories, in the interests of holistic practice. Being able to express spiritual needs can enhance wellbeing, help foster therapeutic rapport, and enable people to engage more fully in the rehabilitation process.

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“God be to the  
glory”  
(Joel)

Many things have happened during the writing of this thesis, not least the deaths of a very dear friend and godfather to my son, and of my father.

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## Prologue: In the beginning.....

Stories and the telling and retelling of stories are integral to the human condition (Frank, 2010, p 3). In childhood, we listen to stories in order to be soothed or frightened, calmed or prepared for what might lie ahead. Fairy stories are notoriously dark and full of monsters, preparing children for possible dangers of life, or perhaps taking the fear away by naming it. As children, we share the storytelling process with adults we trust, and in turn we learn to tell stories ourselves. Reading to our children can continue long after they themselves have acquired the requisite reading skills; it is a joint enterprise, a pleasurable sharing of attention and of experience.

Stories can teach. From the mythical stories of creation to the parables of Jesus, sacred texts attempt to explain the inexplicable, and provide guidance in an accessible way.

Stories can provide a framework on which we hang our experience. Joyful experiences - weddings, births, celebrations of all types - are told and retold until they become part of our life narrative. Traumatic experience, too, must be formed into narrative, in order for it to be assimilated, made sense of. After serious illness, the patient is often heard recounting the events - operations, near-misses, treatment by nurses. It is as if, in the “shipwreck” of catastrophe (Frank, 2013), we make sense of our situation by creating a story, a story to be told and retold until we have managed to escape the wreckage and have headed for, or attained, dry land.

Healthcare professionals take a case history (*une histoire* – a story) in order to hear their patient’s story of illness or disability. Done well, a case history becomes a journeying with the patient, accompanying them as they travel through, and make sense of, their story (Kvale and Brinkmann, 2009). Frank tells of a surgeon who wrote to him and divulged that he had “finally learn[ed] the difference between taking a history and hearing a patient’s story” (Frank, 2013, p 58). Stories of illness are messy and sometimes incoherent, non-sequential and often seemingly inconsequential. Facts and events expressed in the narrative may not on the surface contribute to clinical diagnosis; it may be argued that these narratives cloud the clinician’s ability to reason clinically and to differentially diagnose. On the contrary, however, hearing a person’s illness story tells us what the experience of that illness is from their unique perspective (Carel, 2008, p 10), and therefore arguably adds richness and clarity to the diagnosis, and more importantly, to the management of the illness experience. If clinicians are able to bracket off their presuppositions of what illness and disability are and mean, they are more likely to hear and be open to what *this* particular illness or disability means to *this* particular client. As Elwyn and Gwyn (1999, p 186) state, if, as clinicians, we “listen carefully to

the stories we hear”, this will in turn open up a “new way of listening to the signals which so often pass unnoticed.”

So, if stories are integral to our lives, helping us face fear, celebrate the important, narrate illness experiences and survive calamity, what of those for whom storytelling is difficult? What of those whose verbal skills deny them the opportunity to tell their stories?

Imagine you have survived a catastrophic event. Your life was in danger but you pulled through. Instead of starting to formulate your recovery story, your survival narrative, language has deserted you. Despite being able to think and reason, to problem-solve and attend, to remember and to understand, you have lost the power of expressive language. Vocabulary and syntax are gone; you are reliant on some residual speech and non-verbal skills, such as drawing, gesture and facial expression. How do you create your story?

Now imagine what you might want to include in this survival story, which has now become so problematic to formulate into words. What has happened to me? Why me? Why did I survive? Is this part of some bigger plan? What meaning can this have for me? How do I adjust to being this new “me”?

This is the scenario that can affect people with aphasia following stroke. The catastrophic event (stroke) has deprived them of their verbal skills, whilst leaving the majority of their other cognitive skills intact. How do people with aphasia create their survival narrative? How do they grapple with existential questions which can arise following life-threatening illness? How do they tell their spiritual stories?

This thesis describes how eight people with aphasia expressed their spiritual stories to me, and how members of the multidisciplinary stroke team talked about their experiences of listening to stories of spirituality in their work.

## Chapter 1: The Background Story

**“are you able to see and acknowledge the person beyond even the most overwhelming of symptoms?”**

**(Chochinov, 2006, p 94)**

Part of my role as a practising speech and language therapist working with people with aphasia was to facilitate functional communication. Neuroplasticity and subsidence of oedema and other temporary damage demand that clinicians work to improve the language abilities of people with aphasia at an impairment level (WHO, 2001), but an equally vital component of intervention is to ensure that clients are able to express their basic needs in a compensatory fashion, via whatever modality may be viable, not just speech, in order to enable full activity and participation, and enhance wellbeing (WHO, 2001). Lessening frustration by enabling clients to, for example, ask for a drink or to express that they were in pain was a worthy goal. However, I began to recognise, too, that less concrete or more nebulous concepts were not so conducive to a picture chart or iPad application. Yet it seemed as important to be able to ask ‘why did this happen to me?’ as to ask for something to eat. I knew from my own experience how illness and bereavement can evince existential questions, and the need to express them. As a Christian, I questioned God and priests about why my sister had died so young. She herself had written poetry, in an effort to understand what was happening to her:

“Without me come words  
Words, pictures, messages which  
Give this suffering  
Life” (Alexandra Crossland, 1995)

Voicing these intimate parts of our life’s narrative help us make sense of them. For those with intact language skills, this is difficult enough, but what of those for whom language has become problematic, elusive? Is it possible for healthcare professionals, such as speech and language therapists, to help people with aphasia express more than just their basic needs? What follows in this chapter are some definitions of the topics under discussion and a review of the current literature relating to speech and language therapy and spirituality.

## 1.1 Aphasia

Aphasia<sup>1</sup> is the disruption to receptive and/or expressive language, following damage to the language areas of the brain, most notably as a result of cerebrovascular accident or stroke. It is estimated that 33% of people who have a stroke will present with aphasia (The Stroke Association), and that there are approximately 350 000 people currently living with aphasia in the United Kingdom. Aphasia may affect the individual's ability to express language verbally or in written form, or their ability to understand spoken and written language. In severe cases of so-called global aphasia, both receptive and expressive abilities may be impaired.

Language function is normally considered to be located in the dominant (usually left) hemisphere of the brain. Although the locationist view of individual brain functions prevalent in the nineteenth century is now tempered by increased empirical knowledge of cortical functioning (such as via the use of positron emission tomography) and the current understanding that "every identifiable human activity is actually served at some level by both hemispheres" (McGilchrist, 2010, p 1), it is nevertheless a truism that damage through stroke to certain parts of the cortex does result in aphasia of some kind. In general terms, haemorrhagic or ischaemic damage to the frontotemporal region known as Broca's area usually results in an expressive-type aphasia, where the individual is able to understand spoken and written language but has difficulty in expression. Individuals who fall into this category may present with word retrieval difficulties and output which is telegraphic in nature, and lacking in syntactic complexity. This type of aphasia has been referred to variously over the years as expressive, Broca's and motor. Conversely, those people who suffer damage to the cortex more posteriorly, in the temporoparietal area in a region known as Wernicke's area are more likely to present with difficulties in understanding what is said to them, whilst at the same time being able to produce fluent, syntactically correct output, albeit output often lacking in meaning.

This locationist view became unpopular with aphasiologists and speech and language therapists in the early 1980s, however, as site of lesion did not seem to equate fully with a patient's functioning. Two patients with similar lesions could present quite differently in terms of the detail of their language deficit. Hence a conceptual model – the cognitive neuropsychological model of language processing (Morton and Patterson, 1980) - was propounded. This model (a diagrammatic representation of which is supplied in Appendix I) was arrived at through detailed investigations into individual case studies, plotting the areas of breakdown in terms of function, and thereby creating a plausible conceptual model of

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<sup>1</sup> Aphasia is the most widely used term currently, although some literature still refers to 'dysphasia'

language processing at the single word level. Broadly speaking, individuals with more frontal lesions who present with a Broca's type aphasia are likely to have difficulties at the output level of the model, below the level of the semantic system, but possibly including the semantic system. The language difficulties of people with aphasia of all types exist in the context of other cognitive functions being reasonably and contrastively intact.

People with aphasia may use total communication strategies (Moss et al, 2004, p 755) or "ramps" (McVicker, 2007) in order to augment – or indeed replace – their impaired language skills. For example, an individual's ability to use written language may be superior to their ability to use spoken language, and so they employ the strategy of writing down words whose spoken form eludes them. This also forms the adjunct function of providing a term of reference as the conversation progresses. Individuals might also employ gesture or drawing to convey an elusive word or concept. Other forms of non-verbal communication can also be used to good effect to augment, or supplant language, such as facial expression and intonation.

People who have had a stroke may present with various communication difficulties, such as aphasia, dysarthria or apraxia of speech. Aphasia involves problems with understanding or expressing language, whereas dysarthria and apraxia of speech are both motor speech disorders, affecting neuromuscular activity, and speech programming and planning activities respectively.

The participants in this study who have had strokes all present with expressive aphasia, in the context of intact (or near intact) receptive abilities. In the first group, some presented with overlaying speech difficulties, as well as their language problems. They all had some residual expressive language and used varying types of alternative or augmentative communication systems.

## **1.2 Spirit and spirituality**

Spirit is derived from the Latin 'spiritus', meaning soul, courage, vigour or breath and is related to the verb 'spirare', to breathe (Barnhart, 1988). 'Spiritus' was the word used within the Latin vulgate translation of biblical texts to translate the Greek word 'pneuma' (from which we derive pneumatic – to do with air or breath) and the Hebrew 'ruah', meaning air or wind. The spirit (ruah) of God is described in Genesis (1:2) as "moving over the water", waiting and ready to begin the process of creation. Spirit is, therefore, portrayed within the Bible as something intrinsic to life, something necessary for life.

In his 1637 work *Discours de la Méthode*, Descartes (1980) contests that the soul is distinct from the body:

“l’âme, par laquelle je suis ce que je suis, est entièrement distincte du corps”.

He maintained that a person’s soul resided in the pineal gland, and that was where body and soul interacted (Garber, 2005, p 185). We have travelled a distance from this belief in an anatomical site for the soul’s residence, yet theories still abound as to where our spirituality can be said to originate. Foster (2010), for example, discusses the possibility of spirituality being found in neurology, sexuality, psychoactive drugs and near-death experiences.

Defining a term such as “spirituality” is an impossible, and arguably a potentially reductive, task. The spiritual realm reaches into so many different facets of the human condition and experience – culture, art, nature, theology, philosophy – that it cannot be comfortably minimised into a sound bite. Its power perhaps lies, in fact, in its inability to be reduced to a definable concept (Swinton and Pattison, 2010); spirituality means something different – but equally important – to each person. Van der Veer (2012, p 169) puts it like this:

“Spirituality is notoriously hard to define and I want to suggest that its very vagueness as the opposite of materiality, as distinctive from the body, as distinctive from both the religious and the secular, has made it productive as a concept that bridges various discursive traditions across the globe.”

My position from the outset of this research project was that spirituality is what it is to an individual, and therefore to each of the participants; that is, spirituality is whatever that person considers to be spirituality. I was open to any and all manifestations of how spirituality might look. For me, spirituality can and does include religious belief, but also awe in nature, and human relationship. As we shall see, the participants also expressed myriad concepts of spirituality, as they experienced it.

Yet, many authors have at least attempted a definition, and most people have an understanding of what spirituality is even if they have difficulty in then putting that understanding into words. It is perhaps useful to gather some of the terms which are frequently mooted in attempts to define spirituality, in order to start to create some of the vocabulary which may be helpful. So it is that Cobb, Puchalski and Rumbold (2012, p vii) talk about “purpose and meaning of human existence”, Swinton (2010, p 19) of “meaning, purpose, value, hope and love” and Vanier (1999, p 97) of how “spirituality flows from being fully human”.

Egan et al (2011, p 3) propose that there are three main positions when it comes to the possibility of a definitive definition of spirituality. The first position asserts that there is not enough agreement amongst the definitions that exist in the literature, and that this hinders useful research in the area. The second is that there is commonality in most definitions, so that most people in most disciplines understand what is meant by the term ‘spirituality’. The third

position is that there is indeed no consensus as to definition, but that this is immaterial and does not affect the ability of people from all disciplines to study spirituality.

Some definitions include a religious element (Van der Veer, 2012), however it is recognised that spirituality is distinct from religion (McSherry and Cash, 2004; Swinton, 2010; Swinton and Pattison, 2010), but that religion may constitute a part of someone's spirituality. Striving for some clarity in the terms associated with definitions of spirituality, Koenig, King and Carson (2012, p 46) devised three distinct groupings, namely people who are religious and spiritual, those who are religious but not spiritual, and those who identify as neither spiritual nor religious but humanistic or secular. Perhaps we may add a fourth grouping, which has become so accepted a term that its acronym is now widely used (e.g. Harvey, 2016); that of spiritual but not religious, or SBNR (Erlandson, 2000).

Spirituality may or may not constitute the same phenomenon as religion. Many people without adherence to an organised religion nevertheless describe themselves as spiritual beings.

Some putative definitions of spirituality contain the words 'meaning' and 'purpose', aspects not necessarily allied to the concept of a god or higher being. Viktor Frankl, an Austrian neurologist and psychiatrist, who spent three years in Auschwitz and Dachau, alludes to his spirit being able to rise above all hardship in order to find meaning in the meaninglessness and horror of the concentration camps:

"I sensed my spirit piercing through the enveloping gloom. I felt it transcend that hopeless, meaningless world, and from somewhere I heard a victorious "yes" in answer to my question of the existence of an ultimate purpose." (Frankl, 2004, p 51).

Relationship and love are, for Frankl, integral to this spiritual freedom, as illustrated by the words he writes when thinking about his wife, who, in fact, he never saw again:

"In a position of utter desolation...man can, through loving contemplation of the image he carries of his beloved, achieve fulfilment." (Frankl, 2004, p 49).

He speaks of "spiritual freedom" (Frankl, 2004, p 75), which can be willed into continuation, even in the most dire of circumstances:

"Man *can* preserve a vestige of spiritual freedom, of independence of mind, even in such terrible conditions of psychic and physical stress." (p 74).

For Frankl, then, the spirit can be viewed as a separate facet of the human condition, one that can rise above the body and mind, but one that is nevertheless integral to the whole; in fact he views spirituality as the central kernel of being, around which the mind and body form (Frankl, 2011, p 35).

Spirituality, then, remains a vague and ill-defined phenomenon, but perhaps justifiably so (Swinton and Pattison, 2010). It seems apposite that this thesis seeks to explore this concept which is so difficult to put into words with a population for whom creating words and putting

thoughts and concepts into language is inherently difficult. McGilchrist (2010) puts forward the compelling argument that the human capacity for reverence, awe and spirituality, is housed in the right hemisphere of our cerebral cortex, with the left being the hemisphere of logic, order and, of course, language. This will be discussed further on in the thesis; for now, it is interesting to note that the very essence of what spirituality might be is difficult to enunciate, to verbalise; perhaps its residence in the right, non-dominant, so-called non-verbal hemisphere renders definition impracticable.

### **1.3 Body, mind, spirit**

Speech and language therapists (SLTs) have long worked with people with aphasia in order to maximise their residual linguistic and functional communication skills. As a profession, emphasis is placed on an holistic approach to therapy and intervention, seeing the client as a whole person, in a person-centred way (Koubel and Bungay, 2008; Health and Care Professions Council, 2013; Royal College of Speech and Language Therapists, 2016).

Therapy clients can be regarded as 'tripartite' in nature; that is, the essence of the individual comprises body, mind and spirit. As we have seen, Frankl (2011) extends the concept of a person's wholeness being dependent on the interaction of all three aspects (body, mind, spirit), by suggesting that, not only should all aspects be present, but that the spiritual aspect creates the inner core around which the body and mind develop.

Seeing the client as tripartite in nature, SLTs working with people with aphasia have become accustomed to assessing and intervening with the 'body'. Impairment-based assessments and interventions, exemplified perhaps in the cognitive neuropsychological model of language processing and the assessments that partner it, such as the Psycholinguistic Assessment of Language Processing in Aphasia (Kay, Lesser and Coltheart, 1992) and the Comprehensive Aphasia Test (Swinburn, Porter and Howard, 2004) have long been the bedrock of aphasia therapy. SLTs hoping to maximise the period of spontaneous recovery, providing the best support and environment in which spontaneous recovery and perhaps neuroplasticity (Vargha-Khadem et al, 1997) can take place, will advocate this emphasis on working with the body element of their tripartite clients. In more recent years, although therapies which focus on the body and impairment still maintain a large presence both in the efficacy literature and also in practice, emphasis has shifted slightly to incorporate the 'mind' within therapy. This is exemplified in the literature of the last 20 years, which has focused on the psychosocial elements of living with aphasia (Code and Herrmann, 2003; Hilari et al 2003). Issues of quality-of-life (Cruice et al, 2003; Hilari et al, 2003) and identity (Ellis-Hill and Horn, 2000; Shadden, 2005) have rightly begun to be more thoroughly explored.

But what of the 'spiritual' aspect of the tripartite client with aphasia? Do SLTs address this aspect as part of their management of the tripartite client – and should they? If we consider Maslow's (1954) Hierarchy of Need, are we as SLTs focusing only on those needs at the base of the pyramid (ie physiological and safety needs) and not being cognisant of our clients' need to progress to self-actualisation? Greenstreet (2006, p 13) believes that self-actualisation is linked to spirituality and is evidenced in "personal autonomy, self-acceptance, *open communication and interaction*" (my italics). It may be incumbent on the whole stroke rehabilitation team to enable the person with aphasia to convey that self-actualisation, and the speech and language therapist is best placed in terms of training to fulfil a prime facilitative role.

Given that the NHS constitution cites dignity and respect as key ways of showing person-centred, compassionate care (NHS England), and that the Health and Care Professions Council demands that its registered members "promote and protect the interests of service users and carers" (HCPC, 2016), treating the body, mind and spirit facets of our clients seems to be a professional imperative. Chochinov (2006, p 94) clarifies the correlation between holism and dignity:

"acknowledging patients as whole persons is one of the most ardent predictors of maintaining dignity".

Holism is at the heart of modern healthcare, and is integral to the practice of healthcare professionals, including SLTs. Other healthcare practitioners, such as chaplains are accustomed to acknowledging and working with the concepts of "total care" and "total pain", a term adopted by Dame Cicely Saunders, physician, nurse, social worker and founder of the hospice movement (Fitchett and Nolan, 2015, p 197). The term encapsulates all facets of human suffering, be they physical, psychological or, indeed, spiritual. It acknowledges that both physical and mental illness may be accompanied by existential pain, often illustrated by questions such as 'why is this happening to me?' or 'is this all there is?'.

## **1.4 Spirituality and illness**

Throughout history, it seems that mystics and holy people who are suffering through mental or physical ill health have enjoyed a "privileged access to the divine" (Clark Power et al, 2008, p 375), almost as if the suffering has drawn them closer to God or to spiritual wholeness.

Perhaps the most well-known example of this is Julian of Norwich, the fourteenth century anchoress and Christian mystic. Julian wrote in her "Revelations of Divine Love" of the divine 'showings', or apparitions that appeared to her as she suffered a severe illness. It seems that sickness brought Julian "vivid perception" (Julian of Norwich, 1998, p 3) which enabled her to see and feel more intensely. She was close to death (p 5), and she relates mysterious

sensations (such as the pain in her body completely disappearing) and visions (such as blood trickling down from a crown of thorns on the crucifix in front of her).

The title of the poem by St John of the Cross - "Dark Night of the Soul" - has been adopted by the Roman Catholic church to refer to a spiritual crisis in a journey towards union with God, such as that depicted in the poem. St John was imprisoned and it is thought many of his poems were borne out of this suffering (Thompson, 1999, p 8).

The French author, Jean Vanier, has devoted his life to living and working with people with learning disabilities, believing that to become fully human, one must grow spiritually through relationship with others. He found that "community life with men and women who have intellectual disabilities...taught [him] a great deal about what it means to be human", in terms of loneliness, belonging, inclusion, freedom and forgiveness (Vanier, 1999, p 6).

All these examples suggest particular access to spirituality through illness, disability and suffering. There exists, perhaps, a human need to question and to reach out for existential answers when in the midst of physical or emotional hardship:

"existential experiences such as serious illness and the death of a loved one have an uncanny way of stopping us in our tracks, as we pause to reflect on life's most important meanings" (Burke and Neimeyer, 2012, p 127).

Koenig (2012) carried out an extensive and comprehensive review of the quantitative research studies published between 1872 and 2010 concerned with the effects of spirituality and/or religion on different aspects of health. He stressed in this systematic review that he was not exploring studies that investigate "supernatural or transcendent forces" (p 13) but rather what effect belief in these forces might have on physical and mental health. He concluded that the majority of research (quantitative studies) on religion/ spirituality and health involved studies on mental, as opposed to physical, health. Factors associated with religion/spirituality that were shown to have positive effects on mental health in the majority of studies included coping with adversity, a sense of optimism, and identified meaning and purpose in one's life. In terms of physical health, Koenig (2012) found many studies that demonstrated a positive correlation between religion/spirituality and health outcomes. These included studies into coronary heart disease, hypertension and stroke, as well as dementia and cancer. Better health behaviours in people who profess to be religious or spiritual (such as better diet and lower alcohol and drug consumption, better coping strategies and higher levels of social support), all led to improved health outcomes. When he looked at studies related to longevity and religion/spirituality, Koenig (2012) concluded that "the cumulative effects of R/S [sic], if it has any benefits to physical health, ought to have an effect on mortality. The research suggests that it does." He cited 68% of studies examining the relationship between religion/spirituality

and mortality predicted significantly higher longevity, whereas 5% of the studies reported lower mortality.

Koenig (2012) concludes his systematic review with implications of the research for clinical interventions. He proposes eight key reasons why spirituality should be incorporated into healthcare:

- Unmet spiritual needs may negatively impact health outcomes and increase mortality
- A patient's spirituality/religion influences their ability to cope with illness or disability
- A patient's religious or spiritual beliefs may affect the decisions they make about their medical care
- A doctor's religious or spiritual views may impact on their clinical decision-making
- A patient's religion/spirituality may affect both their mental and physical health
- A patient's religion/spirituality may impact the sort of support system they have available to them
- Failure to address patients' spiritual/religious needs may have cost implications (for example, not being willing to turn off a life support machine)
- Healthcare systems in the developed world demand that patients are afforded respect at all times, and that includes respect for their spiritual beliefs

Evidence linking spirituality with improved health outcomes (Koenig, 2012) has resulted in the emergence of a mind-body-spirit paradigm in Western medicine, or a bio-psycho-social-spiritual model (Sulmasy, 2002), where the person is seen as a complete individual comprised of many facets, as opposed to a disembodied illness entity.

## **1.5 Spirituality and healthcare**

Until the eighteenth century, when science and reason began to take precedence, religion and healthcare were inextricably linked. Pre-enlightenment, body and soul were treated together. Religious orders took care of the sick, and throughout the Middle Ages, medics were in fact also clergy (Koenig, 2012). Up until the 1950s, female nurses wore a wimple-like headdress, and senior female nurses can sometimes be referred to even today as 'sister'; both these facts bear testament to the legacy of nuns carrying out early healthcare.

As science began to gain dominance in the eighteenth century, care of the body and soul began to become separate. As science provided better diagnoses and treatments for physical complaints, so the spiritual aspect of patients became disconnected and seemingly irrelevant. In this biomedical model, the physician was seen as the expert, bestowing his knowledge and skill on ignorant patients. Physical illness had a cause; pathogens and bacteria were discovered using newly invented machinery, and medicines were devised which targeted these. But in this

new world of positivism and proof, of cause and effect, did the soul get subsumed, so that only part of the patient was being treated?

If the science-oriented nineteenth and early twentieth centuries produced a biomedical model of care, where positivism was king and medics enjoyed a certain hegemony, recent years have seen a resurgence of the spiritual in healthcare, with holistic practice and the patient as expert in their own condition being the prevalent narratives.

If we accept that, as well as religion in some instances, spirituality encompasses concepts such as purpose, meaning, love and value, it is not unsurprising that it then becomes an important component of illness, health and well-being.

From an international perspective, the World Health Organisation has recognised for some time the integral role that spirituality plays in health and well-being, and this is perhaps best illustrated in the development in 2002 of a field-test instrument (questionnaire) designed to measure quality of life and health. The tool comprises 100 questions relating to such issues as pain and fatigue, body image and relationships. In addition, however, there are 32 Spirituality, Religiousness and Personal Beliefs questions, such as “to what extent do you feel your life has purpose?” and “to what extent do you feel spiritually touched by beauty?” (WHO, 2002b).

More locally, in the aftermath of the situation in Mid-Staffordshire<sup>2</sup>, the NHS strove to create a more values-based approach within healthcare staff, instilling values such as respect, dignity, compassion and working together for the good of the patient (NHS England). Central to these values is a person-centred approach which has been the bastion of UK and other healthcare pre-registration programmes for many years (HCPC, 2013; NMC, 2015).

Literature exists which suggests that attending to the spiritual needs of patients is not only desirable from a respect and dignity perspective, but that alleviating spiritual distress and encouraging spiritual expression may contribute to the healing process (Koenig, 2012), or to the individual’s ability to cope with illness. McClain, Rosenfeld and Breitbart (2003) carried out several standardised assessments of spirituality, depression, hopelessness, and attitudes to impending death, and discovered that “spiritual well-being offers some protection against end-of-life despair in those for whom death is imminent” (p 1603). Their argument is that spiritual care may help “bolster” (p 1603) psychological functioning which enables adjustment to death and dying.

If addressing spiritual needs is seen as a national and international imperative in health, healthcare professionals need to ensure that this prerogative is open to all, including those

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<sup>2</sup> In the late 2000s, high mortality rates in Mid Staffordshire NHS Trust were reported and failings of patient safety and quality of care identified in the Francis Report (Francis, 2013)

who find verbal expression difficult, such as people with learning disability, dementia or, indeed, aphasia.

Although, as already discussed, spirituality is notoriously difficult to define, within the specific sphere of spirituality in healthcare, Murray and Zentner (1989, p 259) offer the following attempt:

“A quality that goes beyond religious affiliation, that strives for inspiration, reverence, awe, meaning and purpose, even in those who do not believe in any god. The spiritual dimension tries to be in harmony with the universe, and strives for answers about the infinite, and comes into focus when the person faces emotional stress, physical illness or death.”

Is this a helpful definition or does it restrict us in our thinking about spirituality? McGilchrist (2010) posits that too often in science and in research we are tempted to reduce constructs into manageable, graspable concepts, which in turn negates their full meaning. In terms of spirituality in healthcare, Bash (2004, p 15) would appear to agree:

“If we are claiming that there is an over-arching, inclusive description of spirituality that fits all – or even the majority of – patients and clients, we are mistaken.”

Swinton and Pattison (2010, p 226) discuss the need for a “thin, vague, and useful understanding of spirituality” within the field of nursing care. They argue that if people within healthcare, both patients and care-providers, are using the term ‘spirituality’ and find it meaningful and useful, the task of academics and others is to “understand the function and direction of the language of spirituality, not to question its validity or right to exist” (p 229). It would seem that, definitive definition or not, spiritual issues can and do impact on illness, well-being and healthcare, and as such perhaps healthcare professionals should be ready to offer “supportive-expressive interventions that encourage the expression of feelings towards illness and changing life circumstances” (Chochinov, 2006, p 98).

## **1.6 Spirituality and nursing**

Just as nursing retains the vestiges of religion, so, as a profession, it continues to embrace the concept of spirituality being an important part of healthcare.

There exists a plethora of articles related to spirituality in the nursing literature since the 1980s, and nursing continues to be the profession at the forefront of regaining a spiritual dimension to healthcare, following the dominance of the biomedical model of the nineteenth and first half of the twentieth centuries. Nurses have contributed widely not only to understanding spirituality and spiritual care in their own profession, but in healthcare in general (e.g. McSherry and Cash, 2004; Swinton, 2010; Hudson, 2012;). Academics with a

nursing background, such as Swinton (2010, p 19), have provided helpful definitions and meanings of spirituality and spiritual care.

Perhaps not unsurprisingly, given that “a holistic approach is established as both a philosophy and a model of care” (Ellis and Lloyd-Williams, 2012, p 257) in the world of palliative care nursing, the palliative and end-of-life care literature is a rich source of spirituality and nursing articles. People coming to the end of life are likely to consider issues of existence and meaning, death and suffering:

“the reported desire for spiritual and/or religious conversations increases at end of life and severe illness situations” (Berg et al, 2012, p 45).

For example, Carroll (2001) carried out semi-structured interviews with palliative care nurses, in order to explore their experiences of providing spiritual care for patients with advanced, terminal cancer. These nurses defined spirituality using terms such as soul, essence, core and interconnectedness and they recognised that, as well as physical pain and discomfort, their patients could “also experience psychological and spiritual distress” (p 91). All the nurses interviewed recognised the need for spiritual, as well as physical and emotional, nursing care. Reid (2012) agrees that spirituality and addressing spiritual needs has a place in the care of the dying, and acknowledges that nurses (as well as other healthcare professionals) need to “look beyond medical therapies as they listen to people who are struggling with their dying” (p 122). In their study, Ronaldson et al (2012) compared spiritual care given by palliative care nurses with that given by acute care nurses, by using questionnaires to measure the nurses’ spiritual perspectives and their spiritual care practice. The study found that nurses working in palliative care had both higher spirituality perspective scores, and more developed spiritual care practice. It is perhaps interesting to speculate whether being a palliative care nurse enhances one’s spiritual perspectives, or whether those individuals with a more developed idea of spirituality and spiritual care are attracted to that specialism.

Unsurprisingly, spirituality also features highly in the cancer care literature, supporting the idea that life-threatening disease often forces us to confront the numinous, as existential questions come to the fore (Burke and Neimeyer, 2012, p 127). Swinton et al (2011) interviewed fourteen women in the first year after a diagnosis of breast cancer. Using a hermeneutic phenomenological approach, they explored the women’s experiences post-diagnosis, and whether spirituality was useful in terms of coping with that diagnosis. One key finding which emerged from the rich qualitative data was that the women often needed time and space to reflect on existential issues, and that this reflection may include spiritual and religious reflective practices.

Other nursing literature includes the voices of patients talking about their spiritual needs, distress and well-being. For example, Mohlzahn et al (2012) conducted in-depth interviews

with various groups of people with severe illness, in order to tell their stories of spirituality. Participants included patients with end-stage renal disease, cancer and HIV/AIDS, the nurse researchers recognising that “narrative inquiry...provides a window into understanding the experiences of people living with serious illnesses and the multiple narratives used in facing existential life questions” (Mohlzahn et al, 2012, p 2349). Participants are quoted verbatim, in order to illustrate the themes uncovered in the study, namely reflection on spiritual, religious and personal beliefs, crafting beliefs, finding meaning, and transcendence beyond words. The authors hope that the richness of the narratives will give clinicians a deeper understanding of spiritual issues related to serious illness, which in turn will result in “respectful care”, where spiritual and personal beliefs are recognised and acknowledged.

Narayanasamy, Gates and Swinton (2002) describe an empirical study, where learning disability nurses were encouraged to discuss critical incidents which illustrated how they met the spiritual needs of the clients with whom they worked. This departure from the interview technique led to rich and revealing discussions of spiritual care in action with this client group. Other papers, such as Daly and Fahey-McCarthy (2014) also aim to describe how nurses provide spiritual care to a particular client group, in this instance people with dementia. Rather than gathering empirical evidence, they seek to shed light on the idea of people with cognitive impairment still being spiritual beings, and conclude that “the need to explore spiritual care in dementia is pressing” (p 790), not least because of the growing number of people living with dementia (Harrison Denning et al, 2016). Carr, Hicks-Moore and Montgomery (2011) explore the possibility that “spiritual identity might actually increase and strengthen as dementia progresses” (p 2), and interviewed people with dementia, their family members and healthcare professionals to create spiritual stories, in which themes were identified.

Despite the rich wealth of literature pertaining to nursing and spiritual care, not all nurses agree that spirituality is necessarily a separate part of the care they provide, and struggle to differentiate spiritual care from everyday person-centred care. Bash (2004), although not a nurse but a minister in the Church of England entering into the nursing/spirituality debate, poses thorny questions about definitions and measures of spirituality in healthcare, and in nursing in particular. He sees spirituality in healthcare as divided into three discrete definition areas, namely “the non-theistic, the theistic, and a *via media*” (p 12). It is this latter category with which Bash the Anglican priest takes issue, because he believes it uses religious language to talk about secular matters – what he describes as a “religionless religion” (p 12). His contention, however, is that spirituality not only defies definition, but also defies positivist measurement or analysis. Although spirituality does not, according to Bash (2004), lend itself to nomothetic investigation, he concedes that “phenomenological expressions of that experience” (p 15) may be measured.

Paley's (2008, p 3) is a rare but loud dissenting voice in the nursing literature, promulgating a "reductionist approach" to spirituality. He argues that claims about spiritual care made in the nursing literature and elsewhere are unsubstantiated and often "gratuitous" (p 3). In contrast to Bash (2004) who believes that spirituality cannot and should not be measured in any scientific way, Paley (2008) insists that spirituality's downfall is precisely that it is not "amenable...to scientific study". He claims that "spirituality is an invention of the late 20<sup>th</sup> century", and "a deeply artificial, shallow and...unnecessary concept" (p 9). Of course, as a nurse, he does not dispute that patients – particularly those suffering severe illness and disability – can experience distress which is not physiological, but he claims that these can be understood in psychological and neuropsychological (i.e. nomothetic) terms.

Occurring less frequently in the nursing spirituality literature is the voice of the individual with communication difficulties, be that because of dementia, learning disability or aphasia. There exists, of course, an inherent difficulty in hearing the voice of the participant who has reduced or absent communicative competence. Although narrative and storytelling can be a rich source of qualitative data, this approach can be problematic for those with limited language skills. The speech and language therapist may be best placed to facilitate these narratives.

## **1.7 Spirituality and speech and language therapy**

Compared with nursing, speech and language therapy is a relatively young profession, with the first reference to speech and language therapy being traced back to the late nineteenth century, and a course beginning at the Central School of Speech Training and Drama Art in 1906 (Stansfield and Armstrong, 2014). Initial therapy interventions tended to focus on stammering, but as world events evolved, subsequent therapy intervention in the first half of the twentieth century revolved around war veterans with psychological and neurological injuries. It seems that the profession grew out of necessity following head injuries and shell shock sustained by soldiers in the Great War. Unlike nursing, SLT developed independently in response to an identified need, and did not draw on an existing profession or institution, as nursing drew on religious orders. The origins of SLT would therefore seem more inherently secular in nature, and the profession appears to be one in which spirituality and religion have not, until recently, played a part.

A study of the literature using the search engines Medline, CINAHL, Library Search and Google Scholar reveals an embryonic interest in spirituality within speech and language therapy<sup>3</sup>.

Whilst other health and social care professionals, most notably nurses, occupational therapists

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<sup>3</sup> Speech-language pathology was also included in the literature search, the title used in the United States and Australia

and social workers, have well and truly grasped the baton and started to explore the extent to which spirituality plays a role in their patients' lives and in the care provided to their patients, speech and language therapists have only just left the starting blocks.

Why should spirituality concern speech and language therapists in their management of clients with speech, language and swallowing difficulties? Does the spiritual realm enter into the therapy room, or should it? In this outcomes-driven world of healthcare where quantitative results are often seen as king, is there room for the nebulosity of the numinous?

Spillers (2007, p 191) opened up the dialogue within the field of speech and language therapy by remarking that "an individual's experience with a communication disorder can have spiritual implications". She posits that any disability or illness (including communication disability) can bring up issues of a deep and existential nature and that perhaps as clinicians we should be ready and willing to listen to these issues as expressed by our clients. Spillers (2007) sees this not only as an empathic and humane undertaking, but also one that could be integral to the success of traditional therapy programmes, in that "[r]esolution of these spiritual issues may undergird clients' abilities to face and sustain the changes that the communication disorder imposes upon them" (p 192). Spillers (2011) later develops her argument, asserting that speech and language therapists are integral to the "soul work" (p 231) carried out by our clients, as they attempt to redefine themselves after illness and create a new, meaningful existence. The therapeutic relationship, she suggests, may be viewed as "an act of communion" (p 236), an environment conducive to the well-being and sense of belonging of both the clinician and the client.

Spillers et al (2009) gave a presentation at a conference hosted by the American Speech-Language-Hearing Association (ASHA) in New Orleans, entitled "Exploring the role of spirituality in professional practice". In this study, SLT clients (both adults and children), clinicians and student SLT practitioners were interviewed, to obtain qualitative comments, and given a Likert-scale questionnaire to complete. Questions under consideration included "what is spirituality?" "is it the role of the SLT to discuss spirituality with their clients?" and "should spirituality be included in SLT pre-registration curricula". Interestingly, although over 80% of adult SLT clients stated that it was appropriate for SLTs to address spirituality within their caring remit, and 92% of the adult clients reported that spirituality played an average to very large role in adjustment to their communication impairment, only 35% of the practising SLTs felt that it was appropriate for them to address spirituality in their clinical practice. There seems to be, from this albeit limited example, a marked disconnect between what clients feel is part of the SLT role in regards to spirituality and what SLTs themselves feel is within their professional remit. Interestingly, 65% of SLT student practitioners were open to inclusion of spirituality in the pre-registration SLT curricula.

Most recently, Mathisen et al (2015) have considered spirituality and religion, citing their “largely neglected clinical relevance” (p 2309) within the sphere of speech and language therapy. They cite the World Health Organisation’s International Classification of Functioning, Disability and Health – pastoral interventions (2001) and the WHO International Classification of Diseases: Australian Modification of Health Interventions of the International Classification of Diseases and Related Health Problems (2002a), as possible imperatives for speech and language therapists to consider the spiritual facet of their clients, if they are indeed to treat in an holistic manner. Indeed, one of their implications for practice is the suggestion that SLTs begin to use WHO spirituality/religion coding in their goal setting and outcome measures (p 2320). Given that religion/spirituality has been shown to provide coping strategies for people with illness (Koenig, 2012; Homan and Boyatzis, 2010), may lead to healthier lifestyles (Koenig, 2012) and that being aware of a client’s spiritual concerns may foster empathy, compassion and rapport (Mathisen et al, 2015, p 2312), Mathisen et al (2015, p 2315) query why “few SLPs include it in their clinical practice.” They cite a previous study of occupational therapists (OT) by Kirsch et al (2001), which explored why OTs were reluctant to include spirituality in their assessment and intervention with clients, and proposed that similar issues and attitudes may be influencing SLTs. These included a lack of or perceived lack of pre-registration training in the area, a lack of time, willingness and opportunity, a perception that it was outside of their scope of practice, and a difficulty in thinking about and expressing their own spiritual beliefs. Although needing to respect professional boundaries, Mathisen et al (2015) propose that spirituality could be encompassed in SLT practice in a number of useful ways. Firstly, SLTs may be involved in carrying out spiritual assessments, such as the FICA Spiritual Assessment Tool © (Puchalski, 1996). Arguably, SLTs may be the best-placed professionals to facilitate completion of such a word-based assessment with clients with communication impairment. Secondly, SLTs may find it useful to use religious artefacts and texts within therapy sessions, in order to make those sessions meaningful and functional for the client. Thirdly, use of WHO coding in pastoral and spiritual care may make for more holistic and client-centred goals.

Negative impacts of not including spirituality in SLT practice include the following:

- Therapy may become superficial by not including religious or spiritual beliefs
- Good therapy outcomes may be negated by not considering spiritual issues which may impact on the success of therapy
- Without SLT help, clients may be unable to access meaningful spiritual resources or practices which may help with the “restorative, healing or educational processes that would enhance or sustain therapy goals” (Mathisen, 2015, p 2318)

Integration of spirituality into the frameworks and practices of speech and language therapy have not occurred to date. There is no mention of spirituality in either the American Speech-

Language-Hearing Association (2016), nor the Speech Pathology Australia (2015) scope of practice document. In the United Kingdom, SLTs refer to two main documents in terms of the scope of their clinical practice: Communicating Quality Live (Royal College of Speech and Language Therapists, 2016) and the Clinical Guidelines (RCSLT, 2005). The term spirituality does not appear in either of them.

The literature pertaining to spirituality in speech and language therapy is therefore, at the present time, limited. Spillers being from the United States and Mathisen and her colleagues from Australia, my chapter (MacKenzie, 2015) in *Speech and Language Therapy and Professional Identity* (Stokes and McCormick, 2015), and a subsequent 2016 article in the *Journal for the Study of Spirituality* (MacKenzie, 2016) are to date (and to my knowledge) the only publications about spirituality in the field of speech and language therapy in the United Kingdom.

## **1.8 Spirituality and other therapies**

Occupational therapists (OTs), by contrast, seem to have travelled much further than the other therapies (by which I mean physiotherapy and speech and language therapy) along the road of inclusion (or not) in their clinical work of issues relating to spirituality. In their conference of 2004, occupational therapists drew up a definition of spirituality:

“Spirituality can be defined as the search for meaning and purpose in life, which may or may not be related to a belief in God or some form of higher power. For those with no conception of supernatural belief, spirituality may relate to the notion of a motivating life force, which involves an integration of the dimensions of mind, body and spirit. This personal belief or faith also shapes an individual’s perspective on the world and is expressed in the way that he or she lives life. Therefore, spirituality is experienced through connectedness to God/a higher being, and/or by one’s relationship with self, others or nature.” (Johnston and Mayers, 2005).

Because OT is inherently interested in the integration of all facets of the client in occupation, it makes intuitive sense that spirituality be included in models of occupation, and indeed it is, such as in the Canadian Model of Occupational Performance (Canadian Association of Occupational Therapists, 1997). In fact, not only is spirituality included in the model, it is at the very centre of it, surrounded by other personal facets of the human condition such as the physical, cognitive and affective.

Kang (2003), another OT this time in Australia, has produced a new practice framework which she calls the “psychospiritual integration frame of reference for occupational therapy”. She discusses the fact that spirituality encompasses centredness, connectedness, transcendence and meaning, and how these aspects of our clients can sometimes be neglected by healthcare

professionals. Her framework therefore aims to encourage OTs to engage with the spiritual facet of their clients in a systematic way.

Physiotherapy (Turner and Cook, 2016, p 59) and speech and language therapy (MacKenzie, 2016, p 79) seem to be lagging behind, in terms of discussing spirituality's role in the therapy arena and in contributing to the literature. Both therapies seek to treat their clients holistically, and therefore consideration of the spiritual dimension of their clients seems apposite. Turner and Cook (2016, p 65) identified a majority of the physiotherapy respondents to a questionnaire who agreed that spirituality was an important component of "health, therapy and well-being of patients". A majority (75%) deemed their role as one of referral on to another professional, and almost a half of all respondents felt that identifying spiritual needs was part of their physiotherapy role. Despite this, it seems that pre-registration training did not equip physiotherapists for this aspect of their role:

"The majority of respondents (76%) disagreed or strongly disagreed that their academic training had prepared them to deal with patients' spiritual needs, with only 8% agreeing or strongly agreeing" (Turner and Cook, 2016, p 70).

Interestingly, the recently published *Oxford Textbook of Spirituality in Healthcare* (2012) contains no contribution from allied health professionals.

## **1.9 Spirituality and aphasia**

Mundle (2011), in his capacity as hospital chaplain, has explored the "existential crisis of stroke" in relation to patients with severe expressive aphasia, those who have lost most or all their ability to express themselves verbally. He uses Frank's (2013) typology of illness narratives in order to explore whether the stroke trajectory of clients with aphasia potentially follows a path from one of these narratives to another. He describes the "co-creation" of the therapy process, with the listener attentively co-creating stories with their client. The language difficulties of someone with aphasia attempting to tell their story is identified by Mundle, as is the onus on the story-listener to become an active and interested participant in the interaction, learning from the person with aphasia "how to communicate and understand" (p 233). Mundle (2011) also rightly points out, however, that the voice of the person with aphasia, "unmediated through the fallible voices of others" is often missing from aphasia research in general and research into spirituality more particularly. In fact, it is missing from his, perhaps because his emphasis as a chaplain is on the clients' spirituality, rather than their aphasia.

Another recent and welcome study, carried out by nurse researchers (Bronken et al, 2012), reports a single case study of a woman with aphasia and, indeed, direct quotes ensure that her

voice is heard. The researchers encourage storytelling of her stroke journey, not just verbally but through many expressive modalities, including symbols, signs, gestures, pictograms and drawings. The participant is given the opportunity to tell and retell her illness and disability narrative, as it is recognised that “for stroke survivors with normal communication and language skills, assistance with framing life stories and illness narratives has been found to be an important part of successful recovery” (Bronken et al, 2012 p 1304). Barrow (2008), a speech and language therapist, also reports on a single case study of Anne, a woman with aphasia, who speaks about the effect of her disability as she lives with her aphasia; spiritual issues are, however, not directly mentioned. In this article, the author uses direct quotes from Anne so that the latter’s voice is heard. She includes, too, her own voice as researcher, “therefore the tapestry of Anne’s life living with aphasia is woven with my [Barrow’s] needle” (p 36).

This is in contrast to a study about stroke patients’ fatalism, optimism, religion and depression by Morgenstern et al (2011), where the subject matter did include spirituality but participants with aphasia were specifically excluded, presumably because of the inherent difficulties in gaining data from people with little or no expressive output.

McLellan et al (2014) carried out a sensitive and inclusive study with Māori with aphasia and their whānau (extended family). The aim of the study was to explore, describe and interpret the experiences of Māori with aphasia, which included spiritual issues, with some people “gain[ing] emotional support from their faith in God” (p 464). The researchers understood that the voices of both the Māori with aphasia and their whānau were vital in the study, given that well-being of one was dependent on, and inextricably entwined with, the well-being of the other, and that this indivisibility carried a spiritual dimension:

“For this group of Māori with aphasia, there was a deep, almost spiritual, reason for taking responsibility for the well-being of the PWA [sic]. That is, the indivisibility of individual and whānau well-being” (p 467).

McLellan et al (2014) successfully convey the stroke experiences of this specific cultural group, using culturally relevant methodology, in order to inform service delivery for this population. Other studies in the literature which do address the spirituality of people with aphasia, carried out by nursing colleagues, contain no examples of output from the people being studied, i.e. the people with aphasia (Sundin, Jansson and Norberg, 2000; Sundin and Jansson, 2003). Nyström (2011) considers the “existential consequences” of being a relative of someone with aphasia, and provides some fascinating insights into changed dynamics and identities. However, she does not consider these changes from the perspective of the person with aphasia themselves, but rather from the perspective of those around them.

There is an imperative to hear the voice of the person with aphasia in aphasia research in general, and in terms of the research around spirituality in particular. Facilitated storytelling and attentive story-listening may present just such an opportunity for people with aphasia to express their spirituality.

## **1.10 Storytelling**

Spirituality is an integral facet of the human condition – and indeed of human suffering and pain (Ross, 2010, p 5) – and therefore worthy of being encompassed within the remit of therapy, and specifically speech and language therapy. Similarly, storytelling can be considered as one way that humans make sense of life events. Specifically, stories and storytelling are used frequently in medicine in order to facilitate healing and to make sense of what has happened; as Frank (2013, p 3) says, there is an “inherent *need* of ill people to tell their stories”. He explains how “they need to become storytellers in order to recover the voices that illness and its treatment often take away” (Frank, 2013, p xx).

Importantly, these stories need a listener in order for them to be stories. An unheard story is an untold story:

“a story requires listeners; it must be told” (Frank, 2013, p 62).

Stories in health research and practice can create empathy and mitigate the often marked, though sometimes unacknowledged, power differential between the clinician (or researcher) and the patient (or participant) (O’Malley, 2011, p 94). Such power differentials are perhaps even more prevalent in conversations or encounters when one party has more ability to communicate effectively than the other, as is the case with patients (participants) with aphasia. Through storytelling and story-listening, a humanitarian balance of power can be established:

“Narrative, on the other hand, expresses the uniqueness of each person and addresses the listener, not as a professional, but as a fellow human.” (Hurwitz, Greenhalgh and Skultans, 2004, p 4)

Through stories, patients are able to create their own illness or disability narrative, which may be shaped and sculpted through multiple tellings over time:

“The patient’s illness narrative is more than an account of symptoms: it is a form of self-creation through autobiographical literary expression” (Hurwitz, Greenhalgh and Skultans, 2004, p 5).

## 1.11 Conclusion to the background story

Although spirituality remains an elusive concept and one that is not easy to define, it has nevertheless gained prominence in the healthcare literature over the last thirty years. Nursing is at the forefront of research in spirituality in relation to health and caring, with occupational therapy, speech and language therapy and physiotherapy being newer to the debate.

Various studies have concluded that people undergoing severe, life-threatening illness often face - and need to voice - existential questions. One way that healthcare workers have attempted to facilitate this is through the use of narrative, or storytelling.

Given that storytelling is important for the human condition in general, and for coping with illness and disability in particular, we need to consider how people with impaired communication skills tell their stories.

In this study, I intend to shed light on the spiritual stories of people with aphasia. There is no problem to be solved, no hypothesis to state (Holliday, 2007, p 31), but rather an area of humanness to explore with people with an acquired communication impairment. I wanted to ensure that each of my research questions was “sufficiently open-ended to allow open-ended exploration and the emergence of factors and issues which the researcher might not have previously thought about” (Holliday, 2007, p 30). Finlay (2011, p 8) explains how qualitative research needs to be inductive and exploratory, “typically asking ‘what’ and ‘how’”, and van Manen (2016, p 36), too, expounds the need in qualitative research in general but specifically in phenomenological research for researchers to pose the “eidetic question of whatness” and the “formative question of thatness”. Perhaps it is fitting that in a project where an ambiguous and “vague” (Swinton and Pattison, 2010) concept such as spirituality is under discussion, the research questions, too, are, if not vague, at least very open and inclusive:

- What is it like to express your spirituality when you have aphasia?
  
- What is the lived experience of members of the multidisciplinary stroke team when discussing spirituality with their clients with aphasia?

The questions, then, are vague but deep, allowing the reader to be struck by wonder, wonder which van Manen (2016, p 37) asserts “may be the antecedent to inquiry”. The questions “what is it like...?” and “what is the lived experience...?” reflect my curiosity as to what the participants had to say, and to how they said it (Moustakas, 1994, p 104).

## Chapter 2: The Epistemological and Methodological Journey

**“To summarize a poem in order to present the result would destroy the result because the poem itself is the result. The poem is the thing.”**

**(van Manen, 1990, p 13)**

In order to listen to the spiritual stories of people with aphasia, I had to be completely open to new ideas and fresh ways of expressing those ideas. My epistemological stance changed and developed as I progressed with the study, as I met and interacted with different people, read different material and generally grew as a researcher.

### 2.1 Qualitative Methodologies

The concept of exploring spirituality with participants with aphasia lends itself to a qualitative approach, as the data is to be words and other forms of communicated material, and the research is inductive in nature (Silverman, 2006, p 56). Although quantitative methods of questioning people about spirituality exist (such as the FICA Spiritual Assessment Tool© (Puchalski, 1996) and the Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS) (Fetzer Group/National Institute on Aging working group, 1999, in Baldacchino, 2010)), and undoubtedly have their place in spirituality assessment and research, these could be viewed as reductive in nature, in that questions are set, ideas are planted, and multiple choice answers are given. By contrast, I wanted to shed light on a concept I had my own ideas about, but that I wanted to explore in others, with no preconceived ideas such as are present in these questionnaires.

Spirituality questionnaires are also, by definition, verbal in nature; they demand a high level of reading or auditory comprehension, processing skills, and the ability to respond to a question by selecting a multiple choice answer, or by generating a verbal response. Although not precluding all people with aphasia – those with good auditory and/or reading comprehension may be able to understand and respond appropriately – the language-based nature of these assessments may make them difficult for some people with aphasia to access. By choosing a qualitative approach, I hoped to enable people with aphasia to express novel thoughts about spirituality. I wanted to facilitate their comprehension of questions and concepts through careful phrasing, use of pauses, and slowing down of my own speech, and I wanted to encourage augmentation of their spoken expressions of spirituality with the use of writing, gesture, intonation, facial expression and artefacts. In this way, I felt that data would be rich, novel and unhindered.

As I embarked on the project, many different qualitative approaches presented themselves to me. Initially, I found the idea of an ethnographic methodology appealing. A passing comment made to me by a chaplain on a stroke unit who used to walk past the people with aphasia on the ward because of the very real difficulty of ministering to people who are not able to speak, made me fascinated by the idea of how people with severe expressive difficulties make their spiritual needs known, and how professionals might be able to help. This interest led to a desire to immerse myself in the life of people with aphasia, in order to experience first-hand the difficulties (and successes) of communicating with an acquired language difficulty.

However, the anthropological roots of ethnography suggest that one is immersed in “the culture and social structure of a social group” (Robson, 2011, p 142), and I was unsure as to whether people with aphasia constituted such a group. People with aphasia are from all sorts of different social groups and cultures; the very fact of their aphasia did not necessarily mean that they had entered a new social and cultural grouping. Ethnographies are also often in-depth and of long duration, a challenge when carrying out a research project at the same time as working. Above all, I could never be a member of that group, if indeed such a group exists, experiencing what the members with aphasia experienced; I could never explore “the culture from inside” (Robson, 2011, p 143) because I did not have aphasia.

Grounded theory was another qualitative approach which I initially contemplated for the study. Grounded theory is an inductive methodology, and was appealing to me because “with flexible guidelines you direct your study but let your imagination flow” (Charmaz, 2006, p 15). In grounded theory, the emphasis is still on obtaining rich data, which are “detailed, focussed and full” (Charmaz, 2006, p 14), however as the name of the methodology suggests, the researcher is hoping also to create an abstract theoretical understanding of the experience under investigation. Although the approach was attractive – I did indeed want to explore “what our research participants’ lives are like” (Charmaz, 2006, p 2) *vis à vis* spirituality – I did not envisage, or indeed anticipate, that a theory would be arrived at. The aim of the research was to shed light on the concept of spirituality, and explore how people with aphasia expressed their spiritual needs and concerns; there was no theory to reveal, but rather ideas to explore. Charmaz (2006, p 25) summarises grounded theory thus:

“seek data, describe observed events, answer fundamental questions about what is happening, then develop theoretical categories to understand it”. In this study, data would be sought and some questions about whether and how spirituality was communicated would be answered, but I did not envisage theoretical categories being developed to give meaning to the data, but rather stories would be told, collated and commented upon.

## 2.2 Phenomenology

**“Phenomenology is about wonder, words, and world.”**

(van Manen, 2016, p 13)

Ethnography and grounded theory, therefore, were considered and discounted as potential qualitative paradigms for this study. I knew I wanted to find a methodology that allowed participants' experiences to be illuminated, and that enabled the very essence of these experiences to be perceived by the reader. Through reading, seminars and discussion, I discovered phenomenology, an approach which resonated with the subject matter, participants, methods of the study and with my ontological stance. If “[p]henomenology is concerned with understanding a phenomenon rather than explaining it” (Sadala and Adorno, 2002), then this chimed with my desire to understand participants and acknowledge their stories, through an unveiling of human experiences to me. If ontology is considered “a certain way of understanding what is” (Crotty, 1998, p 10), then the participants' understanding of spirituality is what they experience as spirituality, just as my understanding of spirituality is what I experience as spirituality.

Phenomenology is a philosophical movement concerned with the essence of things. Essence is derived from the Greek word ουσία (ousia), which is to do with being. This fits well with Heidegger's (1962, p 27) concept of Dasein and its literal translation of 'there-being'. We might consider spirituality as a fundamental part of being, an essential facet of our being human.

Phenomenology is concerned with *perceiving* this very essence of things. Moustakas (1994, p 29) talks about the noema – that which is perceived – and the noema is perceived via our consciousness. Moustakas gives the example of a tree and explains that the noema is “not the tree but the appearance of the tree”. We can extrapolate this to other objects and other phenomena; for my purposes, the noema is the participants' stories, and the spirituality they tell me about; I perceive this spirituality noema as I listen.

A phenomenological orientation might be described as one which seeks to avoid depersonalisation (Finlay, 2011, p 8) and promote the acknowledgement of lived experience (van Manen, 1990, p 35). As such, it is an approach redolent with therapeutic essence, which helps us to understand others in a gestalt manner. As Thomas (2005, p 63) says, using phenomenology not only in research but also in practice, can “take clinicians into the lifeworld of their patients in a deeper way”. Phenomenology as a research methodology began to appear in the nursing literature in the 1970s (Thomas, 2005, p 66), but what is it about the theoretical perspective of phenomenology that renders it so relevant to working with people with aphasia and to the study of spirituality with that population? Heidegger (1962, p 24)

suggests that “every inquiry is a seeking [Suchen]”. For Heidegger, each of us is Dasein (p 27), an entity in the world, interacting with others (“Mitdasein”). As Dasein, we are able to think about our own existence and being. We are Dasein, regardless of ability or disability, our aphasia or our intactness of language. Phenomenology affords the privilege of seeking what makes a person a person and part of what makes up that personhood is spirituality.

Phenomenological research is an intersubjective undertaking, and one that makes it attractive for the purposes of this study. This approach demands understanding and empathy, and that the researcher be fully present with her participant. Moustakas (1994, p 57) explains that for Husserl, arguably one of the founding fathers of phenomenology as a philosophy, the world is perceived as a community of people:

“Each can experience and know the other, not exactly as one experiences and knows oneself but in the sense of empathy and copresence.”

A review of the qualitative literature within aphasiology by Simmons-Mackie and Lynch (2013) reveals that qualitative approaches (which include phenomenology, as well as ethnography and grounded theory) are a frequent “guiding tradition” in aphasia research. Qualitative methods per se are “well suited to exploring complex social phenomena such as communication and communication disorders” (Simmons-Mackie and Lynch, 2013, p 1282), and the occurrence of published qualitative aphasia research articles has risen sharply in the last decade. Viewing phenomena from the perspective of the patient in health research in general and in aphasia research in particular has become popular, not least with the rise of the respect and dignity agenda within the National Health Service (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013; NHS England), and this approach also lends itself to a phenomenological theoretical framework, where the individual’s story is listened to and valued.

If, as Hinckley (2013, p 95) posits, phenomenology is a “philosophy that studies experience, and results in understanding how we experience”, it seems apposite to harness this philosophical approach in order to create a methodology congruent with the topic under discussion, namely the experiences of spirituality of people with aphasia, and their rehabilitation team.

Can one, however, use a phenomenological approach – which is perhaps traditionally recognised as primarily verbal - using individuals’ verbal responses and writing up what is said in text form – with people for whom expressive language is difficult? Is it possible, then, for the essence of our human-ness to be expressed without words, or with limited ability to produce language? To my mind, if a participant only has non-verbal means to hand – or a combination of both verbal and non-verbal – phenomenology can still serve to “reveal the mystery of the world and of reason” (Merleau-Ponty, 2002, p xxiv). Despite the assertion of Simmons-Mackie

and Lynch (2013) that many of the qualitative approaches are becoming common in aphasia research, the literature suggests that phenomenology is perhaps used less widely, and this could in part be due to its perceived inherent emphasis on the verbal. However, in their case study of the understanding of rehabilitation with a patient with aphasia, Hjelmlink et al (2007, p 94) assert that it is indeed possible to search for and explore meaning in the, at times, “obscure language” of the person with aphasia.

As well as the Hjelmlink et al (2007) article cited above, other studies discovered when using the search terms ‘aphasia and phenomenology’ included two by Nyström (2008; 2011). One of these (2011) explored the lived experience of being a close relative of someone with aphasia, and the other (2008) looked at professional aphasia care from the patient’s perspective. The first of these includes the voice of the relative but not that of the person with aphasia. The second includes the patients’ own voices in the form of direct quotes. Interestingly, Nyström is a nurse rather than a speech and language therapist. The voice of the person with aphasia is also heard in a phenomenological study by Bronken et al (2012), looking at promoting psychosocial well-being through stories. However, by their own admission, the voice of the person with aphasia has been “adjusted slightly to convey the meaning as clearly as possible” (p 1306), so is somewhat distant from language “unmediated through the fallible voices of others” yearned for by Mundle (2011).

What had become clear during this investigation of qualitative paradigms was that a phenomenological approach was congruent with the research topic of spirituality; my interest was in how the participant’s ‘lifeworld’ (van Manen, 1990, p 7; van Manen, 2016, p 133; Finlay, 2011, p 19) presented itself to me, how it was communicated to me. Phenomenological approaches also appeared to mirror therapeutic concepts with which I was comfortable, such as being attentive, dwelling with the data and allowing oneself to be awed.

### **2.3 Phenomenology influences: van Manen, Gadamer and Merleau-Ponty**

Different phenomenologists encouraged me to explore the stories of spirituality in different ways. From Husserl, I learnt the importance of “co-presence” (Moustakas, 1994, p 57), from Heidegger, the concept of “Dasein” (1962, p 27). When reading Moustakas and then, later, Merleau-Ponty, I learnt that perception is “the source that cannot be doubted” (Moustakas, 1994, p 52); Moustakas encourages the art of noesis, and exhorts researchers to “look, see, listen, hear, touch” (p 65).

Phenomenological research may broadly be categorised as descriptive or hermeneutic in nature (Finlay, 2011, p 87). Phenomenology as espoused by Husserl is concerned with

describing a phenomenon as it presents itself; in research terms, the researcher brackets off her own experiences and describes the essence of the phenomenon. Heidegger and, later, Gadamer, propounded an hermeneutic phenomenology, where “the purpose is to reveal that which lies in, between, and beyond the words while staying close to the phenomenon of interest”. (Crowther et al, 2017).

I adopted descriptive and hermeneutic phenomenology at different stages in the study, and when I assumed different roles or identities (see chapter 5 for more on ambiguity of identity). At the stage where I was interviewing and collecting the data, and assuming the identity of researcher-therapist, I adopted a more descriptive approach, seduced by van Manen’s imperative of “thoughtfulness” (1990, p 12), rapport and relationship. Van Manen tells us how it is inappropriate in phenomenological research to expect a conclusion, rather having the aim of “transform[ing] lived experience into a textual expression of its essence” (1990, p 36). Van Manen helped me to prepare to explore spirituality with the participants with an attitude of openness, ready to wonder at their stories. During the interviews, the participants’ thoughts and opinions about spirituality were collated, noted and appreciated, using van Manen’s “phenomenological attitude” (van Manen, 2016, p 32). Listening to the participants’ conversations and then writing their stories was in some ways a descriptive phenomenological task, in that I wanted their stories to be told, unfiltered through my own experiences. However, Finlay (2011, p 120) recognises that “the space between description and interpretation is ambiguous”. She identifies Gadamer’s suggestion, that interpretation may be viewed as pointing out the meaning of something, rather than pointing to something. Gadamer’s (2013) thoughts on the phenomenological reduction and bracketing brought clarity as to how I might listen to the stories with an open and curious mind. Although I was focussing on acknowledging and describing the participants’ spiritual stories in my role of researcher-therapist, nevertheless Gadamer’s hermeneutic phenomenology encouraged me to see my role as an active one, bringing myself into the research arena. Listening to and transcribing the participants’ words, then, was a broadly descriptive task, in that I tried to relay the participants’ ideas faithfully and verbatim; their words were not altered and crafted as in some studies (Crowther et al, 2017). However, as I wrote their stories, my approach became more hermeneutic, as they intertwined with my own cultural, clinical, societal, and spiritual experiences.

In order to point out the meaning of the participants’ stories, I also chose to look at, or listen to, them through the lens of Merleau-Ponty’s (2002) ideas of ambiguity, wonder, lived body, and thought and language. Merleau-Ponty’s philosophy has influenced much nursing research of recent years (Sadala and Adorno, 2002; Thomas, 2005; Hjelmblick et al, 2007; Nyström, 2011; Kitzmüller, Håggström and Asplund, 2013). Thomas (2005, p 63) asserts that Merleau-

Ponty is an “excellent fit for nursing”, as he taps into the “antireductionist and antipositivist stance” espoused by many current nurse researchers and, indeed, nurse practitioners.

Merleau-Ponty’s philosophy focusses on the relationship of our bodies to the world and to ourselves; according to Merleau-Ponty, our body is our means of being in the world. People who are ill or who have a new disability are “living an unreliable body” (Kitzmüller, Håggström and Asplund, 2013, p 24), which has a different way of being in the world to the body they once had. Although by contrast Merleau-Ponty has been little used in the speech and language therapy literature, his emphasis on embodiment, his leitmotif of ambiguity and his ideas on thought and language render his work highly applicable to people with communication impairment; indeed, one of the chapters in his magnum opus, *Phenomenology of Perception*, is entitled “The Body as Expression, and Speech”, and he uses the phenomenon of aphasia to illustrate key concepts (Merleau-Ponty, 2002, p 202).

Merleau-Ponty is known as “the philosopher of ambiguity” (van Manen, 2016, p 130), which perhaps also qualifies him as an apposite philosopher when a nebulous concept such as spirituality is under consideration (Thomas (2005, p 73) says of him that he identifies as “the philosopher who does not know”). Although Merleau-Ponty has thus far been little used in the speech and language therapy literature, these key aspects of his philosophical stance also make him an “excellent fit” (Thomas, 2005, p 63) for thinking about aphasia and spirituality.

## **2.4 Phenomenological attitude**

Phenomenology requires the researcher to be fully present in and perceptive to the situation, or “reflectively attentive”, as van Manen has it (2016, p 58), just as a therapist must be fully present with her client. Some phenomenological approaches, such as that propounded by Husserl, for example, require researchers to bracket off bias and to strive for “the elimination of suppositions” (Moustakas, 1994), in a process referred to as epoché. The understanding is that researchers need to set aside their preconceived ideas, prejudices and biases, in order to listen wholly and completely to what is being told to them, or given to them in the form of data. Moustakas (1994, p 85) suggests we listen to researchers with an “unfettered stance”, unhindered by our own ideas, opinions and biases.

Although through using epoché, “everyday understandings, judgments, and knowings are set aside” (Moustakas, 1994, p 33), this does not necessarily imply a cold objectivity. Finlay (2011, p 23) suggests that it is possible to apply epoché, whilst simultaneously bringing pre-existing experiences to an interview:

“bracketing in phenomenology is wrongly understood to be an exercise in objectivity”.

It would appear that researchers are not being called to distance themselves from the participant or from the phenomenon under scrutiny; on the contrary, phenomenology is asking them to become fully involved, fully present, but to encounter “even the familiar as something strange, wondrous and unfamiliar” (Kim, 2016, p 56). It is through this process of phenomenological reduction that we are able to put aside our lifelong prejudices or biases and see phenomena with fresh eyes. They are “revisited, freshly, naively, in a wide open sense, from the vantage point of a pure or transcendental ego” (Moustakas, 1994, p 33). In Husserl’s words, phenomenologists are using bracketing for a process of “ausschalten” or a putting out of action of our preconceptions (Lewis and Staehler, 2010, p 14). Rather than bracketing and then ignoring our preconceptions and all the influences of our lives (cultural, educational, social), researchers can acknowledge these prejudices but attempt not to allow them to interfere with the acceptance of the other and their stance.

It would appear, then, that epoché does allow the researcher to bring some of herself to the interview to a certain extent, whilst employing a stance of neutrality and openness. This resonates with the therapeutic encounter, where the therapist listens with “congruence” but also with a “non-judgmental attitude” (Rogers, 1951).

I attempted, then, to be open as I listened to and then transcribed the participants’ stories. However, through reading more of Gadamer’s work, I began to appreciate the “central interpretive relationship of the researcher within the qualitative research process” (Regan, 2012, p 286). Despite the descriptive nature of data-gathering stage of this study, hermeneutic phenomenology, specifically the work of Gadamer, has also exerted an influence, particularly in the writing up and analysis of the stories. Gadamer recognises that language is fundamental in our understanding of the other and is the primary means by which we share experience with others (Regan, 2012). Hermeneutics was initially a term used in relation to interpreting, and thereby understanding, biblical texts (van Manen, 1990, p 179). It has since become widespread within various disciplines – including health – as a method of understanding things from another’s perspective, when meanings are not overt or easily understood but “require some effort to interpret” (Clark, 2008). Pertinent to health research and practicum is Gadamer’s insistence that we must “transpose” ourselves into the interpretive situation; in order to understand the meaning of another we have to bring all of ourselves into the interview, conversation or consultation:

“But into this other situation we must bring, precisely, ourselves” (Gadamer, 2013, p 314).

Gadamer employs the metaphor of a horizon in order to illustrate how the teller and the listener within a hermeneutic discussion might relate. Each has her own horizon, full of her own experiences, prejudices, biases and opinions. Gadamer chooses the picture of a horizon in order to convey the all-encompassing nature of the openness to the other:

“the concept of ‘horizon’ suggests itself because it expresses the superior breadth of vision that the person who is trying to understand must have” (Gadamer, 2013, p 316).

However, horizons have limits, imposed by the question set between the two interlocutors (Gadamer, 2013, p 372), so that there exists a certain liminality at the edge of the question.

Perhaps this liminality is more pronounced when the subject matter is spirituality; when the subject is numinous and indefinable, the liminal space assumes more significance.

It is only when we have fully appreciated and opened ourselves up to the other’s horizon that true understanding can begin to happen. We may not concur with their opinion, but we are able to understand it:

“when we have discovered the other person’s standpoint and horizon, his ideas become intelligible without our necessarily having to agree with him” (Gadamer, 2013, p 314).

It is within a “fusion of horizons” (Gadamer, 2013, p 317) of both parties that true understanding begins to occur. Our own horizon continually changes because we have constantly to test our prejudices as we listen to the opinions of the other. If we have not fully accepted and acknowledged our prejudices, we risk sullyng the conversation with the “tyranny of hidden prejudices” (Gadamer, 2013, p 282) which hinders understanding. It is the recognition of prejudice and the testing of these that gives potency to the hermeneutic inquiry:

“The recognition that all understanding inevitably involves some prejudice gives the hermeneutical problem its real thrust” (Gadamer, 2013, p 283).

Gadamer’s terminology is useful here. He explores the etymology of the word ‘prejudice’, claiming it did not originally (pre-Enlightenment) carry the negative connotations it perhaps does today. He gives the accurate definition as:

“a judgment that is rendered before all the elements that determine a situation have been finally examined” (Gadamer, 2013, p 283).

This implies that prejudice can shift when new knowledge and understanding is accrued, and for him this occurs within the fusion of horizons. He provides an alternative term – namely fore-meaning – which avoids the negativity with which ‘prejudice’ has become imbued. He also employs the concept of “foregrounding” or “abheben” (Gadamer, 2013, p 310) in order to describe the process of bringing fore-meanings to prominence. In this process of fusing horizons, Gadamer insists that we do not lose ourselves, or hide our fore-meanings from the other, but that we use ourselves within the interchange in order to arrive at understanding:

“this kind of sensitivity involves neither ‘neutrality’ with respect to content nor the extinction of one’s self, but the foregrounding and appropriation of one’s own fore-meanings and prejudices” (Gadamer, 2013, p 282).

More congruent with the subject matter, methods and participants than pure epoché seemed Gadamer's useful concept of horizons and fusion of horizons. Gadamer provided an alternative way of being with research participants in a phenomenological study which resonated with my desire to empathise with each interviewee, and to bring part of myself into the interchange, whilst simultaneously being "completely open, receptive, and naïve in listening to and hearing research participants describe their experience of the phenomenon being investigated" (Moustakas, 1994, p 22). According to Gadamer (2013), bringing of myself to the interviews and to the study in general necessitated firstly revealing my own fore-meanings, so that I could acknowledge these and allow myself to be open to the other.

## **2.5 My fore-meanings**

Fore-meanings in relation to my faith and career seemed pertinent to this study, and needed to be revealed to myself and to the reader. This is both so that I was able to be, what Gadamer (2013, p 281) terms, "open to the meaning of the other person" during the interviews, but also so that the reader of the stories would understand my perspectives. Gadamer (2013, p 281) explains how "this openness always includes our situating the other meaning in relation to the whole of our own meanings or ourselves in relation to it." So it is that I need to be explicit about relevant life experiences, beliefs and upbringing.

I was brought up by a Christian mother and agnostic father, and going to church was always part of my life. I was baptised in the Church of England as a baby and confirmed as a teenager. My faith was strong as I grew up; I attended youth groups and helped run the Sunday School. When I went off to university, although I sought out churches and church groups, I was enjoying the freedom of university life and did not want to feel constrained by what I perceived as restrictive Christian rules; I ended up estranged from church and Christianity and my faith wavered. When I met my future husband, it transpired that he, too, had been brought up in a Christian (Catholic) household but he, like me, had moved away from Christianity, never outright rejecting it but not encompassing it in his life. We both started going back to church as we approached our wedding, hearing our banns being read, and then just continuing to go because we enjoyed it and derived pleasure from the new relationships we were building. Shortly before our son was born, we both attended a course which transformed the way we thought about God and the church. We became what I would term committed Christians, which led in due course to my husband pursuing a career as a Church of England priest. Exploring Christianity deeply in the mid 1990s meant that we were exposed to the idea of miracles, such as the Toronto Blessing, and to the idea of a powerful Holy Spirit, who could

work everyday miracles. The death of my sister in 1995 challenged my beliefs about an all-loving God; after all, how could a loving God leave three young children motherless? The safe birth of our son after a traumatic labour restored my faith somewhat, and events around the birth seemed miraculous and God-given. However, when I experienced a succession of ectopic pregnancies over the next few years, my faith in God waned once more, and I became angry when well-intentioned people told me of supposedly comforting visions of babies I had lost. Since that time, I have remained a Christian, with my faith waxing and waning but never disappearing. My openness to the miraculous is more muted than it once was, but I still have a strong sense of the presence of a higher being, and I still read the Bible, attend church and pray.

I also have a strong sense of the presence of God in my life when I look back at my career. It feels as though I have been guided in the decisions I have made and the paths I have taken. Although I studied French and German at university, I had always been drawn to medicine. A chance meeting with someone with aphasia, and studying a module in French linguistics and phonetics, both led me to explore speech and language therapy as a career; it seemed to combine the arts (which I had always been told I excelled at) with science (with which I had always struggled, though it fascinated me). I soon realised I had a passion for working with adults with communication impairments, and ideal jobs seemed to present themselves, despite having to move several times because of the nature of my husband's job. I worked for many years in both rehabilitation and acute settings, with many multidisciplinary team members, especially occupational therapists and music therapists.

As I developed an interest in the spiritual lives and expressions of my patients, I determined that spirituality for me included religion and religious belief, but was not, most assuredly, limited to it. This stance meshes with many of the definitions of spirituality cited in chapter 1, as well as with the thoughts and comments of the participants. By not confining my understanding of spirituality to religious belief, I was able to hear more openly the diverse spiritual stories given to me.

My fore-meanings, then, include a wavering but present Christian faith, in the context of a fully involved church life, and embracing of myriad forms of spirituality, and a career as a speech and language therapist spanning over twenty-five years, the majority of which I have spent in neurorehabilitation. These are the fore-meanings I needed to foreground when I listened to the participants' stories of spirituality, so that I endeavoured not to "stick blindly to [my] own fore-meaning about the thing if [I] want to understand the meaning of another" (Gadamer, 2013, p 281).

## 2.6 Co-creation

Forever at the forefront of my adopted epistemology has been the aspiration to enable the voice of the voiceless, or rather the language of the language-less, to be heard. From the outset, I recognised that I wanted, as far as was practicable, to include the participants in a collaborative and non-exploitative manner. I wanted to ensure that they were not researched upon, but rather researched with, with the ultimate aim of the research having been a transformative process for them as well as for me, and that they might recognise a practical, clinical, relevant application.

I wanted the voices of the people with aphasia to be heard loud and clear. I wanted this research not only to include them but to be inherently about and for them, in a truly collaborative and egalitarian way. I researched participatory action research (Koch and Kralik, 2006), hoping to include my participants every step of the research way, relying on them to help me mould the methodology and construct my approach, as well as to tease out the results, in a way that was meaningful to them.

The premise of participatory action research is “collaboration between researchers and those who are the focus of the research” (Robson, 2011, p 188). Involvement of people with aphasia in the whole research process seemed crucial if the project was going to be a conduit for some sort of change in the lives of people with aphasia. I wanted to empower people with aphasia to gain some ownership of the research process.

The concept of co-constructivism is desirable both from a research and a therapy perspective, but in both instances true parity is difficult to achieve, and this has led to a certain amount of tension within the research project. As a therapist, I was very aware of the potential (or actual) power differential between me (as trained professional, pursuing a qualification, with intact language skills) and the participants. They, after all, were generously giving of their time because they were responding to my plea for participants; their reasons for taking part were, I am sure, multifarious, but may not have included an inherent interest in, or understanding of, the project. I was the one with the voice recorder and the official-looking documentation, with University logos and tick-boxes. I was the one with an agenda and (albeit loose) set of questions. The participants in my first group were literally a captive audience, confined through hospitalisation and physical disability to their bedside. Although of course consent was carefully sought, still the power rested with me; after all, I could stop and start the interviews at my convenience, with a cursory “is it OK if...” Added to this, of course, was the language difficulty of each of the participants with aphasia. The communication power differential was most marked with those with the most severely impaired language output but also limited augmentative or alternative communication methods. So, although the expressive

spoken language skills of a participant called Lindy in group 2 are limited, her excellent use of the written word mitigates this to a large extent. Because I met this participant at her home, potential differences which could lead to a perception of power imbalance, such as education level, did not arise; one quick glance at her extensive bookcase demonstrated a woman of high intellect and education level. Contrast this with a participant in group 1, Liam, whose expressive abilities both verbally and non-verbally were so much more limited; in addition, he was not in his own environment, where his competence could shine through, but in a vulnerable state in hospital, in the passive role of patient.

Co-researching was therefore desirable from a therapist's perspective, and from a researcher-therapist perspective, but I began to consider whether it was indeed practicable.

Within the confines of a PhD project, I soon recognised that my pure participatory aspirations might not be possible to achieve. In a true participatory model, co-researchers would be free to design the methodology and collect data as they saw fit. Time constraints and time pressures of the PhD process – imposed both by the fact of my working fulltime and of the ethical approval process – meant that participants could not be approached and included until after the research planning process had got underway.

McMenamin, Tierney and MacFarlane (2015, p 917) acknowledge that people with aphasia are “often marginalised and excluded” both in society and in research. They, however, did successfully employ a participatory research methodology (participatory learning and action) during their research process (O'Reilly-de Brún et al, 2015), which encouraged democratic involvement of participants with aphasia who were able to share their emic experiences of taking part in a conversation partner scheme. Far from tokenistic, their involvement of people with aphasia was at all levels: design, data collection and evaluation. They employed focus groups and discussions, using data generation techniques from participatory learning and action methodology, namely flexible brainstorming, card sort, direct ranking and a seasonal calendar (McMenamin, Tierney and MacFarlane, 2015, p 921), in order to answer their research question related to the best and worst things about the scheme, and suggestions for improvements to the scheme.

Perhaps counterintuitively, my research with its subject matter of spirituality did not lend itself so readily to a full participatory approach. McMenamin and her colleagues had three discrete areas to discuss; I did not have specific questions to be answered but was rather opening up discussions around any aspect of spirituality, whatever that may have meant to each participant. Topic areas were therefore unformed and nebulous, and interviews became conversations, with no boundaries and no preconceived ideas. Some of the excellent data generation methods used in McMenamin, Tierney and MacFarlane's study (2015), such as card sorting, required a predetermined set of concepts and therefore would not have fitted with

the incredibly diverse, individual and idiosyncratic data obtained in these 'shedding light on' interviews.

In addition, the participants in my study might be divulging intimate thoughts and feelings within interviews, necessitating an atmosphere of trust and acceptance. A focus group in order to plan methodology perhaps would not have allowed this atmosphere of full acceptance.

That is not to say that further research on spirituality with people with aphasia may not be more participatory in nature. Perhaps now that research has begun with people with aphasia and spirituality, and initial concepts have been explored, techniques such as flexible brainstorming or card sorting may become more practicable.

My research project, then, was not co-constructed in the same manner as McMenamain, Tierney and MacFarlane's (2015) study, in terms of planning the research methodology, however, I endeavoured to create a "collaborative and democratic stance" (Robson, 2011, p 189) within the data collection by seeking out a 'critical friend', someone who knew what living with aphasia was like, someone who was comfortable with expressing her own spiritual story, and whose opinion regarding how to listen to others' stories I valued. My participatory aspirations in terms of planning the research methodology, then, began with Lindy in group 2, with whom I had open discussions at the beginning of the project related to the best way of gathering the data. She gave helpful suggestions about suitable questions to ask, and also acted as an understanding guide as I began to assume the mantle of research interviewer. Lindy may perhaps be viewed, borrowing a phrase from Heidegger (1962, p 155), (*Mitdasein* – being with others in the world), as a "Mit-researcher", that is to say, she was 'with me' in the interview design process, and indeed, integral to it. She was an expert collaborator in the process of planning how to go about interviewing people with aphasia.

Although I involved Lindy and other participants in checking back over the data and assuring that the meaning I had derived was correct, this was the extent of their involvement.

Perhaps it may appear disingenuous to refer to the participants as co-researchers, as Finlay (2011, p 175) suggests one might; I did not give them enough ownership of all aspects of the research design, implementation or analysis. However, Finlay (2011, p 175) does intimate that the term "co-researcher" might be used not only for those fully engaged in all aspects of the research process, but also for those engaged in a "dialogal method", where the researcher is committed to a "relational-centred" paradigm.

Although the planning of the methodology was not co-constructed, the stories, by contrast, were co-created in what Finlay describes as a dance, "a tango in which the researcher twists and glides through a series of improvised steps" (2011, p 74). Although planning and evaluating data is challenging to facilitate with people with aphasia, the collection of data by contrast must be collaborative, with the participants' skills of non-verbal, augmentative

communication, and the listener's skills of facilitation and listening both vital in the co-construction of the data. Finlay (2011, p 17) states that at the heart of phenomenological research is the desire to allow the individual's emic experiences to be heard; these experiences, "often arise out of participants' narratives which the researcher synthesizes and elaborates further".

During the conversations from which the stories emerged, I strove to enable the voice of the participants with aphasia to be heard. Hence, each participant has their own story chapter, and each chapter contains verbatim quotes to illustrate emerging themes or ideas. The stories were told, listened to and collated as a collaborative enterprise.

Constructivism with a population of people with severe expressive aphasia is challenging but enriching. Stories are produced verbally but also through gesture, intonation, writing or even silence. They are sometimes fragmented, or repeated, or their meaning is hidden. The person with aphasia produces a version of their story – through whatever modality is available to them – and their interlocutor moulds that story using attentive listening, questions, artefacts and acknowledgement. Stories are heard but also facilitated and coaxed. The epistemological process becomes at once cooperative and mutual.

Data in the form of the stories were therefore co-constructed, with the planning of the methodology and the analysis stage being carried out non-collaboratively.

## **2.7 Illness and disability narratives**

In health studies and research, patients' stories can be used to explore illness and disability (Holloway and Freshwater, 2007; Barrow, 2008; Brown and Addington-Hall, 2008). At a time when control over the body and over a future can seem compromised, individuals can successfully steer their stories and construct them as they want in order to navigate through that existential crisis:

"For patients facing serious illness, telling their stories is one of the few aspects of their lives that remain somewhat under their control" (Shapiro, 2011).

Frank's (2013) illness narrative typologies have been used in health literature for some time, such as in nursing (Holloway and Freshwater, 2007), chaplaincy (Mundle, 2011) and speech and language therapy (Moss et al, 2004; Mitchell, Skirton and Monrouxe, 2011) and these also helped in my study in terms of the planning of the interviews, the interviews themselves, and the analysis of the stories. As Frank (2013, p xx) says, patients "need to become storytellers in order to recover the voices that illness and its treatment often take away". Although Frank is perhaps talking figuratively here about lack of patient voice, in the aphasia population this concept of giving voice to the voiceless is even more pertinent. He distinguishes three different

illness narratives which can be heard in the voices of those who are ill. Although many of his examples pertain to illness such as cancer, I believe, like Couser (2016) that his typology can also be applied to disability states as a result of illness or accident. The three narratives are: restitution, chaos, and quest.

Restitution allies itself comfortably with the medical model of illness and disability. In this narrative, the patient is a passive recipient both of the illness and of its management. The medical professional is called upon to cure the illness which has attacked the individual, with the belief that “for every ailment there is a remedy” (Frank, 2013, p 86). Old medical terminology is pregnant with restitution phraseology, such as stroke victim, wheelchair bound and, indeed, the word patient itself (from the Latin *patiens* “one who suffers or endures” (Barnhart, 1988)). Patients are encouraged to adopt a ‘doctor knows best’ attitude, and wait ‘patiently’ for a cure from the expert.

A restitution narrative may have both a positive and negative impact on the patient. On the one hand, speaking in restitutive terms may engender hope and a desire to ‘fight’ against disease, knowing that it can be conquered. It is interesting, for example, that so much vocabulary surrounding cancer involves a lexicon of war; brave patients battle the disease, and sometimes lose their fight against cancer, often, incidentally, despite the best efforts of doctors. On the other hand, a restitution narrative may be unhelpful for those with a lifelong illness that cannot be cured, or for a permanent disability resulting from an illness. Their ability to accept and get on with and enjoy life may be hindered by an unrealistic aim of complete cure.

Frank (2013), interestingly, refers to the chaos narrative as the “mute illness” (p 97), the “anti-narrative” (p 98) that cannot be told but is only really lived. In the chaos narrative, individuals are adrift, mired in a morass of pain and trouble. There is a hopeless narrative, where there is no discernible end to suffering. Whereas in the restitution narrative, modern medicine and clinicians are available and ready to heal, in the chaos narrative, there is no hope of recovery; no one is in control. Frank (2013) gives examples of the words people living in chaos use, but he also suggests that the chaos narrative is “beyond speech” (p 101), that the terribleness of that state cannot successfully be put into coherent words. This has particular resonance for people whose language skills are compromised by the very illness that has plunged them into chaos.

If the restitution narrative aligns itself with the medical model of disability, the quest narrative is its antithesis, and exemplifies the social model. In the quest narrative, former patients are getting on with their lives, “searching for alternative ways of being ill” (Frank, 2013, p 117), which mean they can enjoy a meaningful life again. The disease entity may not in itself disappear or be cured, as is longed for in the restitution narrative, but nor does it define the

individual, as in the chaos narrative. Rather, people in the quest narrative are able to make “significant vocational and personal changes to [their] life following illness” (p 116), and so their stories are full of reports of a changed but meaningful existence. The process of therapy fits well into this narrative, with the therapist accompanying the individual, as together patient and therapist solve problems and compensate in order for the person with a disability to live well again.

The spiritual stories of the people with aphasia were therefore listened to through the prism of these disability narratives, in an effort to understand the participants’ stroke and aphasia journeys. In chapter 5, I explore the different narratives expressed by the participants with aphasia, and in chapter 6, I discuss the clinical relevance of listening to disability stories using Frank’s narratives.

However, for people with aphasia, telling their stories can be a challenge because “language can no longer be assumed to be a means of exploring, discussing and shaping experience” (Moss et al, 2004, p 755), therefore communication means other than language often had to be implemented.

## **2.8 Stories and story-telling: the case for using narrative inquiry**

Central to the methodology was hearing the voices of the people with aphasia, to ensure that the research was *about* and *for* them and other people with aphasia, rather than research *on* them.

If we accept that in order for a thought to be fully realised or accomplished, it must somehow be put into expression (Merleau-Ponty, 2002, p 206), then finding a way of enabling that expression for people with aphasia is of paramount importance. Stories and storytelling, using a Mosaic approach (Clark, 2001) is one way of doing this.

Storytelling and story-listening are part of the human condition. Stories are intrinsic to being human, “a basic aspect of human life and an essential strategy of human expression” (Kim, 2016, p 6). Stories have formed a part of human existence from as long ago as we have records. The indigenous peoples of Australia told their stories through elaborate rock art, drawn and painted onto the walls of the caves in which they dwelt. They formed a record of their history:

“The art in the stone temples and the mythology are the visual and oral history of an astonishing people who were highly intelligent, energetic, resourceful and responsible” (Trezise, 1993, p vii).

Not only did these pictorial stories tell of important animals, such as dingos, echidnas and kangaroos, major events (such as a man with a rifle being thrown from a horse (Trezise, 1993,

p 50)) and family history (as evidenced by the multifarious discovered handprints) in the lives of the aboriginal peoples, but they were also crucial in their spiritual lives, the so-called “Dreamtime”. So it is that storytelling and spirituality are inextricably linked in aboriginal culture.

Similarly, parables in the Bible were used by Jesus and have been used down the ages often, although not exclusively, to explain and to teach:

“Parables...revolve around one point of comparison between the activity in the story and Jesus’ understanding of the kingdom of God.” (Blomberg, 1990, p 30).

In an oral, preliterate tradition, truths or morals could be explained and understood via a story remembered. Some of these stories have become so ingrained in our collective consciousness that they are no longer about religious belief but rather form part of our secular moral learning (for example, the parable of the good Samaritan (Luke 10: 30)).

However, parables were not always clear to the listener. In Matthew 15: 15, the disciple Peter exhorted Jesus to “explain the parable to us.” Jesus seemingly wanted the listener to engage in the process of understanding as much as the storyteller. This is a two-way process, with the listeners actively having to open their minds to what was being conveyed. Jesus was employing a strategy which Kierkegaard refers to as “indirectness” (Strawser, 1995), in an effort to facilitate deeper, and more meaningful, understanding:

“Kierkegaard’s writings are indirect in the primary sense of not wishing to speak to readers directly, as from one person to another, from an ‘I’ to a ‘you’, but to have each reader communicate in private with her or himself, from an ‘I’ to a ‘me’” (Strawser, 1995, p 73).

There is perhaps a parallel here with conversations with people with aphasia; the meaning of what is being communicated may be obfuscated by word-finding difficulties, paraphasias and limited syntax, and therefore the listener needs to be proactive in working towards an understanding.

Using the method of story-gathering in order to explore the spirituality of people with aphasia, and indeed of the professionals working with them, therefore seemed apposite. Narrative inquiry enables the researcher (or the listener) to give free rein to participants, to communicate what is important to them, and crucially for this study, in a way that is conducive and useful to them. Away from the constraints of responding to closed questions, or forced alternative questions which can be imposed by questionnaires and surveys, participants are free to express themselves how they want and are able to. In order to shed light on this facet of humanness, the best method appeared to be to allow the participants to speak, or rather to communicate. Storytellers are able to express freely in their chosen modality and story-listeners are tasked with working with them so that the story can be successfully told.

According to Kim (2016, p 53), there is a “close kinship between phenomenology and narrative inquiry”. We can gain knowledge of phenomena through using phenomenological methods, such as subjectivity, phenomenological reduction, bracketing and intentionality, and all these methods are well-suited to a narrative approach.

Van Manen (1990, p 20) describes subjectivity as paying close attention to the object, being receptive to an object in order to fully understand it. He refers to being “strong in our orientation to the object of study in a unique and personal way”. In narrative inquiry, one is involved in the story, actively listening and appreciating the tale. In narrative inquiry with people with aphasia, perhaps the role of listener becomes even more involved in the process of conveying meaning, as the listener facilitates, probes and encourages output.

The concepts of phenomenological reduction and epoché - terms often used interchangeably (Kim, 2016, p 56) – were a source of intrigue and slight confusion throughout this study, perhaps appropriately so, given the ambiguity pervasive throughout. I struggled with wanting to be completely objective and open in my listening to the stories, keeping my preconceptions at bay, whilst wanting, and indeed needing, to give of myself during the interchanges. Talking to the members of the multidisciplinary team, I could not put aside my years as a therapist myself. My understanding of what it is like to engage with people with aphasia post-stroke enabled me to ‘get alongside’ these participants, to empathise, to show understanding and, hopefully, to engender trust. Likewise, when talking to the participants with aphasia, I could not put aside my skills as a therapist in terms of facilitating functional communication, nor could I detach myself from my desire to create a therapeutic interview space. I could not separate myself from my role of therapist, but nor did I think this was detrimental. On the contrary, I think it enabled me to encourage communication about a difficult subject, when it might otherwise have proved problematic. As discussed, I doubted if pure epoché was compatible with therapeutic interviewing of this nature, and recognised that perhaps Gadamer’s “fusion of horizons” (Gadamer, 2013, p 317) was a more therapeutic method of acknowledging my fore-meanings as a way of understanding the other’s. Was I an interviewer or a therapist during these interchanges? All the participants knew from the information provided that I was there in my capacity of researcher, in order to find out about their spirituality and its expression. However, I think and hope that the process was a therapeutic one for them, inasmuch as they were made to feel at ease, able to express freely in an atmosphere of acceptance and unconditional positive regard (Rogers, 1951).

Fusion of horizons, then, is integral to narrative inquiry (Kim, 2016, p 233). It enables the researcher to listen attentively and openly to the stories being told, whilst acknowledging her own fore-meanings and experiences. It truly allows the stories to “breathe” (Frank, 2010, p 3).

The final aspect of phenomenology which renders the phenomenological approach suited to narrative inquiry is intentionality. In fact, not only does intentionality lend itself to a narrative inquiry approach but it also, to my mind, is a vital aspect of listening to and understanding the expressive language and non-verbal communication of a person with aphasia. Kim (2016, p 57) explains that in order to know something or someone, we have to exercise “phenomenological comprehension”, whereby we attempt not only to understand the essence of that thing, but also its intentionality, that is, its being-in-the-world (Lewis and Staehler, 2010, p 67). When talking with people with aphasia, I had to strive for an “inseparable connection to the world” (van Manen, 1990, p 5) of the person with a language difficulty, a world of acquired disability and of altered roles.

Stories and narrative inquiry are rare in the speech and language therapy literature. Indeed, in some stroke research studies, participants with aphasia have been intentionally excluded from verbally-based (i.e. using interviews, narratives) studies “as it had been assumed that using these participants could reduce data quality and increase research time” (Mitchell, Skirton and Monrouxe, 2011). It perhaps sounds counterintuitive to use a narrative-based method to gather data from a population for whom narrative is difficult. However, as Mundle (2011) says, “missing in much qualitative research in aphasiology are the voices of those very persons with expressive aphasia speaking for themselves”. People with aphasia are able to tell their stories; we just need to be good listeners.

There is an element of co-construction of narratives with participants with aphasia; as listener, the researcher is facilitating expression by providing time, “ramps” (McVicker, 2007) or artefacts (such as in my interview with Joel in group 2). Sometimes, the listener has to clarify or paraphrase to ensure the correct meaning has been conveyed and understood. At times, during this study, I had to interpret the meaning of a word or phrase in my transcription; paraphasias and neologisms<sup>4</sup> sometimes required ‘best fit’ interpretations. Bronken et al (2012) discuss the case of constructing – or co-constructing - stories with a young woman with aphasia, recognising that “the telling and sharing of stories is seen as a primary tool for persons struggling to regain coherence and meaning in the chaos that often accompanies life-changing disease”. The process of co-constructing narratives in this study includes facilitation of communication between the participant (Maria) and the researcher (a nurse) by a speech and language therapist. The researcher describes how she strove to “act in a way that made Maria feel seen, heard, and acknowledged as a competent adult person” during the interviews.

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<sup>4</sup> A paraphasia is a word related to but different from the target word. In literal or phonemic paraphasias, more than 50% of the phonemes of the target word remain. In semantic or verbal paraphasias, an erroneous but semantically-linked (ie linked in meaning) word is selected. A neologism is an attempt at the target word which contains less than 50% of the target phonemes.

They conclude that it is indeed possible to tell one's story with aphasia, and that this story-telling is integral to recovery and coping.

Similarly, Barrow (2008) explains how she used narrative inquiry in her study of Anne, a woman with aphasia in her forties. She elucidates how both Anne and those close to her were able to express stories of living with aphasia, which contained themes of limited competence and being disabled as seeming less than whole. Barrow was then able to interpret these themes in the context of a "grand narrative" of a pervasive culture of restitutive medicine, where disability must be fixed.

Narrative inquiry and story-telling is therefore possible and, indeed desirable, for people with aphasia. Narrative inquiry ensured that the voice of the participants was central to the study; to paraphrase van Manen (1990, p 13), "the story is the thing".

## **2.9 Communication Mosaics**

It was clear that in order to hear the stories of the participants with aphasia, I would have to use more than my understanding of the spoken word; I would be collecting data in myriad forms. The stories were told through a form of the Mosaic approach, propounded by Clark (2001). This approach is co-constructivist in nature, where both researcher and participant are "engaged in the process of constructing meanings" (Clark, 2001, p 334) together. Originally devised as an approach whereby children were listened to and their opinions respected, it has developed to be accepted as a method of knowledge generation for any age group (Clark, 2011, p 328).

The Mosaic approach enables children who are pre-verbal or who have limited, developing verbal skills to express their feelings and opinions using methods which are "not reliant on the spoken word" (Clark and Moss, 2011, p 7). Methods include traditional observation and interviews, but also incorporate non-verbal expressions, such as use of photographs and maps. Clark (2001) used this method to explore the feelings and opinions of pre-school children attending a play centre; the participants were able to explain what they enjoyed and what they did not enjoy so much within their play environment. Similarly, careworkers in a different study were able to express how they felt about different parts of their working environment, through taking photographs and creating visual maps (Clark, 2011, p 324).

When the Mosaic approach was first devised, Clark and Moss (2005, p 5) articulated the following premises on which it was founded:

- Children as experts in their own lives
- Children as skilful communicators
- Children as rights holders

- Children as meaning makers

A person-centred approach with people with aphasia would look very similar, if not the same. By employing verbal and non-verbal techniques, people with communication difficulties are enabled to express their opinions, desires and feelings via whatever modality is easiest for them. In the research environment, the approach becomes participant-centred, allowing the participant to express their opinions and be intrinsic to the process of answering the research questions.

This project used some basic principles of the Mosaic approach, such as encouraging non-verbal communication methods (such as gesture) and artefacts as objects of reference (Ockelford, 1994), and other verbally-based but non-interview methods, such as email, text and Facebook. However, some barriers to using it in its full form were identified. For example, Clark (2001; 2011) suggests giving cameras to her young participants and enabling them to take photographs in order to convey meaning. In this way, children were able to 'articulate' favourite areas of the centre, or important people in their day-to-day lives. Although doubtless also a useful strategy for people with limited communication due to stroke, the often concomitant physical disabilities such as hemiplegia make this physically more problematic.

## **2.10 Conclusion to the epistemological journey**

My epistemological journey took me through explorations of various methodological approaches, including grounded theory and ethnography, before finally deciding on phenomenology. Phenomenology proved congruent with the essence of my study, inasmuch as I was determined to "grasp attentively" (van Manen, 2016, p 39) the stories of spirituality relayed to me by the participants. My approach whilst collecting the stories was more descriptive, and whilst transcribing and analysing the data demanded a more hermeneutic approach, employing the work of both Merleau-Ponty (1964; 2002) and Frank (2010; 2013) as an interpretive lens through which to view those stories. The stories themselves were listened to employing a phenomenological attitude of openness, awe and curiosity (Finlay, 2011, p 77), and facilitated through the use of total communication akin to Clark's (2001) Mosaic method. The following chapter outlines in more detail how the stories were collected.

## Chapter 3: How the stories were collected

**“for countless patients it is the telling of their stories that helps to make them well”**

**(Elwyn and Gwyn, 1999, p 188)**

### 3.1 Introduction to the method

In order to shed light on the experience of people with severe expressive aphasia expressing their spirituality, a method of data collection was demanded which was collaborative, participant-focused and facilitative; collaborative and facilitative because the communication skills of the participants necessitated an approach which maximised their ability to convey their thoughts and feelings on the topic, and participant-focused because the study aimed to be about and for people with aphasia.

Constructing the meaning of spiritual stories of people with aphasia was approached from a phenomenological perspective, which meant that I was interested in hearing the voices of the participants themselves. I was not interested, as some researchers are (Koenig, 2012), in determining spirituality or engagement in spiritual pastimes using measurement scales, or in the efficacy of certain spiritual practices, such as prayer, in healing (McCullough et al, 2000). From the outset, I questioned the feasibility or indeed the desirability of using questionnaires or scales with this particular population. For example, the FICA Spiritual Assessment Tool © (Puchalski, 1996) is a spirituality questionnaire devised in order to help physicians and other healthcare professionals to start to measure and address the spiritual issues of their patients. The acronym stands for faith, importance, community and address in care (or assessment and plan), and the questionnaire involves a series of questions related to each of these areas. Although Puchalski (1996) explains that the tool is not supposed to be a rigid checklist, but rather a way of facilitating discussions around spirituality, I still felt that, for the aphasia population with restrictions on their ability to give full verbal responses, it was preferable to be looser in my questioning style; not using a formalised questionnaire meant I was free to make my interviews real conversations. Although some of my questions overlapped with Puchalski's (1996) recommended ones in the FICA (see appendix IV for the topic guides), I was able to approach each participant in a flexible way, treating each one differently and individually, depending on the circumstances, and being led by them. For example, some interviews took the form of a 'getting to know you' chat, before the subject of spirituality could be broached. Spiritual assessments seem in the main to be geared towards patients giving verbal responses to verbal questions; I was keen to involve non-verbal facilitation in my conversations, as well as to welcome non-verbal responses.

I also questioned whether a positivist, quantitative, questionnaire-type method would satisfactorily give voice to the participants with aphasia. Although of course it would be possible to facilitate a person with aphasia to complete a words-based questionnaire, the use of verbal questions requiring verbal responses does put people with problems processing language at a disadvantage. Having to concentrate on the form of one's language rather than the content (Bloom et al, 1980) means that the spontaneity of one's thought processes is constrained. Questionnaires with fixed questions and restricted possible responses also did not feel flexible and creative enough in order to illustrate what spirituality meant to the participants. The severity of aphasia of the participants in the first two groups suggested to me that a facilitative, conversational approach would be more conducive to both the topic and to the communication methods of the participants, and would therefore elicit richer (or, as Geertz (1973, p 312) expressed it, "thicker") data.

In order to gain insight into expressions of spirituality from a number of different stroke and aphasia perspectives, three different groups of participants were sought, namely people who had very recently had their stroke (group 1), people who had had their stroke more than six months previously (group 2), and members of the multidisciplinary stroke team (MDT) who worked on a regular basis with people with aphasia (group 3).

Purposive sampling (Silverman, 2006, p 306; Robson, 2011, p 275) was used to recruit all the participants in all three groups. This study is an exploration or illumination of how people with aphasia express their spirituality and, as such, controlling for variables, or ensuring a spread of age or experience did not seem relevant. Because of the subject matter being so personal and individual to each participant, saturation of data could also not be, and was not, reached. Each participant gave their own unique story, so although themes sometimes overlapped between participants, saturation was not sought.

Qualitative researchers must ensure their work is dependable and trustworthy. In a quantitative research paradigm, the researcher would be compelled to seek a high level of reliability, that is, they would need to show explicitly how each step of the process was carried out, so that another researcher would be able to replicate the study (Silverman, 2006, p 282). A phenomenological methodology, by contrast, will be carried out differently by each different researcher, each perceiving, interpreting and writing in her own unique way; replicability of research and generalisability of data are not sought. Similarly, a quantitative paradigm demands validity, in order to "guard against the possibility of spurious correlations" (Silverman, 2006, p 289), but in a phenomenological study, no correlations are being sought, nor hypotheses proved or disproved. The more helpful concepts of trustworthiness (Robson, 2011, p 155) and rigour (Finlay, 2011, p 264) were instead considered. Trustworthiness was ensured by being explicit and transparent about my methods. I attempted to show a rigorous

approach to the research by extensive use of participants’ own words, so that their original, pure voices could be heard throughout. When I came to transcribe the conversations, and identify themes, I checked back with the participants that what I had written was a correct and true representation of their voice. The research is evaluated in more detail in chapter 6.

The different group members were as follows:

<b>Group 1: people recently diagnosed with aphasia</b>	<b>Group 2: people living with their aphasia for more than six months</b>	<b>Group 3: members of the multidisciplinary team</b>
Amy	Lindy	Speech and language therapist
Liam	Joel	Occupational therapist
Rosemary	David	Physiotherapist
	Peter	Nurse
	Francesca	Lay chaplain

Anonymity was preserved by using pseudonyms, so that only the participants’ gender was specified. However, Lindy in group 2 gave permission for me to use her real name, as well as to quote from one of her published works (*The Sudden Spoon* by L.E. Usher). Some facts were also changed in the interests of confidentiality. The members of the multidisciplinary team were identified by profession but not by name; it was important to be able to ascertain their job role in relation to their input with clients. I deemed the experience and time working with people with aphasia possibly to be relevant in terms of their ability or willingness to discuss challenging issues, therefore their grade was stated. All professionals were qualified in their field, bar the lay chaplain who was not an ordained minister but a volunteer. The chaplain in the hospital (an ordained minister) had felt that the lay chaplain was more appropriate to interview because of his experience of working on the stroke unit; she herself had more experience in other clinical areas.

All the participants in groups 1 and 2 had expressive aphasia, and their particular language strengths and weaknesses are outlined at the start of each story. None was formally assessed, and so their speech and language therapy diagnoses vis à vis their language and speech skills were derived in part from their speech and language therapist’s referring information (if applicable – see appendix III), and in part from my own informal observation during the interview or interviews.

This decision not to assess formally was a conscious and defensible one. I was uncertain what the benefits of a comprehensive, formal assessment of language skills might be. The types of language errors and limitations experienced by each participant are amply portrayed within their written story, and had need of no further extrapolation. In addition, in order to discuss a potentially personal and emotive subject such as spirituality, I felt I needed to forge a level of therapeutic rapport (Ardito and Rabellino, 2011; Stokes and McCormick, 2015, p 7) with the participants with aphasia. I also wanted to treat them as equals in the quest for an understanding of their experiences; I wanted to avoid the power differential between expert and client which can be engendered by formal assessment procedures (O'Malley, 2011, p 94). Although I have experience in working with people with aphasia, I was not an expert in their expressions of spirituality, and I did not wish to be perceived as such. Inevitably, participants may have regarded me as expert, and therefore with unintended power, but I tried to mitigate this by being as informal in my approach as possible, attempting to foster a relationship of friendship, rather than professionalism. So it was that I chatted to Francesca (group 2) about our shared university experience, and to Peter (group 2) about gardens. Testament to this is Amy's (group 1) introducing me to the patient in the next bed as her friend.

Throughout the interviewing, I attempted to employ a "phenomenological attitude" (van Manen, 2016, p 32; Finlay, 2011, p 73) as opposed to a "natural attitude" (van Manen, 2016, p 34), where I inquired "wonderingly" (van Manen, 2016, p 39) about participants' stroke stories and about their spirituality. This involved "holding on to a stance of non-judgmental acceptance, wondering openness and respectful empathic dwelling" (Finlay, 2011, p 79). In practice, this meant I strove always to present an open and interested mien, through eye contact, facial expression and body positioning.

Data in this study encompasses not only the words the participants said but also the neologisms and paraphasias they expressed, the words they wrote, the gestures they made and the intonation of their speech. I had originally planned to video-record all the participants with aphasia, in order to capture accurately this non-verbal data. However, having videoed an interview with Lindy, Joel and then with Peter in group 2, I came to recognise that this method of capturing expression was highly invasive and could even be a hindrance to effective and comfortable interviewing. I felt vindicated in my opinion about this when I was explaining the recording of interviews to a member of group 2 (Francesca). I said to her that I had been intending to video-record participants but that it felt – and she immediately supplied the word "obtrusive". Instead, I relied on audio-recording, combined with accurately noting down of non-verbal behaviours in my research log as soon as possible after each interview. Clark's (2001) Mosaic approach, used by her in interviewing very young, often pre-verbal, children, was adapted and employed with the people with aphasia. Clark (2001) encouraged children to

express their thoughts and feelings via a number of different modalities. For example, she encouraged them to take photographs of specific areas of the classroom and playground, in order to illustrate their thoughts about these areas. In a similar way, with my participants who were not pre-verbal but rather post-verbal, I wanted to encourage use of any modality useful to them which helped them to express their thoughts about spirituality. The mosaics for the participants in this study comprised writing (whole words and parts of words), poetry, gesture, intonation, facial expression and artefacts. Some participants added to their mosaics by using additional communication media, such as texts, email and Facebook. Thus, the data collected produced a colourful mosaic, full of shards of many different communication tiles, which made for a rich composite story.

### **3.2 People who had just had their stroke (Group 1)**

Participants in group 1 were inpatients on a stroke unit in a local acute hospital. People who met the inclusion criteria were identified by the speech and language therapist (SLT) on the ward, who then informed me via email using a tick list (see appendix III). Inclusion criteria were: having had a stroke resulting in aphasia less than 6 months prior to the interview, being medically stable, and having expressive aphasia in the context of good receptive skills.

There were many difficulties in recruiting to this group of participants. The stroke ward to which I had access was short-staffed, which meant that the SLT had other priorities rather than identifying and referring potential participants. In addition, there were fewer people who met the inclusion criteria than I had envisaged. Some people were physically well soon after their stroke, despite having considerable communication issues which would have made them eligible, and were therefore discharged before referral for the study could take place. Others were suffering from concomitant medical issues, which precluded their inclusion.

I organised a convenient time with staff members to enter the ward and talk to the potential participants. I made sure I did not interfere with therapy sessions or care. If she was available, the SLT took the time to introduce me to the participant. As I was in possession of a research passport issued by the NHS Trust, I was able to come and go on the ward as if I were a member of staff, which gave me flexibility in terms of number and timings of visits.

All group 1 participants were interviewed at bedside, either in single rooms or in four-bedded bays. The curtains were drawn round the bed space but inevitably the interviews were conducted in a noisy environment with minimal privacy. This was particularly evident in my interviews with Liam; concentration was problematic for him with so much noise going on, and from my perspective, I found it difficult to broach subjects of a sensitive nature with the to-ings and fro-ings of hospital life going on all around me. In fact, I felt out of place; nursing and

other staff were busy dealing pragmatically with the practical details of making people physically comfortable and well, whilst I was asking questions of spirituality and numinosity. It almost felt irrelevant; I felt irrelevant.

I met each of the participants beforehand, just to check that they would be happy to be interviewed. This also enabled me to begin the process of getting to know them a little, of becoming familiar, perhaps even of creating a therapeutic alliance (Stokes and McCormick, 2015, p 6). At the first interview, I made sure I explained the research in accessible language, and I also read through the accessible information sheet with the participants (appendix II). I then gave them the consent form to sign, reading through each question with them to ensure understanding. I realised early on that I needed to spend a good deal of time over this process, in order to be confident that the participants fully understood what inclusion in the study entailed. Even from a purely physical perspective, gaining consent was time-consuming and difficult for the participants; signing a form when you are lying in bed and not able to use your preferred hand due to hemiplegia is challenging. For one participant (Rosemary), I had the impression that this was the first time she had attempted to write since the stroke; responding to her confusion at this new-found difficulty necessitated a respectful and thoughtful response.

Participants in this group were seen more often but for shorter sessions than the other participants. Liam was interviewed three times, Rosemary twice and Amy four times, all over a period of one week (Liam and Rosemary) or two weeks (Amy). This was for a number of reasons; although they were medically stable, they had all recently suffered a stroke and, as is common post-stroke (Markus, Pereira and Cloud, 2016, p 451; Michael, 2002), they were apt to fatigue quickly. In the busyness of an acute hospital ward, there were many pressures on their time, including therapy sessions and the need for personal care. There were also mealtimes, which also understandably took precedence over interviews.

Interviews were loosely based on a pre-devised topic guide (appendix IV) but really became conversational interviews (Kim, 2016 p 262; van Manen, 1990, p 63) rather than semi-structured interviews (Robson, 2011 p 285). It was important to forge a relationship with these participants before being able to broach a subject as sensitive or personal as spirituality. I believe I managed to do this to a greater or lesser degree with Amy and Rosemary but not Liam in group 1; on my last visit to Amy, she asked if I would be able to come and see her at home, once she was discharged.

It soon became clear to me as I embarked on these interviews, that I was talking to participants as a therapist. I was not and could not be an objective question-poser, primarily I think because of my training and many years practising as a therapist. Interviews were facilitative, with many attempts to encourage or facilitate expression via whatever modality

was useful to the participant. I could not bracket off (van Manen, 1990, p 175; Moustakas, 1994, p 85; Lewis and Staehler, 2010, p 5; Finlay, 2011, p 23) the therapist in me; it is too much a part of who I am. I also think it would have been unhelpful to have bracketed myself off; I think I needed to bring myself into the interview sessions in order to forge rapport, which in turn allowed the participants to open up and express sometimes quite personal issues. The essence of epoché that I did attempt to bring to the interviews, however, was an ability to listen with an “unfettered stance” (Moustakas, 1994, p 85), being open and accepting of what was said to me, without bias or prejudice in my response or mien. Thus, I hope I employed a phenomenological attitude (Finlay, 2011, p 73; van Manen, 2016, p 32), meshed with the concept of “fusion of horizons” (Gadamer, 2013). The concept of epoché and the tension between the role of researcher and that of therapist are discussed in more depth in chapters 5 and 6.

Video-recording seemed particularly inappropriate in an acute ward setting, where patients are often in a state of semi-undress, sometimes (like Liam) with a nasogastric tube in situ. In the interests of dignity, I quickly recognised that audio-recording would be the optimal method of recording the interviews, supplemented by note-taking and reflection immediately after each encounter.

Interviews were therefore audio-recorded only, using a Sony ICD-PX312 digital voice recorder. I captured any written or drawn communicative material, either by keeping the paper on which words, numbers or pictures were written, or by photographing these. I also made quick notes after the interview in my research log, to remind myself of gestures or occurrences in general which might not be immediately apparent merely from an audio recording.

After interviewing, I listened to each of the recordings and made preliminary notes. Listening to the interviews helped me picture the interview better, and remember intonation patterns and gestures used. In Heidegger’s terms (1962, p 80), I took time to dwell with (“aufhalten”) the conversations, allowing myself to become familiar with the storytellers’ words, prosody and tone. I then attempted to transcribe each interview verbatim, including using phonetic script (International Phonetic Alphabet) to transcribe neologisms and literal paraphasias. Pauses and fillers (for example, “um” and “er”) were noted, as was the surmised communicative intent of intonation. Some of the utterances were impossible to transcribe, due to concomitant apraxia of speech and dysarthria in some instances, and due to noise on the ward in others. An example of part of a transcribed interview can be found in appendix V. Periods of latency of over 2 seconds were also noted in the transcript. The transcriptions were then analysed using a thematic analysis approach (Braun and Clarke, 2006), and key themes were identified.

The thorny issue of epoché needed to be addressed in the analysis, as well as in the data collection, stage. Just as I found it impossible, and indeed undesirable, to bracket off my experience during the interviews, so I found myself also drawing on that same experience in the analysis stage. I brought into the analysis my history, culture, religious background and my clinical experience (for example, in interpreting obfuscated meaning in some aphasic utterances). Gadamer (2013) legitimises this need to bring oneself into both data collection and analysis, by advocating the use of the hermeneutic circle in order to optimise understanding of a phenomenon.

### **3.3 People who had been living with their aphasia for more than six months (Group 2)**

I recruited participants for group 2 in a number of different ways. I visited Stroke Association and other communication charity groups and gave a short, accessible presentation about my research project. I then invited people to give me their email address or telephone number if they were interested in being interviewed.

One participant (Joel) was taking part in the conversation partner scheme at a local University, and expressed an interest in being interviewed.

Lindy was the first participant I interviewed in this group, and she was very much instrumental in co-constructing the topic guide, and in teaching me how to interview about a topic such as spirituality. We met a couple of times at her house, where we discussed not only her spiritual story but also how I might go about unearthing spiritual stories with other people with aphasia.

These interviews tended to be longer than those for the participants in group 1. The way I carried out the interviews, the feedback I gained from them and the number of times I visited varied from participant to participant for a number of reasons.

I viewed Lindy very much as my co-researcher in terms of planning these interviews, so we met on 2 occasions to chat, but we were also in contact via email and Facebook. She also sent me material extraneous to the actual interviews, such as poems, important jottings and recommendations for books. She is about my age, with, like me, a love of literature and cats, so we have really become friends, as well as co-researchers.

Peter, on the other hand, I met only once. I asked via email a few months later whether I could go back and visit him but I did not hear from him. During our interview, he shared with me that he suffered from mental health issues, and that this seriously affected his ability to take part in activities. Although he volunteered to be interviewed after I had given a presentation to his Stroke Association group, I got the feeling that the concept of spirituality was not in fact a

particularly important one to him. Whatever the underlying reason, he did not consent to a second interview. It transpired later in my study that Peter had been admitted to a nursing home after a recurrence of his cancer, and he sadly died a year or so after our conversation. It was a similar picture with David. Having transcribed his interview, I drew up an accessible summary of the key points he had raised and emailed it to him for comments. He did not respond, and we did not meet a second time.

Joel, on the other hand, was happy to be interviewed again. This enabled me to refer to points raised in the first interview, as well as to bring to the second interview artefacts that I felt might facilitate or encourage expressions of his faith.

Francesca I also only interviewed once, but when I sent her a summary of our discussion, she emailed back some amendments and comments.

Interestingly, the two participants with aphasia who seemed the most engaged with the project were Lindy and Joel, both practising Christians. It could be that these interviews and the questions I was asking resonated more with the people of a prescribed faith. It could also be, as I shared their faith tradition, that I asked questions more pertinent to them. (David and Francesca both said they were spiritual people who believed in something but they did not subscribe to a specific religion. Peter referred to himself as an atheist.)

I met the participants in group 2 wherever it was convenient for them. In most instances this was in their home, the exception being Francesca, whom I interviewed in a quiet room adjacent to the hall where her communication group was meeting. The loose topic guide (appendix IV) was not given to the participants in groups 1 or 2 prior to the interview, as I had found whilst talking to Lindy that the conversation would – and possibly should – diverge in all sorts of unexpected directions, led by the participant. The guide really played the role of prompt for me, if and when conversation lulled.

As for group 1, all interviews were audio-recorded using a Sony digital recorder. My initial interviews with Lindy, Peter and Joel (interview 1) were in fact video-recorded using an iPad or a Sony video recorder, but as discussed earlier, this soon came to feel intrusive and counterproductive in my attempt to forge rapport with my interviewees.

What I had initially thought would be semi-structured interviews soon turned into conversations and, in some cases, therapeutic conversations. For example, Peter shared some intimate details about his mental health and about significant physical health concerns. There is, I think, something about the topic of spirituality which can fast-track therapeutic rapport-building, so that, for example, after my second visit to Joel and a subsequent thank you email from me, I received a reply from his wife saying:

“it’s our pleasure. And thank you much more for taking the time to come” (Sarah, private email).

Once complete, I listened to all the interviews and again “dwelt” (Finlay, 2011, p 229) with the data and noted any themes or topics of interest which immediately presented themselves. I then transcribed all the interviews verbatim, again transcribing any paraphasias or neologisms phonetically, noting pauses, intonation patterns and gestures (see appendix V).

Because I decided to abandon my idea of video-recording, I had to quickly write down after the interview any non-verbal communication that seemed pertinent. My earliest interview (with Lindy) taught me the value of photographing written communication attempts; she uses her pen and paper regularly during conversation to supplement her speech, but I found myself unable to ask for the sheets of paper to take away at the end of the interview. It felt almost as if I would be taking away her thoughts and voice, something that was not mine to take.

Once the interviews were transcribed, I highlighted emerging themes, again using a thematic analysis approach (Braun and Clarke, 2006).

### **3.4 Members of the multidisciplinary stroke team (Group 3)**

I interviewed five members of the stroke multidisciplinary team (MDT), four (an occupational therapist, a physiotherapist, a speech and language therapist and a lay chaplain) from the same unit in an acute hospital. The nurse was from a different unit in a different acute hospital but the same NHS Trust. The participants were all qualified in their respective professions (except the lay chaplain), all had significant experience of working with people with aphasia and all were of a senior rank (apart from the lay chaplain, whose job was not part of the healthcare bandings).

I presented my research proposal to a multidisciplinary team meeting on the stroke unit, and asked for anyone interested in being interviewed to contact me. Team members were also encouraged to take part by a research-active consultant in stroke.

Most of the interviews took place during the work shift in a quiet room off the ward. The exceptions to this were the speech and language therapist, whom I interviewed at the University, and the lay chaplain whose interview took place in the hospital chapel.

Participants were sent the topic guide (appendix IV) prior to the interview, to allow them time to reflect on some of the questions. However, in line with the other groups, we did not adhere to this guide but rather the interviews became conversations between peers.

A form of phenomenological reduction (van Manen, 1990, p 185; 2016, p 215), was used in the MDT interviews, in that I strove to be open and accepting of all information that was given to

me. I was by no means an objective onlooker, however, as I found myself bringing my experience as an SLT and as a multidisciplinary team member to the conversations. Part of this was creating peer-to-peer trust and understanding; I had to give something of myself and of my experience in order to achieve this, and therefore to encourage candour. As with all the interviews then, epoché was employed in van Manen's (1990, p 47) understanding of the term, where my presuppositions relating to various team members' roles were held at bay to enable me to "study the essential structures" (p 175) of the topic at hand. As for all the interviews, the fore-meanings in my own horizon (see chapter 2) were present and acknowledged as it fused with the horizon of my interviewee (Gadamer, 2013).

Conversations were again audio-recorded. If comments were made after the digital recorder was switched off, these were noted down and permission asked of the participant to use this data. The SLT continued the conversation via text over a few days after the interview.

Once completed, I listened to each of the interviews and noted down words or phrases or concepts which immediately leapt out at me. I then had the interviews professionally transcribed. On receipt of the transcripts, I listened to each interview again, and made any small adjustments to the transcripts that were necessary.

Once I had the transcripts in front of me, I was able to identify key themes (Braun and Clarke, 2006) discussed by each of the healthcare professionals. The themes were then woven into a story for each professional, using their own voice to illustrate key concepts.

### **3.5 Data: collating the stories**

Each participant's interview (or interviews) was written up in the form of a story of themes, that is the salient themes were identified and then illustrated by direct quotations from the person's transcript. One further story was created by identifying and drawing out overarching themes from the stories of the people with aphasia. I was keen for the voice of the people with aphasia to be heard throughout the research, at times unfiltered by another's interpretation, so there are a plethora of direct participant quotes.

'Data' seems an odd word to align with what was communicated to me during the interviews, with its positivist overtones and connotations of numbers. However, the etymology of the word 'data' – from the Latin 'datum' meaning 'thing given' – makes a mockery of my squeamishness, and actually renders the term highly appropriate. The words and other expressions were 'given' to and received by me; data did not just emerge but was given. Richards (2015, p 36) talks about "making" the data, as opposed to collecting it. She says that, after all "you are hardly an innocent bystander in this process of data making" (p 27). The interview process itself creates a dynamic and a relationship, and is integral to what data is

actually given. At times, the data from the people with aphasia had to be coaxed out; appropriate clarification questions were asked, non-verbal communication of my own given, artefacts used. I certainly was not an “innocent bystander” (Richards, 2015, p 27) but an active agent in the production of the data, which was given by the participants and facilitated by me as researcher.

### **3.6 Ethical considerations**

The ethical considerations for any research project cannot be overstated and full ethical approval is of course essential. I considered the ethical issues involved in this research very carefully, not least because I was intending to have conversations with people for whom conversation can be problematic. Added to this, I had chosen a difficult and potentially sensitive conversation topic in spirituality. I was, in fact, asking people who find talking difficult to talk about something difficult.

For group one, I applied for and received ethical approval from the NHS (REC number: 14/LO/0718). Interestingly, some concerns the ethics committee expressed were around the filming of people in hospital. Although I defended my decision at the time by explaining that I was eager to capture all non-verbal communication, I changed my mind, as has been discussed, and effectively agreed with the committee that use of video would be intrusive and run counter to preservation of dignity. The ethics committee also wanted clarity as to why I was not intending to assess the participants in group 1 formally – particularly, I think, in relation to gaining informed consent - but essentially my reasoning for this was understood and accepted. Group 1 participants were given accessible information sheets and consent forms, to ensure full understanding of what they were consenting to. I also talked through the information sheet and consent form with them, to ensure comprehension. Participants were reminded that they could withdraw from the study at any time, should they so wish. I obtained a one-year research passport from a local NHS Trust, which enabled me to enter the local stroke unit freely, as if I were an employee.

As I did not intend to recruit group two participants through the NHS – these participants were at least 6 months post-stroke and were no longer in receipt of acute or rehabilitation care – I applied for and received ethical approval via the University’s Faculty Research Ethics Committee. I think it is a moot point whether people living with aphasia post-stroke are ‘vulnerable’, since their cognition other than language is usually largely intact, nevertheless it seemed sensible to err on the side of caution and apply for full University ethics approval. Again, all information and the consent forms were presented in an accessible manner, and I talked through both the form and the information sheet with each participant.

There was no need to seek full ethical review for group 3, as participants in that group were all non-vulnerable adults who were able to give informed consent. Each participant in this group was given an information sheet to read and ample time to discuss participation in the study with me. They were then asked to sign a consent form, which included permission to be recorded. Copies of the participant information sheets and consent forms can be found in appendix II.

### **3.7 Issues related to interviewing**

I had to learn how to talk to people about spirituality. Beginning this project, I was not even sure it was possible to discuss these issues with people with whom I did not have a close and deep relationship, or with whom I did not share a particular faith tradition. As a practising Christian, to an extent I was used to talking to friends and fellow church-goers about their Christianity, and to sharing my own faith, but as a therapist-researcher, talking to people unfamiliar to me about their definitions and experiences of spirituality was a new and unexplored area. I therefore decided to interview some of my own students about their spirituality. I advertised for volunteers and was surprised and delighted to have several students come forward. These 'mock' interviews were invaluable. They helped me shape my questioning, hone my listening, and instilled confidence in me that I was indeed capable of conducting such interviews. One of the most important lessons I learnt from these interviews (and this was also reinforced by my reading Patton (2002, p 379)) was to leave a very open question at the end, such as "is there anything else you would like to discuss?" This, I think, enabled the participants to talk about issues that did not or had not fitted into the previous questions or discussions, and sometimes resulted in rich elements of the story.

### **3.8 Storytelling, story-listening and rapport**

Encouraging people to tell their story about spirituality was at once illuminating but fraught with methodological difficulties. The ability to tell their story comfortably was dependent on many variables, and I felt that the success of my ability to hear the real story varied from participant to participant.

The primary difficulty was a lack of time, time to forge meaningful and genuine relationships. With some participants (for example, Lindy, Peter, Joel (group 2) and the SLT), I felt an immediate and tangible closeness. On reflection, I think this was due to a number of different influences, such as a similarity of age, a shared faith tradition, even a love of cats. Somehow, we connected quickly, and this led, I think, to an openness (on both sides) during the

conversation. People shared intimate aspects of their faith, and of other aspects of their life, such as their mental health.

With other participants (notably Liam (group 1) and David (group 2)), connection was lacking. Why that connection was missing can only be surmised, but may have been in relation to gender, age or lack of common ground. This difference in connection definitely impacted on the stories conveyed and on their interpretation and is perhaps best summed up by this comment from David:

“I can imagine that you’re not...imagine it’s. I tried to tell you yesterday. I really do think you weren’t er...oh well, never mind”.

Within this statement, I think, there is a sense of resentment (“I tried to tell you yesterday”), and a feeling of exasperation (“never mind”). I remember feeling acutely embarrassed and not a little affronted during this interchange, almost as if he had spurned my friendly advances, and consented to an interview he was, after all, not invested in. In fact, of course, he was perhaps more likely to have been expressing his lack of interest in discussing spirituality with me, or his belief that what he might have to convey on the subject was not of interest. He might, also, of course, not have felt comfortable with me as a person, a fact I have had to ponder on.

This inability to forge rapport with some participants was a personally difficult one for me, as well as being unsatisfactory from a research perspective. As a therapist, the ability to forge therapeutic rapport is part of my *raison d’être*. If I was not able to make every participant feel comfortable, what sort of a therapist was I? I wrote in my reflective journal at the time of interviewing David “I felt I didn’t really connect with David”, but reflecting on this was a useful exercise. It helped me recognise that, as a therapist or as researcher, we do not always immediately find connection. Connection is a process which may take time, a luxury I unfortunately did not have during this study. I noted in my journal how my interview with Rosemary was meant as a preliminary ‘get-to-know-each-other’ chat; however, because she was quickly moved to another facility, it became our only discussion, and spiritual matters were hardly touched upon. Rapport, it seems to me, is essential in storytelling and story-listening, not least when those stories potentially comprise personal and intimate details.

### **3.9 Thematic analysis**

The process of drawing out the themes was carried out using a flexible approach, based on the work of Braun and Clarke (2006). They recognise that there are essentially two schools of thought when considering qualitative analytic methods. On the one hand, there are analytic methods which are driven by and wedded to their particular epistemological position, such as,

for example, conversation analysis (Robson, 2011, p 373). On the other hand, there are those methods which are not reliant on or tied to any particular epistemology or theoretical framework. Thus, it is in this case that a phenomenological study, arising from a constructivist epistemology uses a flexible analytic approach propounded by Braun and Clarke (2006). Thematic analysis was used for “identifying, analysing and reporting patterns” (Braun and Clarke, 2006, p 6). The first step was to familiarise myself with the data (Braun and Clarke, 2006, p 160); I achieved this by listening several times to the recorded interviews. Each interview was listened to and the transcripts read multiple times in order to dwell with (Heidegger, 1962, p 80; Finlay, 2011, p 229) and immerse myself in (Robson, 2011, p 476) the data. I found this an invaluable strategy, because by listening to the interview again, I could re-imagine myself with the participant, and could then remember gestures or facial expressions which I had not noted down at the time. For groups one and two, this process of familiarisation was helped by carrying out the transcription myself, so listening to the interviews was followed by multiple additional playings of the recordings as I transcribed all the verbal and non-verbal information. Group 3 interviews were professionally transcribed, but I endeavoured nevertheless to familiarise myself with these by listening to them several times, and then listening to them again with the transcript in front of me.

Initial codes (Braun and Clarke, 2006, p 18) were generated and noted on the transcripts; on each script, I highlighted words and phrases that seemed important, and gave broad names to the theme they illustrated, such as “trauma of the stroke”, “life meaning” or “connection”. Themes were searched for, reviewed and named (Braun and Clarke, 2006, p 22) at first in tabular form (see appendix VI for an example of an annotated script and a themes table), then woven into stories for each participant. Some themes common to both groups of participants in groups 1 and 2 were in turn woven into their own story.

Data was ‘given’ but then moulded and shaped into themes in an active way. With the participants in groups 1 and 2 with aphasia, I felt I was actively involved even during the interview process in nurturing the data and enabling it to come to the fore, through active listening and facilitation techniques. Themes, then, did not so much emerge intransitively but were actively brought into being.

Being mindful of rigour, I did attempt to check back with my participants once the data was recorded and typed up. Some, such as Lindy and Francesca (group 2), gave written feedback. Others were not engaged in this process for various reasons: lack of time (nurse), probable lack of interest in the research subject or process (David and Peter, group 2), illness (Liam, group 1) and loss of contact (Amy, group 1).

Because spirituality is notoriously difficult to define, or perhaps defies definition altogether, I had no preconceived ideas as to what themes might arise during the conversations. The

thematic analysis, then, was inductive in approach, and it was only when I came to analyse groupings of data together (that is, all the conversations with people with aphasia) that themes common to several participants started to be discovered.

### **3.10 Writing a phenomenological study**

I have attempted to write the stories, and indeed the entire thesis, in a manner congruent with the phenomenological approach. The phenomenological approach is, in turn, congruent with the subject matter of spirituality, and with some of the participants having a communication difficulty. The results of this study cannot be “severed from the means by which the results were obtained” (van Manen, 1990, p 13); the stories are the results and the way those stories were collected and collated are part of that bigger story. The methodology, methods, results and discussion are all part of the same story, which is an evocation of the spiritual stories of these individuals. There is no traditional results section, no summary, no conclusion per se, but rather a telling of the process of exploring people’s stories:

“you will listen in vain for the punch-line, the latest information, or the big news. As in poetry, it is inappropriate to ask for a conclusion or a summary of a phenomenological study...The poem is the thing” (van Manen, 1990, p 13).

So, then, the stories are the thing, and within the stories reside the words (and gestures, writing, intonation and facial expression) of the people with aphasia themselves. Adopting a participant-centred approach along the lines of the person-centred or patient-centred approach prevalent in healthcare today (Koubel and Bungay, 2008), I have produced parts of the participants’ stories verbatim, complete with pauses, fillers and paraphasias. This was in order to give them their voice, not their voice mediated through me and my preconceptions and pre-judgements, but their true, pure, unadulterated voice. I wanted their essence (van Manen, 1990, p 177; Merleau-Ponty, 2002, p vii, Finlay, 2011, p 93) to exude through the page via their Mosaics (Clark, 2001) of words, non-words, gestures, pauses and writing.

I have used the first person in most of the chapters of this thesis. This was in order to illustrate an acknowledgement that I bring my own experiences, thoughts and beliefs to the study (Holliday, 2007, p 120). In some ways, I wanted my own voice to be heard, alongside those of my participants. Had someone else with a different life history, different life experiences, different beliefs narrated this research, the story would also have been a different one. In a sense, I am one of the participants of the study, and this is my story.

Each story is also in the present tense, a conceit I have used intentionally in an effort to position, as Hilary Mantel puts it, “the reader and the writer in the same space, as well as in the same moment” (Lea, 2015).

Above all, throughout the writing, I have attempted to encapsulate concepts of acceptance, understanding, reverence and awe:

“The phenomenological method consists of the ability, or rather the art of being sensitive – sensitive to the subtle undertones of language, to the way language speaks when it allows the things themselves to speak” (van Manen, 1990 p 111).

What follows, therefore, are the participants’ stories, both those of the people with aphasia and those of the stroke team. I tried to hear the stories using a “phenomenological attitude” (van Manen, 2016, p 32) of attentive listening, wonder and curiosity throughout. I focussed on respecting the disability narrative as it was given to me, by attempting to adopt a Gadamerian fusion of horizons. Finally, stories were presented in mosaics of inventive and effective communication strategies, both verbal and non-verbal.

## **Chapter 4: The stories**

**“a story requires listeners; it must be told”**

**(Frank, 2013)**

## Annotations used in transcripts of participants' interviews:

...	short pause
( <i>latency</i> )	latency of response in seconds
( <i>comment</i> )	description of non-verbal communication
(word/ phrase)	possible translation of a paraphasia
{name}	actual name removed to preserve anonymity
S:	researcher
[ ]	paraphasias and neologisms written in International Phonetic Alphabet (IPA)

## **The stories of people who had just had their stroke**

## **Amy: the homemaker's tale**

**“ the mole roused himself and dusted and polished with energy and heartiness”**

***(The Wind in the Willows, Kenneth Grahame)***

Amy is an elderly woman in her late seventies, an inpatient in hospital following a stroke several weeks previously. We meet on the acute stroke unit, having been introduced to each other by the speech and language therapist on the unit.

I meet Amy four times in total; sometimes she is in a single room, at other times she has been moved to a four-bedded bay. Wherever our conversations take place, she is always surrounded by family photos – mostly of grandchildren – and get well cards.

### **Amy's communication**

Amy presents with good auditory comprehension skills in the context of significant expressive difficulties. Her speech is dysarthric, typified by the imprecise consonants and slower articulation often seen in unilateral upper motor neuron dysarthria (Duffy, 2012). Her expressive language comprises reduced syntactic complexity and reduced lexical choice. In terms of the cognitive neuropsychological model of language processing (see appendix I), her deficits are probably at the level of the phonological output lexicon; she produces the occasional phonemic paraphasia but no semantic paraphasias during our conversations. Amy has good pragmatic skills; she is able to hold eye contact and take appropriate turns in conversation. Her social speech is relatively preserved, as evidenced in the following example:

A: You feel all right?

S: Yeah, I'm really well, thank you, yeah, I'm really well

A: Good

### **Amy's communication mosaic**

Speech is Amy's most used expressive modality, but she supplements this with meaningful intonation and occasional use of gesture, such as when she indicates 'prayer' and 'blessing'.

### **Relationship**

Much of our early conversation revolves around important relationships in Amy's life. Family photos around her hospital bed lend themselves to discussions about children and grandchildren. On some occasions, she explains how they have visited her:

A: He come to see me

S: Ah

A: And him...him and him

S: and these two have been, haven't they, yeah?

A: Yeah

S: So, this is all your family

A: yeah

S: Mmm

At other times, she is adamant that they have not been, and indeed she seems rather resentful of the fact:

S: So we talked a bit last time about...erm...your...er...children and your grandchildren

A: I don't see them

S: Don't see them? Oh, have they not been in for a while?

A: No

S: Oh, I'm sorry to hear that...ah...(pause)

She expresses the love her children and grandchildren have for her using both language and evocative intonation:

A: Yeah. They come and see me. They give me a kiss.

S: Do they? That's lovely

A: I love you (*imitating child, in a sing-song voice*) he goes

S: Ah, that's lovely

A: He said "I love you!" he said "I love you!"... He really love me

However, she is also very candid in her criticism of the grandchildren and how they behave at times:

S: So what do you say to them?

A: I say "come 'ere!"

S: Do you...oh

A: I say "come 'ere"...bollocks...he says bollocks

S: Oh

A: He's a little...I say "why do you say bollocks?"...(imitates child) "sorry"

and again:

A: Bugger he is...there (*pointing to photo*)

S: Yep, on the photos – yeah

A: "I want, I want", he goes "I want"

Clearly, Amy's children and grandchildren are important to her, and bring her much joy. However, she is also quick to point out their faults, even to me, a comparative stranger. I wonder if this is a reflection of the trust built up between us, or whether she has become a little disinhibited post-stroke (Halpern and Goldfarb, 2013, p 169), saying things she would not normally voice in public?

### **Home**

It is clear that Amy is desperate to get back home after her stay in hospital. She often asks me when she will be able to go home, as if I am a member of staff at the hospital:

A: Oh, I like to go home

S: You'd like to go home

A: Please

S: Yeah, of course, I know

A: Oh, I love to go home

Interchanges like this one leave me feeling somewhat guilty that I am not able to do something constructive in facilitating discharge from hospital to home, and also that I am engaging Amy in discussions about life meaning and purpose when her overriding desire is not to be in hospital at all. Amy's use of the word 'please' makes me feel frustrated that I cannot help but also almost like I am there under false pretences, that is, that Amy believes I *am* in fact a member of staff with control over such issues.

Home, and being and doing at home, are recurring themes in my discussions with Amy. When, in response to her obvious and keenly felt desire to go home I ask her what it is she is missing most about home, she tells me about how she is missing the day-to-day chores:

S: What are you missing most about being at home?

A: Washing

S: Washing?

(*pause*)

A: I do the washing

S: You do the washing

A: Yeah

S: So, do you miss doing those chores?

A: Yeah

In another interview, she talks about her desire to get home in order to resume her chores:

S: You'd like to have gone home?

A: Please

S: Of course, yeah

A: Tidy up...yeah

S: To tidy up the house?

I picture her as a house-proud woman, who has always cared for her family and her home. It seems that this role is one that gives meaning and purpose to her life, and is one that she misses hugely when she is away from her home.

I find it difficult to gauge whether Amy lives alone or not. During one conversation, she implies that her husband is no longer around, although the information conveyed is not clear and I am not convinced that I have fully understood:

S: Yeah, fantastic...and do you have a husband at home, Amy?

A: No, no

S: No

A: No, he stay there

S: Stayed there?

A: He must be sleep...(working)

S: Has he passed away?

A: No

S: No

A: No

S: Just not at home any more...

On another occasion, Amy tells me that she lives with an aunt:

S: You said you live by yourself, don't you, at home?

A: I live with me...er...Auntie. I live with it.

S: You live with your Auntie?

A: Yeah

S: Ah

A: Yes, she moved in to my place

S: Did she?

A: Yeah

S: So, there are two of you at home?

A: Yeah

Because of her age, it seems unlikely that Amy meant 'auntie'. It might be that she has selected the incorrect word in terms of a female relative, a not uncommon error in aphasia (Papathanasiou, Coppens and Potagas, 2013, p 134); perhaps she means niece or daughter. In our final conversation, Amy tells me that her son is getting her house ready for her return:

A: Doing my house up

S: Doing?

A: Painting

S: Ah! Who's doing that for you?

A: My son

S: Oh, brilliant! What's your son's name?

A: Er...{name of son}

S: {name of son}...that's a nice name

A: Yeah

S: It's quite an unusual name, isn't it? So he's painting the house and getting it ready for when you come home? That's brilliant!

A: (*unintelligible*)

S: Be lovely to have it all spruced up

A: You come and see

This is indicative of how important her house and the state of her house is; the proud housewife even invites me to see her home at the end of this interchange.

### **Pets**

When Amy talks about home and what is important to her at home, she talks about her pets. Her response to the question about what gives her life meaning is immediate and unequivocal:

S: So, when you are at home, Amy, what kind of gives your life meaning, what's the most important...

A: I got two dogs

S: Two dogs? Ah!

and when I return to this question during a later conversation, she is just as adamant:

S: Yeah. I know I...when I said to you last time what is it in your life which gives your life meaning, you said "dogs" – quite quickly you said that

A: Yeah – they're lovely

Amy goes on to explain that she also has a cat who gives her as much pleasure:

S: Oh, you've got a cat?  
A: Yeah, he go he go goes where...[twin] your legs  
S: Yeah  
A: Oh, love love love  
S: Is he a friendly cat?  
A: yeah  
S: Yeah  
A: Yeah. He love loves me  
S: Yeah, give you a lot of...  
A: He (*unintelligible*). He go (*unintelligible*)  
S: Yeah? Gives you a lot of pleasure  
A: He does, he lovely

In common with some other participants, Amy speaks about her pets with great affection, and the animals seem to give her life meaning and purpose.

### **Amy's definition of spirituality**

When I ask Amy what the word 'spirituality' means to her, she conflates the concept with religious practice in the form of prayer:

S: If...er...I say the word "spirituality" to you, what does that mean...spirituality?  
A: Say...say prayers

However, it is worth noting that I ask this question directly after we have had a conversation about prayer, church and blessing, so it may be that religion is at the forefront of her mind. If I had asked the question again at a different stage of the conversation, perhaps Amy would have given me a different answer.

In contrast to some other participants (such as, for example, Lindy, Joel and David from group 2), Amy does not mention God, a god or Jesus in her definition of spirituality, despite her claim that her spirituality is about praying.

### **Religion**

Amy is a religious woman but her opinions and belief about faith only come to the fore because I ask her direct questions about this. For some reason – perhaps because we have created a friendly and supportive rapport together – I feel able to ask her if she goes to church:

S: So, Amy, when you're at home, do you go to church or anything like that?  
A: Yeah

S: Do you? Ah – which church?

A: Go [lɪəʊ] go same place

and she, in turn, feels able to do likewise:

A: You...you go to church?

S: I do, yeah

A: You go in the...you go in the...you go in the church?

S: Mm...I go to a church in {name of place nearby}

A: Oh, yes

Knowing that we both attend church gives us common ground, and allows us to explore other areas of faith. For example, in our second conversation Amy intimates how important prayer is to her, and how she attends church in order to pray:

A: Go [lɪəʊ] go same place

S: Do you? Ah, is that important to you?

A: Yeah (*gestures praying with both hands*)

S: Yeah – saying prayers

A: Want to know...want to know come in [tʌtʃ] (*gestured prayer*)

S: to pray, yeah

A: yeah

Understandably in her present circumstances, her prayers seem to be prayers of supplication:

S: So what do you pray about?

A: I pray “please help me”

but she expresses sadness that often prayer seems to go unanswered:

S: Did you find that...er...what do you find you get out of prayer?

A: Doesn't help me

Despite this, knowing that members of her church are praying for her appears to give Amy a certain sense of contentment, exemplified in this extract, where I inadvertently cue Amy in to how she feels about these people:

A: [pleɪ] pray for me

S: They pray for you?

A: Yeah

S: Yeah, yeah – that's...

A: Really nice

On my last visit, I take a holding cross with me to give to Amy, partly as a thank you, but also because I wonder whether it might be helpful to her in terms of prayer and focus for prayer. Indeed, when I ask her what she thinks of when she looks at the cross, she immediately mentions prayer:

S: I wondered whether...er...what that meant to you really. What does that say to you when you look at it?

A: Pray

S: Yeah? It says “pray”

and she intimates that it may become a useful tool in her prayer time, although I recognise I have asked her a leading question:

S: Did you find it useful, the cross?

A: Yeah

S: Did you hold it?

A: I...(gestured prayer)

Interestingly, Amy uses gesture both to convey prayer and also blessing (she says, “he went like that” when describing a visit from a priest, and gestures a hand on her head), and yet gesture is not a natural total communication device during other parts of our conversation. Perhaps because the corresponding gesture is so integral to these two concepts, Amy uses them naturally, and may even have used them prior to the aphasia.

Amy gives conflicting information – or I perceive the information as conflicting - when she talks about visits from her local parish priest. On the one hand, she tells me about a recent visit from him and intimates that this was a positive and welcome experience:

S: And who was that? Who came to see you?

A: Er..Father [æ?] you know him?

S: Er, no, I don't think so

A: He's very nice

S: Right

A: He very nice [pipə]

On the other hand, Amy describes a difficulty in communication between her and the priest on the same (or perhaps a different?) occasion:

A: No (pause) [lɔ] come see me. [t] [t] chat

S: He chats?

A: Yeah – cor he does (*unintelligible*)

S: Does he?

A: I don't know what he say

S: And who was that? Who came to see you?

A: Er..Father [æ?] you know him?

In a later interview, Amy denies that she has had a visit from her priest, and in fact this leads me to attempt to find out who her parish priest might be, in order to request a visit:

S: Good. And does someone from that church come and visit you here?

A: No, don't see them

S: Would you like that?

A: Yes

S: Perhaps I could look into that for you?

I also make a referral to the chaplaincy team at the hospital via the nursing staff after this interchange:

S: What about the chaplain here? Have you seen him?

A: No

S: Would you like to see him?

A: Yeah

### **Physical discomfort overrides other (spiritual) concerns**

Although Amy and I have conversations about prayer, church and what gives her life meaning, such as her family and attending to household chores, the overriding feeling throughout all four interviews is that physical comfort takes precedence. So even after a conversation about prayer (and possibly the Bible, although this paraphasia is not clear), she immediately reverts to her physical needs:

A: (*unintelligible*) they got bring [baɪ] I say my prayers (*with gesture*)

S: You say your prayers, yeah

A: Yeah

S: Mm

A: (*drinks*) That's nice

S: Nice cup of tea?

A: Yeah

S: Good

Pain, discomfort and hunger are recurring themes throughout all four interviews.

### **Reciprocity and rapport**

Despite meeting in a very busy, clinical environment, surrounded by medical machinery and paraphernalia with very little privacy, Amy and I are able to forge a rapport, almost a friendship. In fact, at our last meeting, Amy has this conversation with the woman in the next bed:

Patient in neighbouring bed: Is that your friend then?

A: *(to neighbour)* yeah. *(to S)* You're my friend

She also invites me to visit her at home when she is discharged from hospital:

A: Will you come and see me when I get home?

S: I'd like to...

A: Please

Amy's aphasia does not rob her of her social skills and conventions, and she is eager to reciprocate in our interchanges. For example, she expresses pleasure at our meeting up again:

S: Lovely to see you again

A: Lovely to see you again

She also takes an interest in me and my life, just as I am doing in hers. She asks me where I go to church, and whether I pray. I wonder if our relationship would have got to this level if we had not been discussing issues of a sensitive, personal nature. Does the subject matter of spirituality encourage a deeper level of relationship in some way?

### **Illness narrative**

In some ways, Amy presents as a woman still living in the chaos of illness and disability (Frank, 2013). Pain, discomfort and physical needs override any concern for the spiritual, and this seems indicative of the fact that she remains deep in the chaos, deep in the physical difficulty of acute illness. She appears to be seeking and expecting restitution, as she almost begs to be "allowed" home. The utopian concept of quest, however, feels far away.

## **Liam: the digger driver's tale**

**“It is enough  
To smell, to crumble the dark earth,  
While the robin sings over again  
Sad songs of Autumn mirth”**

**(Edward Thomas)**

I visit Liam three times whilst he is on the acute stroke unit of a local hospital. On the first occasion, I talk to him about the project and gain his written consent. The subsequent two visits are quite short, due to Liam's physical needs, and on these occasions I audio-record our conversations. Although deemed medically stable by the SLT and the rest of the multidisciplinary team, Liam is perhaps the least overtly well of my participants. He has a nasogastric feeding tube in situ, implying that he has significant swallowing difficulties, so significant that he is unable to meet his hydration and nutrition needs orally. He also sounds chesty and coughs often; perhaps again an indication of his dysphagia<sup>5</sup> difficulties.

Liam is a retired digger driver who used to work “down the marsh”. At the time of our meetings, he is in hospital having suffered a second stroke. He is in a four bedded bay in the stroke unit.

### **Liam's communication mosaic**

Liam presents with a complex picture of communication strengths and weaknesses. His functional auditory comprehension is reasonable, but the SLT reports that he has more difficulty with processing longer, more complex commands. She reports that comprehension is helped by writing down key words. The SLT assesses his auditory and written comprehension as good, and he is able to make informed decisions about his care, for example the placement of a percutaneous gastrostomy tube for enteral feeding.

His expressive language is characterised by a general paucity of output. His utterances comprise quite simple syntactic structures, and he shows limited lexical choice. Echolalia and palilalia<sup>6</sup> abound, as evidenced in this short extract:

L: He's a good cat. He's a good cat. He's a good cat. He's a good cat. He's a good cat.

S: He's good

---

<sup>5</sup> Dysphagia is a disruption to the normal swallow process. Assessing and managing dysphagia is also part of the SLT's remit

<sup>6</sup> Echolalia is defined as repetition of another's utterance. Palilalia is the repetition of words and phrases.

L: He's good. He's good. He's good.

Occasionally, Liam's palilalia impedes the flow of conversation, as he appears to become 'stuck' on a word or phrase. In this instance, I employ the technique of interrupting Liam in an attempt to break the repetition; perhaps a counterintuitive strategy from an SLT but one that seems to work:

L: Watch it on TV. Watch it on TV. Watch it on TV.

S: (*interrupts*) Grasstrack

L: Yeah grasstrack

S: Ah, interesting

He uses expletives ("I was there fucking...I was there fucking...about...half an hour") but, as Liam was unknown to me pre-morbidly, it is unclear as to whether this is a part of his usual lexicon, or whether this is a pathological addition post-aphasia (van Lancker and Cummings, 1999; Halpern and Goldfarb, 2013 p 46).

Throughout both interviews, there are marked periods of latency, when Liam either struggles to compose a linguistic response, or struggles to process the question fully, or both. These episodes vary in length from two seconds to thirteen seconds. I sometimes try and encourage a response after a period of latency by saying something neutral such as "yeah?" with questioning intonation, or by framing further questions which I hope aid his processing:

S: Can you tell me a little about what happened to you? How come you are in hospital?

(6 secs)

S: Do you remember what happened?

(7 secs)

S: You became ill at home?

He does not use any total communication strategies but relies solely on his limited speech to convey meaning. Throughout the transcript, I have referred to 'unintelligible utterances' and 'vocalisations'. 'Unintelligible utterances' are those which contain some recognisable phonemes but are indistinct and difficult to transcribe. Vocalisations are pure attempts at voicing, where no phonemes are discerned.

I try and facilitate the conversation using a number of different strategies. I give long pauses after questions and comments, to allow for processing time. I also employ non-committal responses, such as 'uhuh', and a questioning (rising) intonation in an attempt to encourage further output. I ask him very open questions in order to stimulate a response, such as 'tell me about...'. The SLT tells me that Liam's understanding is slightly superior in the written modality

than the auditory, so I write key words for him, in an effort to maximise comprehension, as well as to provide a permanent referent for us both as the conversation progresses.

### **Liam's stroke story**

Although Liam's expressive language is quite limited in syntactic structure and in lexical choice, and he takes time to process the question and to formulate a response, he is nevertheless able to give an account of what happened to him on the day he had this second stroke:

S: Do you remember what happened?

*(latency - 7 secs)*

You became ill at home?

L: *(vocalisation)*

*(7 secs)*

L: *(unintelligible utterance)* Do what I like. What's that? What's that?

S: OK

L: What's that? *(unintelligible)*

S: So, the next thing you knew there was a banging on the door?

L: Mm...mm...*(4 secs)* banging on the door

S: Mm...and who was that, banging on the door?

L: Stroke...I had stroke

S: You'd had a stroke

L: Yeah, had a stroke

He remembers "stroke people" coming to help him:

S: and who was banging on the door, Liam?

L: Stroke people, stroke

S: Right

L: Stroke people

S: Right

L: Stroke people

S: Right...so they'd come to help?

L: Yeah *(yawns)* yeah, cos they'd come to help, yeah. Stroke people, yeah

and also being taken to hospital:

S: and what happened next?

L: Stroke people {name of hospital in neighbouring town}

S: Right, you went to {name of hospital}

L: Yeah {name of hospital}

S: Mm

L: Yeah, I was admitted. I was admitted

S: Yep

L: Yeah, I was admitted. Yes, I went to {name of hospital}

S: Right

L: I was admitted, right? So I was admitted

However, unlike some other participants (such as Lindy in group 2, for example), Liam remembers little else about the time immediately after the stroke:

S: So do you remember much about that time? When you were...

L: No

S: ...in the {name of hospital}

L: Yeah, no nothing. Nothing at all. Nothing at all. Nothing at all. Nothing at all. Nothing at all.

He does admit to a certain amount of fear when he suffered his second stroke but, not for the first time, I am aware of how leading my questions can be:

S: So, it must have been quite scary

L: Yeah

S: Yeah?

L: Yeah...must have been quite scary, yeah

S: Yeah

L: Mm

### **Pets**

I find myself asking a leading question, too, in a section of one of our conversations which revolves around Liam's cat:

S: Bet you miss him, do you?

L: Yeah

S: Mm

L: Miss...miss him

In response to my question about what gives his life meaning, Liam talks about the importance of his cat, Tom:

What are the most important things to you in your life?

(8 secs)

L: I cat...everything

S: Your cat?

L: My cat's everything, yeah...cat yeah yeah

(2 secs)

S: Tell me what your cat means to you

L: (*unintelligible*)

S: Everything (*I guess*)?

L: Everything

He describes him as "good":

S: So, Tom is your cat? So tell me about Tom

(3 secs)

L: He's good. He's a good cat

S: Yeah?

L: He's a good cat. He's a good cat. He's a good cat.

S: (*interrupts*) can you describe him?

L: Yeah I can. Yeah I can. Yeah I can. He's a good cat.

S: Tell me what he looks like

L: He's a good cat. He's a good cat. He's a good cat. He's a good cat. He's a good cat.

S: He's good

L: He's good. He's good. He's good.

S: So, does he bite and scratch?

L: No no

but is otherwise unable to explain or express how Tom lends meaning and importance to his life:

S: Why is he so important to you?

L: yeah, he is...he is he is he is he is

(7 secs)

S: Can you think why he's important to you?

(11 secs)

We'll come back to that, Liam. We'll come back to that.

One can only surmise that, perhaps like Lindy and Amy, he derives companionship and a sense of responsibility for another living being, although this is not made clear in his responses.

## **Family**

Although Liam explains on my first visit that he has parents who are still alive, a brother and a sister and some nieces and nephews, he does not appear to have a partner or children himself. Apart from this short interchange about family at our first meeting, Liam only refers to his family again in response to some direct questions of mine:

S: Have you...have you...have you had some visitors?

L: (*unintelligible*) when they come

S: Yeah? Have your parents been in?

L: No

S: No?

L: No nobody

S: No?

L: No parents

S: Not your parents. How about {name of brother}. Has he been in?

L: No (*unintelligible*)

S: or {name of sister}

L: Yeah {name of sister}

S: {name of sister}'s been in? Great stuff! I bet it was good to see her.

L: Yeah

S: Yeah?

(*pause – 5 secs*)

Liam does not volunteer the importance or otherwise of family members in his life, and does not mention his family in response to my question about what gives his life meaning.

## **Sport**

Sport, on the other hand, seems integral to his life, and to enjoyment and meaning-making in his life. He manages to expand on his answer about the enjoyment he derives from Grasstrack, and in so doing helps an obvious new-comer to this sport to understand better what it comprises:

S: So, Liam, when you're at home, what do you enjoy doing?

L: Grasstrack and that

S: Grasstrack

L: Grasstrack...yeah

S: Tell me about that

L: Grasstrack. Grasstrack...that's big powerful bikes

S: Bikes? Ah, OK

Here is an illustration of fleeting connection between us; Liam understands my lack of knowledge and understanding about the topic by my intonation and facial expression, and is quick to elucidate his response to facilitate my comprehension.

I understand how a sport such as Grasstrack can be a source of enjoyment for Liam, but want to explore its centrality in his life:

S: OK – let me ask you another question...what's important to you in your life? What's important?

*(pause – 8 secs)*

L: Grasstrack. Grasstrack that's good. That's good. Grasstrack. That's good, that is

S: You like that?

L: Yeah

S: Anything else important to you?

L: No...that's about it

Not only is Grasstrack a source of enjoyment for Liam and occupies a position of importance for him, but this sport, along with Speedway, also imbues his life with meaning:

S: Can you think of anything else that gives your life meaning?

*(3 secs)*

L: *(vocalisations)* Grasstrack Grasstrack Grasstrack Grasstrack Grasstrack. Speedway Speedway Speedway

S: Speedway...ah!

L: Grasstrack Speedway. Grasstrack and Speedway

S: Have you always enjoyed those?

L: Yeah

S: Yeah

L: Grasstrack and Speedway

Interestingly, he replaces my word "like" with his word "love", which indicates to me the strength of his feelings on this subject:

L: Yeah. Grasstrack and Speedway. Yeah, Speedway.

S: What is it about those that you really like, do you think?

L: I don't...I love them

### **Loss of ability to engage in life meaning activities**

Like other participants, Liam's physical difficulties post-stroke deprive him of those meaning-making activities he has identified. He is no longer able to take part in the sports he loves:

L: Grasstrack and Speedway

S: And have you ever done it yourself?

L: Yeah, I have yeah

S: Have you? So you've...you've...the bike or...

L: Yeah

S: You've been on a bike?

L: Yeah

S: Yeah?

L: Yeah

S: You raced?

L: Yeah raced

S: Ah!

L: Yeah raced

S: Yeah?

L: Yeah raced and that

S: You've done that in the past, have you?

L: Yeah raced

S: Have you won any?

L: No...not been no no no

In hospital, Liam is not able to carry out any of his normal activities, such as watching sport or caring for his cat.

### **Physical needs**

Unlike the majority of the participants, Liam is not able to formulate a response when I ask him a direct question about his definition of spirituality:

S: What does...I wonder if this word means anything to you, Liam (*I write "spirituality"*)

(*pause for over 10 seconds – interview terminated*)

The ward becomes very busy and noisy at this point, so it may be just an inopportune moment to embark on such a question, but I also feel as if Liam's physical situation and his physical needs are so all-consuming, that there is no space or time to ponder the ineffable. This is

graphically illustrated when he appears to defecate during one interchange about meaning-making; the immediacy of physical need takes precedence:

S: So, we've got Tom, your cat...

L: Yeah

S: and Grasstrack...

L: Yeah

S: ...are the things that are really important to you

L: yeah

S: OK, what about this question – what gives your life meaning? What gives your life meaning?

*(pause – 9 seconds. Vocalisations during which L appears to be defecating in incontinence pad)*

S: You OK, Liam?

L: *(vocalisations)* yeah

It is at this moment that I feel intrusive. I feel acutely the mis-timing of my visit, and the inappropriateness of these questions at this point in Liam's recovery journey.

### **Disability narrative**

Liam appears to be in the midst of a chaos illness narrative (Frank, 2013). All meaning-making components of his life are stripped away, and his physical needs are paramount. It would seem that controlling survival is his main or, indeed only, priority at this time, and even his grasp on this is tenuous, as evidenced by the taking away of autonomous control, in the form of the nasogastric tube and incontinence pad. He makes no mention of recovery or restitution, nor does he intimate at any point that he is entering a quest state, where he is beginning to accept this new post-stroke existence.

## Rosemary: the coast dweller's tale

**“The sea, like a crinkled chart, spread to the horizon, and lapped the sharp outline of the coast, while the houses were white shells in a rounded grotto, pricked here and there by a great orange sun.”**

**(Rebecca, Daphne du Maurier)**

I meet Rosemary on only two occasions, once with her husband there, to explain the project to them both and to gain Rosemary's consent, and once to conduct a short, recorded interview. When I return a few days after the second visit, I am told by the staff on the stroke unit that Rosemary has been referred to a residential home to continue her rehabilitation there. Thus, it was that our relationship was short-lived; indeed, it feels listening back to our discussion, that it never really had the chance to develop at all.

Rosemary presents with very severe speech and language difficulties. Her auditory comprehension is good, but her expressive skills are characterised by severe expressive aphasia, severe apraxia of speech and severe dysarthria. Her non-verbal communication skills are limited to sighing, to intimate frustration or sadness:

S: Yeah, OK. And you've been in hospital for how long?

R: I suppose three and a half (*sighs heavily*) two and a half or maybe it was a bit before that

S: Mm

R: Might be up...three years and er (*unintelligible*)...er...I don't (*unintelligible*)

and laughing, the meaning behind which is not always clear. She has good pragmatic skills, and we use eye contact and facial expression to attempt to connect. Her communication Mosaic (Clark, 2001), then, is limited to speech attempts (including unintelligible output), non-speech linguistic features (such as prosody), and preserved pragmatic skills.

I ask Rosemary about her stroke story but I am unable to gauge exactly what happened from her narrative:

S: So maybe we could start off by talking about what happened to you...how come you're in hospital?

R: Well, don't know... 'spose driver. Drives the...erm...er...the cars...driving

S: uh-huh

R: and they take us to...

S: So, the car brought...a car brought you here?

R: Mm

S: Right. And you had a stroke – is that right?

R: Mm

S: Do you remember much about that?

R: No...drink and drive...but just don't know

S: Right

R: You know...so...we...er...

She either has no memory of the time when she had her stroke, or I am unable to hear the memories that she attempts to relate in her utterances:

S: OK, so you...do you remember much about what happened to you?

R: Well (*unintelligible*) we can only (*unintelligible*)

S: Right

R: (*unintelligible*)

Rosemary lives in a coastal town about twenty miles from the urban hospital in which we now meet. I wonder if the sea is an important element in her life:

S: And can you see the sea from where you live in {name of seaside town}?

R: No

S: No. Not quite that close

R: It's (*unintelligible*)

S: Not too far?

R: It's not too far

S: So you could walk?

R: Yeah

S: You could walk to the sea?

R: Yeah

S: Ah that's good. Do you like the sea?

R: Yeah

S: Yeah

R: But...erm...wouldn't go too far away to (*unintelligible*)

S: Mm

R: So, er...

I also try and engage her in conversation about her husband, but again, expression is limited:

S: So your husband has to travel up from {name of seaside town}?

R: Yeah

S: He comes every day, does he?

R: Yeah

Even with very limited and often unintelligible output, Rosemary's character peeps through at times:

R: Yeah...(unintelligible utterance – laughs)

S: (laughs) you have a good sense of humour

R: Yeah, it's just me

S: Is that you?

R: (laughs) well yeah

S: Is that a part of you?

R: Yeah yeah (unintelligible)

The illness narrative (Frank, 2013) she adopts seems to be restitutive, with hopes for recovery although, not for the first time, I identify a leading quality to my questioning when I listen back to the recordings:

S: And how are you feeling now?

R: All right, I suppose...erm... (unintelligible utterance – laughs)

S: Be good to get out

R: Mm

S: Yeah. Is there any news on how long it might be?

R: No

S: Take one day at a time

R: Yeah

S: So, are you seeing a physio and a speech therapist and all the other...

R: (unintelligible)...but...(unintelligible)...or not

S: Mm

R: Er... (unintelligible)

S: Mm

R: Mm

Trying to get to the heart of how she is feeling is problematic and, again, my questions are leading in nature, and yet I think one gets a sense of her despair through her non-verbal communication:

S: It's not easy being in hospital, is it?

R: No, so...erm...you know...just...(unintelligible)

S: Mm...stuck in here all the time

R: Mm... (*long unintelligible utterance – sighs*)

S: Tired?

R: Mm

By the end of our second conversation, I feel that we are only just getting to know each other, a process that is hindered by Rosemary's expressive difficulties and my lack of skill at framing my questions and comments more accessibly. I feel like we are 'warming up', and that we are at a stage of acclimatisation, before issues of a sensitive or spiritual nature can be broached. I ask her at the end of what was to be our final conversation what she is missing about being away from home:

S: So what do you miss most about not being at home?

R: (*unintelligible*) watching the telly

S: Watching the sea, did you say?

R: TV

S: Oh, the TV

R: On the telly

S: On the television, yeah

R: (*unintelligible*) and...er...(*unintelligible*)...TV

S: uh-huh...so yeah, so you miss being able to watch TV

R: Mm

S: Yeah yeah

This question was, in my mind, most definitely a prelude to thinking about life meaning and purpose, but we unfortunately never had the opportunity to explore these concepts together. My brief conversations with Rosemary emphasised for me how crucial relationship is in any therapeutic or research-therapy situation; rapport must be forged before real connection through communication can begin.

**The stories of people who have been living with their  
aphasia for some time**

## **Lindy: the poet's story**

**“And when he thus had spoken, he cried with a loud voice, ‘Lazarus, come forth.**

**And he that was dead came forth”**

**(John 11: 43, 44)**

Lindy is a woman in her forties who has been living with aphasia since a stroke in 2008. So, when I interviewed her, she was five and six years post stroke respectively. She is a real wordsmith, a published novelist and now poet. We had corresponded by email prior to our first meeting, after Lindy had heard about my research through a mutual friend:

Dear Sophie,

“aphasia express spirituality” = YES.

Best wishes,

L

(private email, 2011)

A friendship of sorts had therefore developed, with us corresponding via email and Facebook, as well as meeting at her home for two ‘formal’ interviews.

Lindy’s comprehension of spoken language is excellent. Her expressive language is affected by the aphasia; she is able to produce single words and short phrases but presents with significant word-finding difficulties. She makes the occasional phonemic paraphasic error, such as /sɪndi/ for Sydney. She is, however, a brilliant communicator. Lindy expresses herself using writing (her orthographic output lexicon and buffer appear less impaired than her phonological output lexicon and buffer – see appendix I), gesture, intonation and facial expression. She has no motor speech problems.

We meet at Lindy’s home – we meet three times in all, once as an introduction, and twice to carry out recorded interviews. Whether it is because we are of similar age, or because of our mutual love of reading and cats, I do not know, but I feel an instant connection with Lindy. Our conversation takes place in her living room, over a steaming cup of strong coffee. Books line one wall of her small living room, and it is clear from these that this is a well-read woman who loves art and beauty. She is happy for me to record our conversation on a digital voice recorder, and then on video. She uses her own notepad to write her thoughts during the conversation, and by the end of my visit I somehow feel unable to ask her for the page on which she has written all these thoughts. It feels like an intrusion, an imposition.

### **Lindy's aphasia**

Lindy expresses her preferred method of communication early on in our first conversation:

"me, write it"

Lindy's acquired language difficulty would be classed as moderate-severe expressive or Broca's type aphasia. Lesions causing this type of aphasia are typically located in the left frontal lobe of the brain, and may or may not be accompanied by a motor speech problem, often apraxia of speech. However, Lindy's communication difficulties seem restricted to language as opposed to speech. Using the cognitive neuropsychological model of language processing, Lindy shows problems with output as opposed to input, possibly at the level of the phonological and orthographic output lexicons, although her graphemic output is often better than her phonological, and indeed writing key words can cue her into the spoken word very successfully at times.

As discussed in Chapter 3, I felt that it was not within my remit to assess formally the language skills of my participants; presenting participants with formal tasks which by their nature are often designed for the person to fail at some stage, scoring language assessments and feeding back to the participant what they had succeeded on and what they had failed seemed counterproductive to a good, open relationship. In chatting to Lindy, I got a feel for her language functioning, without the need to assess formally. The point of assessment, after all, is to plan intervention to maximise residual skills and to be aware of any deficits. It was clear that Lindy's auditory comprehension was very good from early on in our conversations because of the responses she gave to my questions, and she knew much better than me what helped her expressive abilities.

### **Lindy's Mosaic**

Lindy is a competent and successful communicator, despite the limitations imposed by her aphasia on her expressive language. She uses all sorts of verbal and non-verbal strategies to enhance her output, to create a Mosaic (Clark, 2001) of expression. To supplement her spoken output, she writes key words and phrases with her left (non-preferred) hand. Writing will either cue her in to the spoken form, or will serve as the primary vehicle for conveying that word or concept. Lindy's notebook, with words from earlier in the conversation, remains in front of her and acts as a referent during subsequent interlocution; she will point to a word previously written if it is needed again. In a similar way, she will point to words used in another conversation using another medium, such as emails or word documents she has previously sent me. She also uses gesture successfully, again either to cue herself into the spoken form, or to convey meaning. Finally, both intonation and facial expression help the listener to understand.

### **My communication strategies**

Interestingly, I, as researcher, also mirror some of Lindy's communication strategies, such as gesture:

S: You went like that (*copies gesture*)

L: Yes (*also does gesture again*)

Perhaps this is a subconscious attempt on my part to confirm equality between us and negate any perceived power differential. I also try to facilitate a "connection through conversation" (Koch and Kralik, 2006 p 8) by checking back with Lindy that I have understood correctly, for example:

S: So, it's praying without words? Would you describe it as that?

or by recapping:

S: You were saying that er...I was saying was the church a community and you said no not necessarily and you wrote "London"

or by paraphrasing:

L: Friends

S: Right, you were with friends

or by overtly seeking clarification:

L: Oh, oh...OK (*surprised intonation*)

S: and then you survived?

L: yes, yes

Sometimes, I attempt to sum up but get it wrong. Lindy is able to correct my misconception with further clarification through speech and writing:

L: Yes...er...beautiful (*intonation = what more can I say*)

S: Beautiful vision, or feeling, or...

L: No...er...beautiful (*gesture of hand sweeping*)...um...beautiful (*nods*) yes

S: So when you woke up...

L: (*nods*)

S: You had that feeling of beauty and...

L: No...um crying

S: Right

At other times I guess again and seem to get it right:

L: Why? why?

S: Why hadn't you died, or...

L: Yes

Sometimes, I try and sum up, get it wrong and we are, between us, unable to repair it:

S: Yeah, so you have a quite a positive attitude?

L: I don't know, I don't know

S: No

L: I don't know

It can be problematic to get the balance of conversational turns equal with someone with expressive language difficulties (Beeke et al, 2014, p 293), particularly, as in the methods used in this study, the conversation takes the form of question and answer interviewing. Sometimes during the interview, I feel myself entering a monologue, not allowing space for Lindy's verbal or non-verbal contributions. This is perhaps illustrative of the power differential (O'Malley, 2011, p.97) often imposed by an interaction where one party has more expressive language than the other.

### **Lindy's poetic use of language**

Despite the limitations placed on her language by aphasia Lindy often selects poetic vocabulary and literary allusion to convey her message. For example, she uses the word "mute" rather than the perhaps more prosaic 'without speech' or even 'dumb'. This poetic vocabulary choice even extends to her gestural lexical choice; at one point she gestures a gag over her mouth, to illustrate lack of speech.

In order to convey the message that, because of the seriousness of the stroke and the length of time she was in a coma she effectively died and then was revived, she uses the well-known example of a biblical character being raised to life in a miraculous encounter with Jesus:

“I am Lazarus” (private email, 2013)

Thanks to her faith tradition and her flair for the literary, Lindy succeeds in powerfully conveying the message of gaining back her life. She also uses literary figures from other faith traditions, such as the angel Azreal from Islam.

### **Lindy’s faith**

Lindy identifies herself as Roman Catholic, and is open about her faith. Of course, much of her spiritual story involves allusion to Catholic or Christian ideas and doctrine, such as her vision of angels. Some aspects of her story, though, belong to a different tradition, such as the ‘black angel’, Azreal. Her faith is important to her:

S: Is that...I seem to remember you telling me last time that you’re Roman Catholic?

L: Yes

S: So you have a faith?

L: Yes, yes

S: Did you kind of draw on your faith at that time?

L: Yes

Lindy and I have a shared faith in Christianity, which explains some of my direct questions during the interviews about her ability to take part in church services and to verbalise liturgy. Lindy explains that she is not able to pray aloud in words, but that there is an inner connection with God which needs no words:

S: OK...and is that talking in words?

L: No (*gestures left hand across lips*) erm...the brain (*gestures left hand at left side of head*)

S: Yeah

L: The brain

In terms of being able to engage in liturgy with aphasia, Lindy appears to give conflicting information, or I misinterpret what she says so that my understanding is of two disparate opinions. At one stage, she appears to say that well-known liturgy remains intact, and is expressed fluently:

S: Yes, OK, so things like...um...things that you would have learnt at an early age, I presume, like the Hail Mary or the Our Father

L: Oh, yes (*emphatic*)

S: Do you remember those? Can you recite those now?

L: Oh, yes

S: OK so they're quite...almost automatic

L: Yeah

S: So they still come out fluently?

L: Yes

This makes intuitive sense, inasmuch as people with expressive aphasia often have a preserved ability to produce over-learned, automatic phrases, such as social greetings and rote-learned rhymes and sequences (for example, the days of the week, nursery rhymes) (Lum and Ellis, 1999; Halpern and Goldfarb, 2013, p 46). One could perhaps surmise from the aphasia literature that liturgy learnt in youth and repeated many times over a lifetime, such as the Lord's Prayer, might be preserved in someone with even quite significant expressive difficulties.

However, in a separate interview, Lindy says – or I hear – that she is, in fact, not able to express even well-known and over-learned prayer and liturgy:

S: So...er...when it comes to saying...er...er...liturgy

L: (*gestures "zip" across mouth*)

S: Is that possible for you?

L: No no

S: No, so it doesn't...is familiar liturgy...so er like the Lord's Prayer

L: Yep

S: or Hail Mary

L: Yes

S: Are you able to say that?

L: No no (*shakes head*)

S: Absolutely not. So do you say it in your head?

L: Yes, uhuh

Is this in fact a contradiction, or is it a reflection of the sometimes inconsistent nature of aphasia errors? Either way, aphasia obviously interferes with some verbal ways of engaging in religious sacrament.

A further intrinsic part of the Roman Catholic faith which could be compromised by reduced verbal output is the act of confession, of openly telling a priest of one's sins in order to obtain absolution. I ask Lindy about this, and she seems to imply that this, too, is not possible in the way it was before the stroke:

L: I don't know, I don't know. Um... Father {name of priest} home

S: Yeah

L: um, one to one...um...Our Father and yeah...um...sins, no

S: U-huh

L: No

S: Expressing sins?

L: No

S: or...right

L: um...sins no

S: Confession, do you mean?

L: No

S: Right, cos that's difficult, or you just...

L: Yes

S: Yes, cos it's difficult

L: Yes

However, all this loss does not seem to have lessened Lindy's faith. She explains how she was a practising Catholic prior to the stroke, and that she still is:

S: Mm...and so did it...can I ask you if that experience...er...changed your...er...attitude towards religion in general? Were you...

L: No

S: No

L: No um me um [k] [kɛɪdʊ]...no, Catholic

S: Mm

L: um...um...mass...er (*shakes head and facial expression = no change*)

S: So you are Catholic and went to mass before your stroke?

L: Yes

S: and so nothing's changed

L: No no

Although the ability to express her beliefs, pray and seek absolution verbally is affected by aphasia, it appears that her intrinsic faith in God has not wavered. Indeed, she says in an email “Why? God is good. Benevolent God” (private email, 2013) and she directs me to evidence of God’s goodness in the world around me:

L: No...um...um...um...(points to self) um...God earth

S: Yeah

L: um...me and you and (sweeping gesture) and everybody

S: Yep

L: um yes

S: So He created all these things?

L: Yes yes

S: and there’s evidence of benevolence there?

L: Yes (nods)

S: Despite what...you know...what you’ve been through?

L: uhuh

S: Hard times

L: mm (nods)

### **Lindy’s stories of spirituality**

Lindy is open and generous in telling me her spiritual stories, and in this way, she becomes my guide, the person with whom I can experiment with wording and concepts, the person with whom I can gain confidence in talking about these personal and nebulous concepts with other participants.

Lindy’s stroke had happened a few years previously, and she relates very eloquently what happened to her. It feels as if this has been mulled over and talked about often. The enormity of the event is palpable in her choice of spoken vocabulary:

“massive, massive”

and written lexical choice; in the first interview she writes “desperation”. There is almost a feeling of piecing together what happened, as if in an effort to make sense of it. According to Frank (2013), this telling of the illness story is crucial; there is the “need of ill people to tell their stories” (p 3). It is as if through rehearsing and retelling the narrative of her illness and subsequent disability, Lindy is attempting to navigate through the chaos and into survivable quest (Frank, 2013), although this narrative, of course, contains more than words, or at least meaning around the words:

L: um...[stərəʊk] um...massive, massive (*writes stroke 2008*)

S: Right, right, a massive stroke in 2008

L: Yes, um... (*writes 25<sup>th</sup> December*)

S: Ah! Christmas day!

L: Yes, yes

S: Yes. Right – so were you alone?

L: Friends

S: Right, you were with friends

L: Friends...um...London

### **Visions**

Lindy is open and generous in describing spiritual events and experiences in her life. A notable theme is that of benevolent visions. Whilst in a post-stroke coma which lasted three days, Lindy describes how she is given a sense of peace by what she thinks are angelic beings:

“...angels? (*questioning intonation*) I don’t know...um...um...God? (*questioning intonation*) I don’t know”

In a subsequent email, she seems more certain of the identity of these beings:

“I experience profound JOY. Angels: intense compassion and androgynous. The most real thing I have ever felt” (private email, 2013)

Whatever the identity of these apparitions, it is clear that their appearance affords Lindy deep calm, and is very much a welcome experience:

L: No, no...um ‘s peaceful...um...worry, no...um...I forget it! Forget it!

S: Right, so it gave you a sense of peace

L: Oh, yes, yes

It seems that the angels appear because Lindy is close to death during those three days of coma:

L: um...joy...um...me...er...dying

S: uhuh

L: um...(writes)...er three days coma

S: Yeah

L: Yes...er...beautiful (*intonation = what more can I say*)

Angels have appeared in many faith traditions – and in art – throughout the ages. Along with Williams (2006), I find descriptions of encounters with angels, including Lindy's, "moving, intriguing and challenging" (p 6). Angels (from the Greek "angelos", meaning messenger) in the Christian tradition serve as a link between God and people, who are "a little lower than the angels" (Psalm 8: 5). They often appear at times of great crisis (for example, when Abraham is about to sacrifice his son in Genesis 22: 11), exciting news (for example, when Mary is told she is to give birth to the son of God in Luke 1: 28) or when protection is needed (for example, when Daniel faces the lions in Daniel 6: 22). Angels also appear at the empty tomb, to inform Jesus' friends and followers that he has risen from the dead (John 20: 12).

The angels described by Lindy are benevolent and "androgynous" (private email, 2013), mirroring early Christian artistic representations of angels such as, for example, Andrei Rublev's Hospitality of Abraham (this picture was used as an artefact in an interview with Joel and a copy can be found in appendix IX). She conveys their appearance through words ("beautiful" "peaceful" "compassion" "androgynous"), as well as intonation. Their appearance seems to signify protection, or even saving from death, perhaps akin to the angels who saved Daniel in an Old Testament story (Daniel 6: 22) or maybe even a bringing back from death, such as the angels at Jesus' tomb on Easter morning (John 20: 12).

Williams (2006, p 66) suggests that individuals are more likely to see or hear angels in sleep, perhaps because "people are more open to hearing when their minds, rational in the daytime, are in the dream world". Perhaps the same is true of the mind during coma:

S: So, while you were in a coma, you had this...you had a vision of angels

L: Yeah, yes

It seems clear that Lindy derives great peace and comfort from the angel vision she sees whilst in a coma and it is testament to her alternative and augmentative communicative abilities that she is able to convey these complex pictures and ideas through not only speech but also intonation and writing.

She contrasts the peace of the angels with the desperation she feels on waking from the coma, when she realises she has not in fact died; she has survived but has lost her language:

"yeah...um...wake up crying crying (*with emphasis*)...um...mute...anguish no maybe...um...die...um why? Why?"

During the coma, Lindy also saw her mother and her father, both of whom had died some years before. She describes these appearances of her parents as a “barrier”, preventing the work of Azreal, the Angel of Death with his sickle, who according to the Qur’an, takes the soul of the dying person and returns it to God (private email, 2013). As with the angels, she sees benevolent, helping visions, who save her from death:

L: Yes yes...um um um um (*starts to write*) Satan...or...um...God...um (*tries to write again*) the one (*gestures with left hand as if using a scythe*) um...death

S: Yeah

L: [s] death...er...um...Oh God

S: You went like that (*copies gesture*)

L: Yes (*also does gesture again*)

S: You mean like a scythe?

L: Yes yes...mm...um...um...me um no...um...Mum and Dad dying all (*gestures with left hand over shoulder*) um years ago

S: OK

L: Yes yes um um. God...um...(*attempts to write*) um (*gestures with left hand sweeping across body*)

S: Like a barrier?

L: Yes yes (*nods head*)

In an email, in response to my questioning her directly about “visual hallucinations or visions” she had mentioned in previous correspondence, Lindy had given a graphic description of this vision experienced during her coma of an image of her dead mother and father protecting her from Azreal, the Islamic angel of death:

“Distressing one: maybe? maybe not?”

mum and father barrier and prevention: Angel of Death (Azreal) sickle of death.” (email, 2013)

Rees (2016, p 149) explains that in Islamic tradition, Azreal (or Azra’il) “accomplishes the separation of body and soul by holding an apple from the tree of life to the nose of the dying person”. In this way, the person is lured from life to death. It is interesting that Lindy uses an allegory from a faith tradition other than her own. Perhaps this is a reflection of her erudition and depth of prior reading. The Islamic story also resonates with the Judeo-Christian story of the temptation of Eve in the Garden of Eden, which of course would be well-known to Lindy.

So, it appears that the angels seen by Lindy during her recovery from the stroke were both “benevolent” and protective, providing her with a sense of peace in catastrophe, but also harbingers of death, thwarted only by the appearance of her other protectors – her parents. Both angelic exemplars are rooted in historic literature.

### **Desperation and Tears**

Lindy is eloquent in her description of the time in coma post-stroke and then just emerging from coma, using speech and intonation to great effect; perhaps this is something she has thought about often and attempted often to convey because of its huge importance and impact on her. During coma, she is in a state of absolute peace:

“Yes,...um...but the angels and me...um...is peaceful, peaceful (*intonation = awe*)”

but this contrasts sharply with her emotions of utter desperation on waking from the coma, again conveyed by speech augmented with powerful and communicative intonation:

“...um...wake up crying, crying, oh”

The vision of angels either represents Lindy’s sense of peace or perhaps the angels create the sense of peace which is then shattered when she awakes and the realisation of the magnitude of her new situation becomes only too apparent:

L: No...er...beautiful (*gesture of hand sweeping*) ...um...beautiful (*nods*) yes

S: So when you woke up...

L: (*nods*)

S: You had that feeling of beauty and...

L: No...um crying

S: Right

L: All the time crying (*gesture*) um...um...l...um...um...um...weeping...I don’t know...I don’t know (*gesture with left hand and intonation/ facial expression*) ...um...um...um (*writes*)

S: (*after reading what L has written*) So that was the 4th day?

L: Yes

S: You woke up weeping?

### **Resurrection, survival and being “born again”**

Lindy talks about the miracle of surviving this catastrophic cerebrovascular accident, seemingly against all odds:

“I am Lazarus.” (2013, private email).

Lazarus was a great friend of Jesus, over whose death Christ famously wept (John 11: 35). Having died and been in a tomb for four days – so long that he “stinketh” (John 11: 39) – Jesus was moved to ask God to raise Lazarus from the dead. It seems that Lindy feels “saved” from death much like Lazarus:

L: Awake no awake no awake...um...die die

S: u-huh

L: Oh, oh...OK (*surprised intonation*)

S: and then you survived?

L: Yes, yes

and because she uses this biblical analogy, one must presume that this is deemed by her a miraculous, God-given experience. Indeed, she goes on to say “Miracle? Maybe?” (private email, 2013). Interestingly, it has been suggested (Welby, 2016, p 16) that Lazarus may himself have had a disability, because at no point in the story does he speak.

This could be viewed using Frank’s (2013) narrative illness typologies as the ultimate in a restitution story; she died but then was restored to life.

Similarly, Lindy views her rehabilitation post-stroke as a sort of growth from babyhood through adolescence to restored adulthood. She uses speech and gesture to illustrate this in a powerful way, firstly her concept of beginning again in terms of function (particularly speech):

L: (*facial expression = yikes*) um...dying...um [f] me, Lindy Usher, dying (*gesture – left hand gesture of chopping down*) um...um...stroke aphasia...um...me...um (*writes*) stroke yeah

S: (*reads*) in 2008, yeah

L: Yes...um...Oh God...um...me...um little...little (*gestures small with left hand close to the ground*) um...um...a baby me (*points to herself*) a baby

and then the gradual, incremental progression, culminating in death:

L: Um grow up little little little little (*left hand gesture – going up step by step*) yes  
yes...um...dying

This restitution narrative is supported by the perceived progress of Lindy in terms of her communication and her need to keep “striving”:

S: Working away...and do you see progress all the time?

L: Oh, yeah (*intonation = absolutely*) oh yeah!

S: Yeah – you work hard at it as well though, don’t you?

L: Yes (*intonation = definitely*)

### **Pilgrimage**

In one of her emails, Lindy mentions the concept of “pilgrimage” as being an important part of her spirituality. When I ask her if she can give me more details of this, she says:

L: Pilgrimage...um...earth...um...the land...um walking all er um [nod] [ld] (*writes*)

S: (*reads*) oh yes Lourdes in France?

L: Yes yes yes

S: Ah – have you been to Lourdes?

L: All the (*gestures “back”*) um yes years ago

Lourdes is a place she would like to visit again, but she sees this as an impossibility, because of her physical difficulties. I do not fully grasp the importance of pilgrimage to Lindy during our interviews, but at the end of the third meeting, she hands me a copy of her novel “The Sudden Spoon” (2001). L.E.Usher’s second novel tells the story of Eliza who goes on a pilgrimage to “the many places where Mary is believed to have appeared and record them with her camera” (p 10). As well as being on an actual pilgrimage of sorts, locating places where the Virgin Mary had appeared to believers, the protagonist also pursues a pilgrimage of love and relationship. I begin to understand from reading her novel, that Lindy uses the analogy of pilgrimage to include searching, striving (a word she uses on a number of occasions during our interviews) and connecting. The gifting of the book and my reading it feels like a further expansion of Lindy’s communication Mosaic (Clark, 2001); through this book, I glean more insight into the concept of pilgrimage and into Lindy’s spiritual story.

### **Nature**

Lindy cites nature and walking within nature as a spiritual experience for her:

“Me...um...walking the fields and God um...angels or God ...um, oh, God...it’s peaceful”

She describes a non-verbal connection with God which gives her solace:

S: Mm...and what is it about nature that helps that dialogue with God, do you think?

L: um...I don’t know um (*puzzled facial expression*) ...soothing? (*questioning intonation, as if not sure she has produced the word correctly*)

Of course, communing with God without words is not an experience reserved for people with communication difficulties, but the unspoken prayer of someone with aphasia perhaps has added poignancy, believing that God can hear prayer without words. Perhaps this is illustrative of the “privileged access to the divine” (Clark Power et al, 2008, p 375), mentioned in chapter one and discussed more fully in chapter six.

Lindy has channelled her literary skills into poetry since her stroke, and much of this poetry relates to aphasia, but also to her experience within nature. So, when asked whether her poems are a way of “talking to God”, she explains that the spiritual essence in her poetry is more related to nature than to God per se:

S: uhuh...and your poems – are they part of your...

L: Yes

S: Sort of spiritual journey?

L: er...no (*rocks hand back and forth, as in maybe, maybe not*) maybe no (*looks puzzled*) the earth maybe...um...river...um...um (*looks at me*)

S: Nature

L: Yeah, nature yeah

### **Writing**

Lindy is a published author, and writing was her profession prior to the stroke. It remains at the core of her identity, now as a poet:

“yeah! I well writer (*gestures writing*) me (*points to self*) a writer (*intonation = that is simply who I am*)”

Writing becomes a part of her therapy, the rehabilitation of her identity and of her language:

“yeah reading all the time um...writing poems (*gestures little with finger and thumb, then increases size between, as if showing increments*) um yeah (*nods*)”

I wonder at one point whether Lindy uses poetry as a means to speak or pray to God. She answers no, and interestingly asks the same question of me. The smallness and simplicity of this question belies its deeply felt (by me) interest in my own faith journey:

S: Do you ever write poems to God?

L: No (*smiles*)

S: (*laughs*)

L: (*laughs*)

S: OK

L: You?

This also strikes me as one of those moments of complete equality and balance, with one person asking exactly the same question of the other. It also, I think, exemplifies that friendship is being formed during this process, of one interlocutor wanting to form more of a complete picture of the other by asking relationship-forming questions.

### **Needing another to hear spiritual stories**

I wanted to find out during my interviews with Lindy whether she was able to reach out to anyone else during her stroke recovery, particularly in terms of being able to express spiritual angst, or tell her stories of spirituality. I was interested in how someone with aphasia might be ministered to – whether indeed ministry was desired and, if so, whether it was accessible.

Lindy did not see a chaplain whilst in hospital, but on several occasions mentioned visits from her local parish priest once she was home from hospital:

S: You didn't see a chaplain at all when you were in hospital?

L: No

S: What about your priest? Did he come to visit you?

L: No, um (*writes* 2009)

S: 2009 yeah

L: Home

S: Right, to this house?

L: Yes

S: OK

L: Father {name of priest}

S: Right, so he's been a good support for you?

L: Yeah

Lindy's spiritual stories are related through speech, writing, gesture, intonation and facial expression. She conveys personal and beautiful narratives of distress, despair, hope, recovery and faith, which successfully guide her listener through the chaos of her stroke to the quest of her recovery (Frank, 2013).

## David: the sculptor's tale

**"I saw an angel in the marble and carved until I set him free"**

**(Michelangelo)**

David has not been living with his aphasia for very long. When we meet, at a stroke club, he is nine months on from the date of his stroke. Although I had recruited him a couple of weeks prior to the date of our interview, I had also by chance bumped into him just the day before. Checking details of time and address with him, he intimates that he is not sure if he has anything useful to say on the subject of spirituality. I reassure him that whatever he communicates will be of interest, but he comes back to this theme at the end of the interview itself:

D: I somehow feel that er...my...(unintelligible) wasn't needed (*laughs*)

S: Your...

D: My...my...er...wasn't needed. I can't say that in another way...how would you say that?

S: I'm not sure what wasn't needed? Going...do you mean going to church wasn't needed?

D: No, seeing you, Sophie

S: OK (*laughs*) I wasn't needed. Right

D: I can imagine that you're not...imagine it's. I tried to tell you yesterday. I really do think you weren't er...oh well, never mind

S: It's been useful, if you were concerned that what you had to say wasn't going to be useful, is that...

D: It was, was it?

This seems to be an ongoing leitmotif throughout the interview, whether in words or attitude, that David is not engaged in the subject matter. He gives consent to the interview and, indeed, talks about some very interesting aspects of spirituality, but he never gives the impression that this is a useful or enjoyable experience for him. I do not feel that I have created a rapport conducive to openness. Once I have completed transcribing David's interview, I send him a synopsis for his comments; he does not respond.

We meet at his home in a suburb of a big city, where he lives with his wife and two young sons. He trained as a fine artist, but has not been able to work since the stroke:

D: I trained as a fine artist and...er...after doing that...and after...I went to the...erm...advertising

S: Right

D: Yep

S: and are you working at the moment?

D: No

S: No, OK

D: No, I don't really think you can I don't know, I wonder whether you can work and at the moment we don't really love really

As our conversation concludes, he tells me that he is starting to create some sculpture for his garden, so perhaps his desire to express himself through art is re-emerging after enforced post-stroke latency.

Books – particularly art books – are strewn around the living room, and it is clear that David is well-read and continues to enjoy exploring these tomes. As we start our conversation, he has a colourful, glossy coffee-table book about mushrooms by his side on the sofa.

### **David's aphasia**

David's auditory comprehension is good; there is the occasional moment of apparent lack of full comprehension but this may be due to lack of clarity on my part, a difficulty processing more complex sentences, or the fact that his significant expressive difficulties sometimes convey a feeling that the utterance has not been understood correctly because of the answer given:

S: Do you find yourself questioning why it happened to you at a young age? Those sorts of things?

D: Er...only once I get out and people go 'Good God you're young, aren't you!' (*laughs*) I go 'really?' and er yeah I am quite surprised by the ...yep.

David's expressive language exhibits some good preserved sentence structure with moderate word-finding difficulties. His relatively strong sentence structure sometimes belies his inability to retrieve a key word:

"Yes, I did. I can't the name for it...of it...it's something like...I can't...it's an age but I can't remember the name of it. My wife will be here...s...at about...you might have gone actually...I'm...she might well know it"

He tries to camouflage his word-finding difficulties in various ways, sometimes producing unintelligible strings of phonemes in place of the target, sometimes filling in with syntactically correct but 'empty' utterances:

"But...er...I find it very very...sort of...I can see all the world...erm...er...(*latency*) er...just because I didn't accept...that...you know...the...(*latency*) erm...I don't know...what's (*laughs*) cos I"

He explains how his language has improved over the months since his stroke, from 'yes' and 'no' to the complexity of language he demonstrates today:

S: Right. Right. And what was your speech and your communication like then?

D: Well, hopefully it's a bit improved, erm...

S: Yeah

D: Yeah, I hope it's been improved

S: Yeah, so it feels like it's improved now to...?

D: Yes

S: ...when you first had your stroke?

D: When I was in hospital I was just going yes and no, yes and...

S: OK

D: ...no (*laughs*)

S: Right, right. So it's definitely improved a lot

D: Yep

Like all the participants with aphasia, David's language skills were not formally assessed. However, if one were trying to plot the level of his linguistic breakdown using the cognitive neuropsychological model of language processing (appendix I), one might well identify his deficits as being at the level of the phonological output lexicon, or the route from semantic system to phonological output lexicon. He does not demonstrate any semantic paraphasias, suggestive of an intact semantic system, nor does he display many phonemic paraphasias, which, in turn, would suggest that his phonological output buffer and the route to it is not affected. It would seem that he has an inability at times to retrieve a word from his phonological output lexicon. There is often a marked latency in his responses, which is perhaps indicative of his inability to find the target word in his lexicon.

### **David's Mosaic**

His verbal output is supplemented by use of communicative intonation and facial expression, but he does not use any other total communication strategies such as writing. I tentatively ask him at one point if attempting to write down a word helps in his retrieval of the spoken word, but he is dismissive of this idea because the hemiplegia resulting from his stroke has affected his dominant hand, and therefore his physical ability to handwrite. Many people (such as Lindy) with hemiplegia on their preferred side do learn to write again with their non-preferred hand but perhaps David is not yet at this stage in his rehabilitation:

S: Does it help you to write things down?

D: Well, this hand's so buggered that no

S: So actually physically writing is tricky

D: Yeah

I wonder how this physical disability impacts on him as an artist, but David does not volunteer this information and I feel that our relationship is not yet (will never be?) such that I could broach this subject. As his therapist, rapport may have developed over time, to an extent where sensitive and potentially emotive topics such as this could be tackled, but as a researcher just passing through, it does not feel appropriate. This highlights the not always comfortable dichotomy of researcher versus therapist.

He uses gesture occasionally to supplement his speech. His use of laughter, I think, is not always helpful in terms of the functionality of his expressive language and sometimes masks his errors or difficulties in word retrieval.

Delivery of speech is slow with many pauses for attempts at word retrieval, some evidence of mild dysarthria (imprecise consonants) and occasional neurogenic dysfluency.

My strategy when conversing with David is to give non-committal, 'filler' type utterances (such as "uhuh") in response to some of his, in the hope that these will encourage further expression. What I perceive as lack of therapeutic rapport results in less 'therapeutic interviewing' and this is exemplified in the speech examples taken directly from the interview: in contrast to some of the other interviews, many of the quotes are David's words only, rather than snippets of dialogue between the two of us.

### **David's stroke story**

David narrates how he was "staying with my brother who used to live just up here" when he had his stroke nine months prior to our conversation. He describes the pain he experienced:

“And I had a really honking headache...and...erm I couldn’t sleep because of it”

but he interestingly uses non-catastrophising vocabulary, as if to play down the seriousness of the event:

“and when I turned over I realised that I was...I realised I must have been slightly concerned because my body wasn’t moving”

This playing down of the seriousness is also conveyed by laughter:

“I remember at about 3 o’clock or something I wonder if I’m going to get anything done today  
*(laughs)*”

He did not recognise what was happening to him as a stroke:

“I had nothing. I did no idea”

and he denies that the experience was a frightening one:

D: and...er...hence I fell on the floor and hence my brother and his...wife came in and decided...I...to call me

S: Frightening experience

D: Not really

S: No?

Unlike some of the other participants in group 2 (such as Lindy and Francesca), David was conscious throughout, and the pain and distress of the situation is evident in his wish that he had not been:

D: No, erm...I remember it all. I wish it wasn’t

S: Do you? Right, so you weren’t unconscious at all?

D: No

S: Right, so you remember it all

David recounts his stay in hospital (“seven weeks there and then five days in {name of another hospital}”) but does not remember the first five days because of the strong drugs he was on:

“Well they put me on these...er...really...they make you feel really knocked out”

His first recollection of that time seems to be the confusion over his diabetes regime; he appears to blame his sister-in-law for providing erroneous information which in turn prolongs his stay in hospital:

D: and erm so I cannot really remember the...one...the five days of that but I remember once that came off and my...my...brother’s wife had this...um...decided to tell them everything so...like I chose...haven’t got a syringe here but I inject syringe because I’m diabetic

S: Right

D: and she said ‘Oh you inject four doses of syringe every day’ and I don’t I inject twelve

S: Right

D: and so I came out of this and then saying no sorry we don’t...so basically I was in there for too long

S: Oh OK

D: Erm...because raising my blood sugars

S: Right – they had the wrong information

D: Hmm

S: Right

D: Erm...yeah I do remember it quite well...yeah...er..apart from that I remember it well

*(laughs)*

### **Faith and the church**

David’s opening gambit when we begin our conversation and I ask him to tell me a bit about himself is that he is “Church of England”. Is it that his religion is an intrinsic aspect of him, at the forefront of any introduction to him and his life, or is it that he knows I am interested in spirituality in this interview, therefore he gives me first what to him might be the most salient piece of information?

The whole issue of faith and religion is a confusing one throughout the interview. There are many - what I perceive to be - conflicting statements, which are possibly a reflection of the difficulty of expressing complex, abstract ideas with aphasia, or a reflection of my lack of comprehension of David’s ideas, or a combination of both.

At one point in the interview, for example, he claims that, although he was brought up in the Church of England, he no longer considers himself to be a member of that denomination, or indeed to have a Christian faith:

“Erm...I really don’t have a [læ] lost faith...I really don’t have a faith really...erm...when I was...when I did have I was brought up Church of England, so that’s sort of where you get things...erm...so yeah, I really don’t have a...have a faith”

Despite using intonation to imply definitude, this discrepancy of belief versus unbelief continues (“one” in the following excerpt refers to a faith):

S: You didn’t have one before the stroke?

D: (*deliberate intonation*) I think...I must say though that one of the areas that’s totally changed...hasn’t changed, it’s totally

S: Hasn’t changed?

D: Hm

S: So, it’s exactly the same as it was before?

D: Hm

S: Right

D: yeah...um...yep

and again later:

“I’m not that religious. I’m when I’d say I’m...I must admit I am very religious”

I wonder if the perceived confusion is related to the fact that the aphasia is making it difficult for David to explain the complexities and nuance between believing in God – or a god – and subscribing to an organised religion. He is clear and categorical about his fundamental belief:

S:...So, can I ask you if you believe in God or a god?

D: Yes, I do believe in a god...a simple thing

S: Yes

D: Yeah. I believe in Jesus Christ

But equally he seems to convey a dislike or a rejection of the faith tradition in which he was brought up, and which, in fact, was part of his introductory comment to me:

D: Yeah...Church of England (*shakes head*)

S: Not Church of England?

D: No

S: Right

D: But I would go to any place

It is of interest that he chooses to introduce himself with the very label he is later keen to shed, but when he asserts that “erm...I do believe that all religions are essentially good”, it seems clear that he is indeed a religious man with respect for religion and a belief in a higher being.

Quite late into the interview, he mentions that his wife attends church, but that he does not:

D: And er yeah they and...my wife's deciding to go to church actually

S: Is she?

D: Yeah, and she's quite in church actually she's very into it and...er...I don't go to church at all.

I am interested in whether his wife has recently started to attend church or whether this has been a longstanding practice for her. I wonder whether the occurrence of the stroke might have encouraged her to seek solace or support from the local church, but it seems on balance that she was attending the church prior to the stroke nine months previously:

S: We've covered everything. Oh, you were just saying that your wife started going to church – is that a new thing?

D: Er, last couple of weeks, years

S: Yeah – last couple of years

D: Yeah, she was born, well, OK...no...yeah

Although he does not attend church with his wife, David mentions that a person from the church comes regularly to visit him, and in fact was due to see David straight after I had interviewed him. It is not clear to me if this person is a minister from the church, or an interested lay person; David is not satisfied with his label for the visitor:

“...actually the person who's last there was a someone who is...er...a spiritualist – not a spiritualist – a...erm...yeah he looks after me. He [gans] me everything”

I try other labels but they are also not accurate:

S: Like a sort of spiritual adviser?

D: No, no, he's...er...he's not a spiritualist, I meant...erm...yeah...he er...he's trying to take me [dʒɛn] er be a...Oh, I don't know...trying to embrace the church like the way he does

S: Oh, OK, so he's sort of mentoring you?

D: No, he's purely just there to help

S: So, he's from the church?

D: Yeah

S: So he's just come to...

D: Yep

S: to talk to you and...

D: Yep. An hour after you!

S: Oh, right, OK (*laughs*)

Whatever this visitor's formal role or title, he obviously is a source of companionship and shared interests for David:

D: Yeah, I know I mostly use him but you know I hope he finds right OK

S: Is that useful for yourself to chat to him?

D: Not really. We don't talk about religion.

S: Right

D: (*laughs*)

S: You talk about other stuff

D: Yeah, mushrooms (*indicates book about mushrooms next to him on sofa*)

S: OK!

### **David's beliefs**

The difficulty of expressing the ineffable – with or without aphasia – is apparent in David's attempts to explain his spirituality to me. At times, it feels like the difficulty in expressing these numinous concepts accentuates his expressive abilities per se; for example, when he wryly repeats my use of the word "struggling":

D: But...er...I find it very very...sort of...I can see all the world...erm...er...(*latency*) er...just because I didn't accept...that...you know...the...(*latency*) erm...I don't know...what's (*laughs*)  
cos I

S: You're struggling to...

D: Yeah

S: put it into words

D: Struggling, that's right

He complains of "forgetting" what he wants to say but perhaps the words and phrases are so abstract, so nebulous, that they are more difficult to locate or activate in his output lexicon than more concrete lexical items (Papathanasiou, Coppens and Potagas, 2013 p 142).

In this extract, I attempt to cue him in by mirroring his output, allowing time and giving what I hope is reassurance, but we are between us unable to quite explore what he is trying to convey:

D: Erm...I don't know really, what does it mean? (*laughs*) you know, it's er...when I'm thinking basically of spirituality or heaven above I'm thinking this must have happened sometime to someone

S: To someone else?

D: Hm

S: Right, OK. So it's just part of a...

D: it's...it's the idea is that the idea as an earth (*gesture*) rotating...erm...where I do believe in things I come...erm...(*latency*) I keep forgetting what I'm meant to say (*laughs*)

S: It's a complicated thought, isn't it?

D: Yeah

In the end, David settles for the concept of "holism" to explain his spirituality and beliefs:

D: But I would definitely... would...view the world as whole

S: Right, OK. So you're not subscribing to the Church of England but you believe in...

D: In...well I believe I'm trying to find the word 'whole'

but he is dismissive of what, to me, is an interesting and valid description:

"so, it's nonsense I know but it's nonsense"

I think I detect a level of embarrassment, perhaps to be expected when discussing these concepts with a relative stranger, and perhaps also a further reflection of the lack of rapport between us. He does, however, give a very candid and beautiful definition of what spirituality means for him:

“erm...(latency) it means...er...comfort...it means...er...blessing...it means...er...it means good things, yeah”

### **Life purpose and meaning**

When I ask David what gives his life meaning, he gives a cursory answer about his children, then moves on to a discussion about his wife attending church:

S: (*pause*) What are the things in your life...erm...that give...particularly give your life meaning and purpose, for you do you think?

D: Having kids, yeah

S: How many kids do you have?

D: I...[grɛ] two

S: Two

D: Two...they're both brothers and er...

S: How old are they?

D: They're eight and seven...er...six

I wonder if he is giving responses that *he* thinks are relevant to my topic. That is to say, does he equate spirituality with religion, and therefore when I try and broaden the topic to include what may give meaning and purpose to his life, he closes this line of questioning down and reverts to a discussion involving religion. Of note, perhaps, is that he does not mention art as a meaning-giver in his life.

### **Vision**

Soon after I ask David directly whether he believes in God or a god, he candidly describes a vision he had when a very small boy:

D: Yeah. I believe in Jesus Christ

S: Right

D: Erm...yep...I had a...I don't know if you need to know...I had a very strange event happen to me about when I was about four which was...I've had it...you know...know that it tells people and they go 'my God just ring the child [æfjʊs] (abuse?) or something (*laughs*) but er this person...all right...someone came to see me...I remember it being of the [drait] frame of mind and I just thought 'I wonder why you're here' and he this man took my hand and...er...and said 'don't worry, it's all right, you're gonna be all right'.

S: Really?

D: Yeah

S: And who do you believe that was?

D: Well...the guy had a beard, so I wasn't (*laughs*) certain it was him

True to form, his language is deprecating ([æfjʊs] may be a phonemic paraphasia of "abuse", and he may be conflating 'Childline' and child abuse in the utterance "my God just ring the child [æfjʊs]"), as if trying to nullify or play down the occurrence. This may be a reflection of embarrassment at divulging something so personal to a comparative stranger. My reaction is one of "unfettered stance" (Moustakas, 1994, p 85), and the final interchange of this episode I hope reflects my acceptance and belief in what he has just described:

S: But was that...was that a good, positive, comforting experience?

D: It was positive, yeah

### **Illness narrative**

Considering David's interview using Frank's (2013) illness/ disability narratives, it is difficult to pinpoint whether his story is one of restitution, chaos or quest. On the one hand, he does appear to still be in a state of post-stroke chaos: he will not countenance the possibility of return to work, for example, and he is quick to blame his sister-in-law for the protracted stay in hospital. At times he refers to his recovery in restitutive terms, such as when he states that his communication has improved. He is perhaps at the very early stages of embracing a narrative of quest, as evidenced by his beginning to express himself artistically by sculpting. Frank (2013) explains that the quest narrative "holds chaos at bay" (p 115), however I feel that during my interview with David, chaos is a nearby presence, a presence that David attempts to mask with laughter and light-hearted deprecation. Knowing that David is only 9 months into his recovery from a major, life-changing event, which has stripped him of his language, his job and his art, perhaps this is unsurprising.

## Francesca: the opera lover's story

**“Nothing quite like it in the whole history of music,’ announced Morse magisterially, after Brünnhilde had ridden into the flames and the waves of the Rhine had finally rippled into silence.”**

***(The Way through the Woods, Colin Dexter)***

Francesca and I meet at a stroke group for people with communication difficulties run by a charity. She is kind enough to approach me after I give a talk at the group about my research and my quest for interested participants. She gives me her email address and we agree to meet in a quiet room at the group's venue a few weeks later.

Francesca is a woman in her mid-sixties. My immediate impression of her is of an independent, forthright individual. She is mobile, although she has a hemiplegia of the right arm and leg, which means her movement is effortful and somewhat slow.

### **Francesca's aphasia and communication mosaic**

Francesca had her stroke fifteen years prior to our interview, when she was in her early fifties. As well as the physical deficits, she has been left with moderate to severe expressive aphasia, in the context of very good auditory comprehension skills and no obvious motor speech deficits.

Francesca's aphasia is characterised by marked word retrieval difficulties, some phonemic paraphasias (such as [twɪp] for top), many repetitive phrases (e.g. “exactly”) and use of fillers (such as “erm”). Her sentence structure is notable in that she uses few function words (prepositions, conjunctions, pronouns); instead she tends to use content words, predominantly nouns. This lends her output what is sometimes referred to in the literature as a ‘telegraphic’ quality (Halpern and Goldfarb, 2013 p 46). Her output comprises very short utterances on the whole, and our interchange assumes the structure of a question and answer session, an interview perhaps rather than a conversation.

Throughout our conversation, I employ a number of strategies in order to facilitate her expressive abilities. I check to ensure I have understood correctly:

F: *(laughs)* erm...accountant

S: Right, you're an accountant, so you studied accountancy

F: Yep

S: At Bath

F: Yep

or sometimes I explicitly seek clarification:

S: Oh, I see...are we talking about money?

F: Yes, exactly

At times, I try and cue Francesca in, by starting off the sentence and enabling her to complete it:

S: and then you had a break and then you went into the

F: Civil service yep yep

I provide pauses in an effort to allow time for further comment:

F: Yep yep

S: (*pause*) and photography you mentioned there...

F: Yeah

and I find I am mirroring her sentence structure in my own:

S: But you not so much...ballet?

Is this in an attempt to normalise her expressive language abilities, to make her feel more comfortable during the interaction? Whatever the reason, or the result, it is a strategy I employ unconsciously.

Although Francesca presents with significant expressive language difficulties, she does not employ many total communication strategies to augment her speech. I offer her a pen and paper at one point during the interview, when she is struggling to convey the difference in pay between being an accountant and working as a civil servant. As this involves sums of money – and numbers can often be particularly problematic for people with aphasia (Abling, Weniger and Willmes, 2006) – she writes the numerical figures. However, she does not seem to routinely rely on writing as a form of expression; she did not carry around a pen and paper like some participants in this study. She uses very specific gestures twice during our conversation, and this proves a successful strategy; she gestures lying back undergoing a brain scan when the word ‘scan’ eludes her, and she also gestures holding hands when describing how her father supported her during the scan process:

F: er...erm...yes...erm...erm...erm...erm...the erm the erm God...erm...the (*gestures lying down with head back*)

S: Scan?

F: Yes

S: The scan – you remember being in the scanner?

F: Yes, yes

S: Right

F: Yep and my father er...erm my father and our...me...and my father (*gestures holding hands*)

S: Was next to you while you were going into the scanner?

F: Yep yep

Francesca overuses the word “exactly”, which perhaps has become a favoured, filling-in word, signifying agreement with the interlocutor, but arguably little else. This palilalic utterance interferes somewhat with the normal ebb-and-flow turntaking of conversation, as Francesca will sometimes insert this into the conversation too often, impinging on the other’s communication ‘turn’.

Laughter, too, is prevalent and the meaning behind this is unclear; could it be embarrassment at her word-finding difficulties, nervousness at talking to someone new, or a way of masking her expressive deficits?

Francesca uses some intonation in order to convey meaning, such as emphatic intonation when she tells me “life” is her definition of spirituality, but she uses less meaning-bearing intonation in general than other participants in the study.

She uses the successful strategy of cueing herself into a target word, particularly in the case of numbers:

S: Right. And what...just being nosey now really because I went to Bath University...which year were you there?

F: erm...nineteen...sixty...erm...3,4,5,6,7

S: 1967 til...?

F: and erm 2, 3 years

S: 3 year course

F: Yep

S: So, 1967 til 1970?

F: Yeah, yep

Francesca uses the word “God” as a term of exasperation when she is unable to retrieve a word:

“er...erm...yes...erm...erm...erm...erm...the erm the erm God...erm”

This appears to have little if anything to do with deity or religion and is more a reflection of the plight of some people with aphasia, for whom expletives (albeit very mild in this instance - if, indeed, it can be termed an expletive at all) are more readily preserved and accessed than they were prior to the stroke (van Lancker and Cummings, 1999; Halpern and Goldfarb, 2013, p 46).

### **Francesca’s stroke story**

In common with all the participants in group 2, Francesca’s stroke story is a traumatic one. She was living alone, and was unconscious on the bathroom floor for 36 hours before help was summoned by some colleagues, after she had failed to arrive for work:

F: Yeah...erm...erm...in the...er...er house...er...erm...erm...falling over...erm...in the bathroom

S: Right

F: Yep

S: Right

F: and...er...and...erm...erm...unconscious

S: Right

F: erm...two, no one and a half days unconscious...yep

S: In the bathroom?

F: Yep, yep

S: Before you were found?

F: Yep

I am shocked by this, but Francesca shows very little emotion in relating this story; perhaps it has been told so often that it has lost its power for her. She links the stroke to the period just after she had finished an important piece of work; perhaps she blames stress or overwork for eliciting the stroke. Maybe it helps her recovery narrative to have something to blame, to have a reason for the stroke to have occurred.

### **Francesca’s definition of spirituality**

Francesca views spirituality as an intrinsic part of life, and defines it thus:

S: Would...how would you define spirituality for you? What does...if I say the word spirituality what does it mean for you?

F: Life (*with definite intonation*) yep

S: Right, so is it part and parcel of life?

F: Yes, yeah

For her, spirituality is separate from religion:

S: And is it to do with...for you does it have anything to do with religion or faith?

F: No no no

S: Nothing at all

F: No

Although she explains that she was baptised (presumably as a child) into the Christian faith, she does not subscribe to any organised religion:

F: My father mother no religion, and my grandfather and grandmother no religion

S: Right

F: Yep yep

S: So you weren't brought up in that way?

F: Christian...erm...I was...erm...christening...yep

S: Yes

F: But...

S: You were christened but have no particular faith?

F: Exactly...and erm...and erm...my father mother no...erm...erm...erm...Church of England and Jesus maybe, maybe not

She describes herself as a spiritual person but one without a religious affiliation:

S: OK...so would you consider yourself to be a spiritual person?

F: Yes (*with definite intonation*)

S: You would, yeah

F: Yes, yep yep

S: Interesting

F: Yep but...erm...Christian, Muslim, Jewish, no

Francesca displays a certain stoicism in relation to her lot in life:

S: Right, so that's a huge thing to go through at quite a young age

F: Yes, thirty...forty...fifty-one

S: 51? So you were young...

F: Yes, yep, yeah

S: and did that sort of throw up any kind of questions for you about, you know, life the universe and everything?

F: (*audible sigh and 6 seconds latency before replying*) No

S: No

F: No no no

S: OK

F: Yeah yeah

S: OK

F: No I [fɔwɪd]...forward march

S: Right OK so you look forward?

F: Exactly exactly

S: Right OK

F: Yep yep

I wonder if I have overstepped the mark by asking the question about possible (probable?) existential crisis. Is Francesca unable to articulate her opinion about this because of the aphasia or is she unwilling to engage in a discussion about this? Is it too personal to divulge to a relative stranger?

### **Communicating with professionals post-stroke**

When I ask more questions about her experience in hospital soon after the stroke, she is reluctant – or unable – to articulate much about this time:

S: Right. Was that a frightening experience? In the scanner?

F: I don't know (*laughs*) exactly I don't know

S: Yep

F: Yep yep yep

S: So you remember being in the scanner?

F: Exactly yeah

Again, it is difficult to gauge whether Francesca is unwilling to discuss such emotive issues with a comparative stranger, or whether her language impairment is hindering her ability to articulate these thoughts.

She describes a period of rehabilitation, but this part of the conversation assumes the form of a question and answer session, almost an interrogation, and I am not able to promote enough trust or encouragement to enable Francesca to elucidate:

S: And do you remember sort of seeing the professionals like the speech therapist and other people?

F: Yes. Yep afterwards...er...erm...2 weeks

S: Yeah

F: Yeah me out and in of [kənʃənəs] (consciousness) but afterwards yep yep

S: So you saw lots of different professionals coming and going

F: Yep...erm...{name of hospital} first and rehabilitation ward er...erm...{name of hospital} yeah

S: Oh OK so they have a rehab ward at {name of hospital}?

F: Yes yep yep

S: And you spent quite a lot of time there?

F: Oh, two, three, four, five, six and a half months

S: Gosh, wow – that's a long time

F: Yes

Conversation feels shut down between us; I am hoping that this line of questioning is leading on to enquire about professionals with whom Francesca felt able to talk through her stroke experience, but the skills of encouraging her to open up elude me.

### **Identity**

Our conversation starts with some general information, as this is only our second meeting, and so I suggest “it would be really nice just to know a bit about you”. She begins not with where she lives, or her family, or where she was born, but by telling me where she studied and what her profession was. This speaks to me of the importance of her education and discipline in terms of creating and sustaining her identity. For a person with limited ability to express their identity through their speech, or through the evolving content of their conversation because of their aphasia, it seems it is vital to somehow convey that identity overtly. So, perhaps ordinarily our identity would naturally unfold during the ebb and flow of conversation, but in the case of someone with aphasia issues of identity need to be declared and obvious.

So, right from the start of our conversation, I know Francesca is a graduate of a good university, a professional woman, who once held down an important job:

F: (*laughs*) erm...accountant

S: Right, you're an accountant, so you studied accountancy

F: Yep

S: At Bath

F: Yep

It is almost as if from the beginning of our relationship, she is declaring that this is who she is, this is her identity, and that the stroke and aphasia may have deprived her of her job but they cannot deprive her of the essence of who she is.

Her erudition is conveyed by her profession, but also by her choice of vocabulary, notwithstanding her significant word-finding difficulties. When I rather unimaginatively describe the city of Bristol as "nice", Francesca retrieves considerably more interesting and evocative lexical items:

F: Beautiful, yeah, yep, Clifton suspension bridge

S: Yes, absolutely

F: Yep, yep, camera obscura

Work was and is an important part of Francesca's identity pre- and post-stroke, so that she refers to her involvement in the local stroke group as "work".

### **Life purpose and meaning**

Busyness and 'work' are some aspects of life which give meaning and purpose for Francesca:

F: Erm...work (*laughs*)

S: Yeah

F: Still

S: Right, you do work now? So what...?

F: No no no {name of stroke club}!

S: Ah

F: Exactly

She is very engaged and involved in several groups which take place at the stroke club, and when I visit the club to recruit participants, I notice that she seems to have a particular role, above and beyond being solely a group member; she assists the coordinator to evaluate the involvement and interaction of the various group members at the end of the session. Although this is a long way from her original work as an accountant in the civil service, it still serves to give purpose to her life.

### **Arts and opera**

Central to Francesca's life meaning, however, are the arts, and in particular opera:

"I love opera...I like erm...the erm...producing words and meanings and...it's wonderful erm music"

When proper nouns are often particularly problematic for people with expressive aphasia (Robson et al, 2004), it is perhaps surprising and testament to her passion for opera, that Francesca is able to name four of her favourite composers without demur:

F: Yep yep yep...and arts and photography and music erm...I love opera

S: Do you?

F: Yes yep yep yep

S: Tell me a bit about that

F: Wagner

S: Wagner?

F: Yes

S: Wow, serious stuff!

F: Yes yep...erm erm erm and erm Puccini

S: Yeah

F: Yeah and Donizetti

S: Yes

F: And er and er oh God...Verdi...yes yep

Francesca is very easily cued into the word "emotional" when talking about opera:

S: And music is so...

F: Emotional yeah yeah

and when I ask her if listening to opera can, in her eyes, be classed as a spiritual experience, Francesca is quite unequivocal in her affirmative response:

S: That's great...so I don't know whether you would say erm...something like opera, listening to music, is a spiritual experience?

F: Yes, yes yep yep yep

Opera appears to be Francesca's first love in terms of art, but she also professes a love of photography. Poignantly, her love of taking photographs – mostly of nature – has been restricted by the physical limitations imposed on her by her stroke:

F: Erm, before the stroke I like...erm...erm...erm...pic...pictures no photography er no photos...no I like photography, yep. Before the stroke, two hands

S: Yep, so you were taking photographs

F: Exactly

S: OK

F: Afterwards...erm...one hand and a little bit of erm erm I like photography but one-handed...

S: It's more difficult

F: Yes, exactly yep

This is perhaps an example of the stroke and its after-effects actually impacting on an individual's ability to engage in spiritual, meaning-making occupations.

### **Relationships**

As much as Francesca adores opera, her mother was a great lover of ballet. She talks rather proudly of a working-class woman who nevertheless watched and loved the ballet. She volunteers this fact, once I have summarised what she has said about loving the arts herself:

S: ...So you like the arts and opera...

F: Yes, yeah and erm my mother loves...er...loved er ballet...yep yep

S: OK

Perhaps telling me about the centrality of opera and the arts in her life, reminds her of her mother and of her mother's positive influence in this regard. I notice the corrected tense in the reference to her mother and wonder if her death was recent; a lack of real relationship over time between us precludes me from asking this question.

Francesca's father is also mentioned in this relatively short interview of thirty minutes. He is portrayed as the strong figure, who stayed with her during the brain scan directly after her stroke and held her hand.

It is clear she is a single woman:

S: So is there something about interacting with other people?

F: Yeah

S: Yeah. Do you live by yourself?

F: Yes yep yep...er...my carer and I go to the erm...erm...shopping...erm food shopping and ironing and domestic work and yes er...2,3,4,5,6,7 times

She makes no mention of a partner or children of her own, so I understand the importance of referring to parents in a discussion around meaning and purpose.

We develop a relationship of sorts, although I am very conscious of this being an organised interview, a contrived chat around a subject of my choosing. There are moments of connection, for example when we discover we both went to the same university:

F: Erm...university...erm...Bath...Bath University

S: Me too!

F: Really?

S: Yes

but thirty minutes has not felt long enough to cultivate rapport, therapeutic or otherwise. When I receive the summary of the interview back from Francesca with her comments included, there is little discernible warmth or connection. During the interview, I try and give a little information about myself in order to foster a more equal interchange, but this does not elicit questions by Francesca to me, which might have served to balance the power differential and foster rapport-building.

### **Illness narrative**

Francesca had her stroke many years ago, and one would therefore perhaps have expected her to have entered a quest narrative (Frank, 2013). Her stoical attitude and involvement in a stroke club – not just as a member but also as a coordinator – suggest this to be so. However, limited rapport meant that possible chaos and restitution narratives, either current or past, were not fully explored.

## Joel: the evangelist's story

**“Take, eat; this is my body which is given for you: Do this in remembrance of me...Drink ye all of this; for this is my Blood of the New Testament, which is shed for you and for many for the remission of sins”**

*(The Book of Common Prayer)*

Joel is a man in his forties with a young family. He is originally from Nigeria, and is a committed Christian. We meet twice at his home in order to talk about his faith and for me to hear his stories of spirituality.

When I first arrive in his street, I inadvertently knock on the wrong door; the neighbour has not heard of my participant or his family. This strikes me as sad, that people living in a neighbouring house have not met each other, and I wonder if this is part and parcel of the social isolation that can arise with disability in general and with the “invisible impairment” (Hewitt and Pound, 2014, p 181; Moss et al, 2004 p 755) of aphasia in particular.

Joel is cheerful and friendly and proffers me his left hand in greeting. His wife is there, but does not stay in the room for our conversations. Two little daughters occasionally float in and out, singing songs quietly and offering me drinks. On my second visit, he greets me from the top of the stairs with a wide grin of recognition before he descends.

### Joel's aphasia

Joel had his stroke 3 and 4 years respectively prior to my interviews with him. He has a right sided hemiplegia but is mobile. It is evident from having a conversation with Joel that his auditory comprehension is excellent. His expressive abilities are characterised by significant word finding difficulties, neologisms (non-words created in place of the target word, such as [məʊ məʊ]) and limited syntactic structure. It is augmented, however, by facial expression, intonation, some gesture and use of other referents. As with all participants, no formal assessment of language and speech was carried out but, on observation, Joel presents with a Broca's-type, expressive aphasia, with no motor speech deficits. Using the cognitive neuropsychological model of language processing (appendix I), Joel's difficulties are at the output end of the framework (phonemic and orthographic), below the level of the semantic system (phonological and orthographic output lexicon and/or buffers). In essence, he understands what is said to him, but has difficulty in finding the vocabulary and syntax he needs for expressing his thoughts.

Understanding within our conversations about spirituality is helped by the fact that we share a faith. For example, at one point when he is trying to talk about Jesus' disciples, he says:

J: Yes, er...four, five, six, seven, eight, nine, ten, eleven, twelve (*with emphasis on last number*)

S: Twelve...? Ah! Are you talking about the twelve apostles?

His own strategy to cue himself into the target word also actually cues in the listener, or at least the listener with a shared knowledge.

Sometimes, his default utterance is “for now”, which seems to mean “that’s enough for now, let’s leave it there”; he uses this if he is struggling to find the word he wants and his interlocutor is not helping.

### **Joel’s Mosaic**

Joel’s communication Mosaic (Clark, 2001) comprises speech, some writing (see appendix VIII), gesture, intonation, facial expression and use of objects of reference. During our first interview, he often reaches for his Bible, in order to explain something, or illustrate a point. For the second interview, I arrive with some objects (see appendix IX for examples), with a view to seeing whether these might facilitate expressions of spirituality, specifically Christian faith.

Interview times and dates were arranged via emails with Joel’s wife. Our final correspondence perhaps reflects some level of friendship and connection, however brief:

*Hi Sarah and Joel – thank you both so much again for welcoming me into your home – I really appreciate it and know the interview will enhance my research*

*With very best wishes*

*Sophie*

*Dear Sophie – it’s our pleasure. And thank you so much more for taking the time to come.*

*Sarah and Joel*

The neologism [ε hε] is used consistently throughout both interviews and seems to convey “yes, you got it”. Some neologisms are more difficult for me to interpret (for example, [məʊməʊ səʊne ɪ]), and indeed these are often accompanied by embarrassed laughter, as if Joel is aware they are not conveying the intended meaning.

### **Joel’s stroke story**

Lindy had taught me the value of listening to my participants’ stroke story. Joel explains how the stroke occurred several years previously, very suddenly as he was driving a friend in his car.

The suddenness is successfully conveyed by choice of vocabulary but also by intonation and gesture:

J: And (*sighs*)...sudden...sudden

S: You, you were driving?

J: (*very animated – points to himself*) me was driving

S: Right

S: So the car

J: I know...er...{local area}

S: Yeah

J: Going in erm...to {local town}...to {local town}

S: Right, OK, so you were driving to {local town}

J: Yeah, and suddenly...suddenly (*with emphasis*)...er so

The devastating physical and cognitive effects of the stroke are also made apparent:

J: No, no, yes...the one is and we got out

S: Yes

J: But gone (*makes sweeping gesture with left hand*) gone

S: Did you know what had happened?

J: [nɛ] but (*touches left side of head then right*)

S: In your head? Could you feel something in your head? Did you feel pain?

J: Yes

However, Joel is quick to correct me during one interview, when I offer sympathy in the form of acknowledging the perceived frustration of people who have aphasia:

J: No, [ɛ ɛ ɛ] (*reads*) in the day that the...oh God...oh God

S: I know, it's there. It's frustrating

J: No no no no...no no no

S: You're not frustrated?

J: Not at all

S: You're amazing

This appears to relate to his acceptance of stroke and aphasia as his lot whilst on earth, and his belief in the "resurrection body" of the Bible. In 1 Corinthians 15: 52, Christians read that in

the afterlife they will receive a new body, a body free from the pain or trauma experienced in life:

“For the trumpet will sound, and the dead will be raised imperishable, and we will be changed.”

Joel explains how he does not blame God for the stroke or complain at his subsequent language (and physical) disability because the situation is temporary; when he dies, he will receive his “new body”:

S: Hmm, do you ever question God? Do you ever say why did this happen to me?

J: *(lots of phonemes – difficult to transcribe)* For me now is...so yeah *(touches left hand to chest)*

S: This is your lot?

J: *(emphatic)* no no no no *(points with left hand)* rise again *(laughs)*

### **Restitution or resurrection body**

Joel’s belief in life after death, and life with a new, perfect body after death is perhaps the ultimate in restitution narrative (Frank, 2013). He conveys a stoical attitude of accepting life as it is, in the sure knowledge of something better to come, something that will last an eternity. At our first meeting, he is keen to show me the biblical verse which illustrates this; he finds it difficult to locate the exact verse he wants and enlists the help of his wife:

S: Yeah, and you said...when I first came in you said something about...erm...this body will rise again?

J: Yes, yeah

S: Can you tell me a bit more about that?

J: Rise again, will rise again...Oh, God *(reaches for Bible housed in the ottoman in front of us – becomes animated. He brings out a very battered, well-thumbed Bible with no cover. He leafs through it with his left hand. His wife enters and he gestures to her)* in the...rise again...no no no

S: J said that this body will rise again and I think he’s trying to find the reference.

J’s wife: OK, that’s John...Is it the one “your brother will rise again?”

J: Rise again...er...er *(taps Bible)*

Although he appears to accept the stroke and aphasia as his lot in life, he also acknowledges the possibility of some improvement in function in this life, as well as in an afterlife. He sometimes speaks the language of Frank's restitution narrative (Frank, 2013):

S: OK and did you see a speech therapist?

J: Well, yes...yeah, yeah, yeah...so better now...[vatli] better

S: Vastly better than it was. Good – so you've made progress?

### **Joel's definition of spirituality**

As one might expect for someone with such a strong and vibrant faith, Joel's definition of spirituality is characterised by impassioned intonation and reference to God, the church and the Bible. He uses the Bible to sum up his definition of spirituality by locating the passage about the fruits of the spirit and enabling me to read them out. By my reading them out, he is cued into the word "spirit", and in this way, it is as if we have both found, read and shared the appropriate passage:

J: (*sighs*) is all in all. All in all (*emphatically*) so...(*taps the Bible with left hand*). The Bible and so...

S: Any other words come to you?

J: [tʃɛgɹɛti]

S: Integrity?

J: Yes

S: Nice!

J: Hm...er...erm...er...integrity...er..[dʒɪtʃ stændɪŋ]

S: Hm...church standing?

J: No, all the time (*laughs*) God...Oh, God...integrity and n...n...(*sighs*) st... (*takes pen and paper spontaneously for the first time, but does not write*) erm... (*long pause – reaches for Bible again*) OK (*finds Ephesians*) aha! (*points to verse*)

S: (*reads*) but the fruits of the spirit are love, joy, peace, long-suffering, gentleness, goodness, faith

J: Yes, yes

S: OK, so the fruits of the

J: Spirit! Yeah

### **Loss**

Despite his positive attitude and belief in a better life to come, Joel does express the extent and depth of loss following his stroke. When I ask him if he remembers his time in hospital

directly after the stroke, he graphically conveys the enormity of this loss using both gesture and apt vocabulary:

S: OK. So do you remember being in hospital?

J: No, no because you have gone (*sweeping gesture with left hand*)

I ask him specifically if he is still able to engage in prayer as a way of communicating with God:

S: And er...can you tell me about praying? Are you able to pray?

J: Well (*sighs*) yes (*emphatically*) but not aloud eh yeah

S: OK so not aloud? But inside?

J: [ε hε]

The sigh perhaps demonstrates a wistfulness, but the following emphatic intonation assures me that prayer still happens but in a different way.

### **Liturgy**

Interestingly, snippets of liturgy are remembered and accessed, sometimes through the prompt of an object of reference. So, for example, when I show Joel a communion wafer, the following exchange takes place:

J: (*struggle behaviour*) testament

S: Testament

J: Yes

S: Fantastic

J: Yes

S: Yeah, so the cup goes with this (*shows wafer*)?

J: Yeah, yeah (*struggle*) blood...the blood

S: Yeah

J: Hmm

S: So, this is the body, the cup is the blood

J: Blood, yeah

S: Yeah

J: Drink

S: Yep

J: In remembrance of me

His choice of vocabulary is reminiscent of liturgy used in the Book of Common Prayer, a text with which he may well have been familiar growing up in Nigeria:

“for this is my blood of the new testament,  
which is shed for you and for many for the remission of sins:  
do this, as oft as ye shall drink it, in remembrance of me.” (Church of England, p 256)

This traditional type of liturgy (from 1662) was and is widely used in the church in Nigeria (Hefling and Shattuck, 2008, p 298).

### **Priests**

I am interested in how someone who has gone through a catastrophic event such as stroke, which has deprived them of language, and who has a strong faith, expresses their spiritual needs. Are chaplains and pastors equipped to minister to people for whom words have become problematic? Joel admits that, although he was visited by the chaplain in the hospital, communication between them was difficult:

S: OK, so did the pastor from your church....

J: No no no...hospital

S: The hospital one, OK. And did you find you were able to communicate with them?

J: Yeah

S: About what you wanted to say?

J: Yeah, but slightly, cos [mɪəsɔl]

S: Yeah, so it was difficult?

J: Yeah but [mɔmɔ] so...

Perhaps the healthcare professional more equipped to facilitate his expressive abilities would be the speech and language therapist but, although she might have had the clinical skills, it seems she did not have the ministry skills necessary:

S: OK. Did you find, so was there anyone else that you saw in hospital, so like the speech therapist for example, would you have liked to be able to talk about...er...talk about what's important to you? Your religion? Your spiritual issues?

J: Well er...er...not because...

S: Not with her?

J: No

## Connection

In terms of understanding one another and facilitating that understanding and expression of spiritual issues, we are helped by having a shared faith in Christianity. This shared knowledge enables me to make guesses when the target word eludes Joel:

S: And were you baptised then?

J: Erm...erm because (*gestures and phonemes which are difficult to interpret*) yes...no...no baptism but there was important

S: Yes, so you sort of committed yourself

J: Yourself yes

or cue him in to a desired word or concept:

S: OK, so the fruits of the

J: Spirit! Yeah

## Life Meaning

When I ask Joel what is important to him, what gives his life meaning he is unequivocal:

“Important is God (*lots of left hand gesturing and animated intonation*) other things, no...no God God God God (*emphatic*), so...”

He uses speech, intonation and writing to convey the prominent position occupied by God and Jesus in his life:

S: So, what does Jesus mean to you?

J: (*sighs – takes pen and paper*) Lord (*writes Lord Jesus*)

S: (*reads*) Lord Jesus. So he is your Lord?

The Bible is also central to Joel’s faith story. When I enter the living room for the second interview, there is a flipchart displayed with a Bible verse written up, along with the words “listening to God”. I assume that a Bible study group has recently taken place in the room, but Joel explains that he and his wife were using this for their own private study. He is quick to locate and use his Bible to explain important concepts to me:

S: Right, right, OK...er...yes, because we talked last time about how important the Bible is for you

J: Yeah, yeah (*gestures to the ottoman in front of us, in which his Bible is housed*)

S: Yeah, it's in there! I remember you reaching in and getting it.

The centrality and importance of the Bible to Joel is conveyed passionately and unequivocally, despite the neologisms:

S: Erm, so the Bible is very important to you?

J: Oh yes [kɒnæsiə] is erm (*animated*) [dɛfəʊ] oh, God

S: It's OK, take your time.

J: But the Bible...is important

S: It's important to you. Are you still able to read the Bible?

J: Yeah yeah yeah

From this extract we can also glean that Joel is still able to read the Bible and to understand what is written. Similarly, he is adamant that he is still able to take an active part in church services, despite his aphasia:

S: And you go to a church nearby?

J: Yeah yeah

S: And do you find being in church that you can still take part?

J: Yeah yeah yeah (*shrugs shoulders, as if to say "why not?"*)

### **Artefacts as prompts**

Knowing the importance of his faith to him from our first meeting, I take a number of artefacts with me when I go back to visit Joel for a second time (see appendix IX for examples). I wondered whether having an object of reference might enable Joel to extend his expressive abilities and thereby convey more complex or nebulous concepts. For example, through looking at a small sculpture representing the Trinity together, Joel is able to express what the Trinity comprises:

J: (*laughs*) God the Father, the Son and the Holy Spirit

S: Yes, all as important as each other, or...?

J: Yes, no no all important

S: All important, yeah

J: Hm

and its particular relevance to him:

S: And which one, which one do you identify most with or feel closest to?

J: All the time...no no...all the time

S: So, they're all equal?

J: Yes

Thus, this notoriously difficult concept of one being but in three parts is successfully expressed in few words but expansive communicative ability.

Similarly, looking at a picture of Holman Hunt's "Light of the World" (appendix IX) together, I begin to understand how Joel views Jesus, that he is in heaven, already seated at God's side, and that therefore this image is not very meaningful or important for Joel:

J: Erm, yeah (*intonation suggests reservation – laughs*) but well now is in heaven

S: Yeah

J: Yeah, so (*laughs*)

S: Yeah, so it doesn't mean so much to you because...

J: Well (*points*)

S: Ah, because he's knocking on the door

J: [εηε]

S: I see

J: No, no, no no ...is seated in the right side of God

Showing Joel a communion wafer leads to a discussion about his church, and the fact that he takes part in the Eucharist at his local church. At the beginning of this interchange, I am unsure as to whether his church tradition would use wafers (as opposed to real bread), but he is able to disabuse me of my presupposition. He uses speech, intonation and writing to get the message across to me:

S: Great. Not sure whether this one will mean anything to you? Might do (*shows communion wafer*)

J: Yeah (*laughs*) [kətə]

S: Does it?

J: Yes (*emphatic*) (*laughs*) All the time, we...in the [αϊδᾰνταϊμ]...Oh God...OK (*writes St. Ad*)  
erm...

S: (*reading what he has written*) St Anne's?

J: Yeah  
S: St. Andrew?  
J: No no no no no it's...hm...OK, for now...no no no er  
S: St.....  
J: [εɪdən]  
S: Aidan

Looking at the wafer together prompts one of our longest interchanges, and results in Joel being able to explain the symbolism of the bread and wine, as well as recall snippets of relevant liturgy:

J: (*laughs*) hm ...eat  
S: Eat, uhuh  
J: And [ɪ]...my body  
S: Brilliant  
J: Is the...mm...remember this...in [kəʊ] OK (*laughs*)  
S: You're doing great  
J: (*sounds of struggle*) Oh God...OK...for now  
S: OK  
J: Cup  
S: Corp? Cup – sorry, I misheard you. Yep  
J: (*struggle behaviour*) testament  
S: Testament  
J: Yes  
S: Fantastic  
J: Yes  
S: Yeah, so the cup goes with this (*shows wafer*)?  
J: Yeah, yeah (*struggle*) blood...the blood  
S: Yeah  
J: Hmm  
S: So, this is the body, the cup is the blood  
J: Blood, yeah  
S: Yeah  
J: Drink  
S: Yep  
J: In remembrance of me

S: Brilliant! Well done – you got there! That’s fantastic

J: Yeah

S: So, there’s the body of Christ and the blood of Christ

J: blood (*said simultaneously with S*)

Other artefacts are less successful in facilitating conversation. In some Christian traditions, the sound of a bell may signify the presence of the Holy Spirit, so I show and play a small bell for Joel and ask him what this means to him:

S: I was thinking about...you know some churches have what are called “bells and smells”. Have you heard that expression?

J: Oh, OK

S: They have bells and incense

J: No

S: To...

J: No no no no (*laughs*)

S: Not in your church?

J: No no no

S: Not in your tradition?

J: No

S: It’s funny how different churches...

J: No no no, well, but not...(*intonation = live and let live!*)

S: But not for you

Even with limited words, Joel does not appear to be dismissive of the significance the sound of a bell may have for someone else. Even with limited output, his intonation portrays respect for others’ views.

### **Giving Glory to God**

A recurring leitmotif in the interviews with Joel is that of giving glory to God. He is quick to divert my praise for his knowledge of the Bible to God:

S: Brilliantly found, well done! Your knowledge of the Bible is amazing

J: Well, God be to the glory. Yes, God be to the glory

S: Yeah, to God be the glory

J: Yeah, yeah

and at the end of our second meeting, he is anxious to attribute all improvement after the stroke to God:

S: Well, I think that's all I wanted to talk about today. Is there anything else you wanted to talk about?

J: No no no no..not at all. Not at all (*laugh together*) erm (*struggle behaviour*) bit by bit

S: Yeah

J: Bit by bit

S: Yes

J: But...God will be glorified

S: Fantastic

J: Yeah

S: So bit by bit...are you talking about...you?

J: Yes, er...

S: And do you mean your communication?

J: Yeah, but...

S: Bit by bit

J: Yes

S: And to God be the glory

J: Yes

S: Yeah

J: Yeah

### **Joel's faith**

I estimate Joel to have been born in the late sixties or early seventies. As part of his spiritual story, he explains that he became a born-again Christian in 1988, as a young man. At least, this is what I interpret from the following exchange, my interpretation being aided by speech and writing:

S: Have you always been brought up as a Christian?

J: No, because...well, yes, but not er...but erm...erm...(*sighs*)

S: Do you want to write it?

J: OK (*takes pen and paper*) erm...nineteen (*writes 198*)

S: Nineteen eighty....

J: Aha (*writes 8*)

S: Nineteen eighty eight?

J: Aha

S: Aha

J: Hmm

S: What happened in 1988?

J: Was but (*laughs*) 1988

S: It was an important date?

J: Yes, yes

S: Was that when you became a Christian?

J: Yes, well...

S: Born again, or...?

J: Yes (*nods*) [ɛhɛ]

Joel's faith is very evident from the moment you meet him – one of the first things he says to me at our first meeting is "rise again", there is a plaque quoting a Bible verse on the wall of his lounge and the well-thumbed, battered state of his Bible is testament to his constant reference to it. One might imagine that suffering a stroke at a young age which has left him with significant language and physical deficits, would have challenged his belief in a benevolent God but again he relies on intonation and gesture to express clearly how his faith has seemingly not wavered:

J: Important is God (*lots of left hand gesturing and animated intonation*) other things, no...no

S: Hmm...and has that changed since the stroke?

J: (*Shakes head*) Not at all. (*More emphatically*) not at all. Yes, so, yeah, hm...

S: So, your faith is as strong now as it was before?

J: Yeah, yep...yep.

Christianity is at the core of Joel's being, and his story of spirituality is thus full of references to Bible verses, church and to God. Despite significant aphasia, he is able to express deeply held religious beliefs, such as the belief that he will have a new, unblemished body on the day of resurrection, as well as complex theological concepts, such as the Holy Trinity. His is a restitution narrative (Frank, 2013), where he has made discernible progress in function during this lifetime, but is also assured of a religious restitution in the form of an afterlife with a complete body. This religious restitution could also be allied to Frank's (2013) quest narrative, in that the assurance of eternal life with a non-aphasic body allows Joel to embrace and accept his current situation, and live life to the full.

## **Peter: the gardener's tale**

**“And the secret garden bloomed and bloomed and every morning revealed new miracles”**

**(*The Secret Garden*, Francesca Hodgson Burnett)**

I had met Peter a few months previously at a Stroke Association group. He had seemed interested in being interviewed and I had duly given him my card and waited eagerly for him to contact. He is a man of late middle age, who had his stroke nearly two years prior to our meeting. I suppose I assumed because of his interest and willingness to be interviewed that he was a man of faith, or a man who might describe himself as spiritual; sitting down, I notice what looks like an order of service for a church event, but I could not be sure. Again, this made me think Peter might be a religious man, a churchgoer.

As he welcomes me into his home, before being offered either a seat or a drink, he ushers me towards the conservatory and points out his extensive garden: “100 foot” is one of the first things he utters.

I feel an affinity with Peter. His cat is a mutual source of amusement, and I notice he has a lamp and a mirror which are exactly the same as ones I have at home. Small things, but they help in relating to someone new and in forging immediate rapport.

It soon becomes apparent when speaking to Peter that he has excellent auditory comprehension skills. He follows my conversation with ease, even picking up on quick-fire comments and interjections. His pragmatic skills are also excellent, including normal eye contact, facial expression and ability to take turns in the conversation. His expressive language, however, is characterised by significant word-finding difficulties, which lend his output a very slow and deliberate feel. Spoken words are often produced in a literal paraphasic manner, so that, for example, “sitting” is produced as [stitin] and worried as [wodid]. Mapping his language skills onto the cognitive neuropsychological model of language processing, his problems seem to be mostly at the level of the phonological output lexicon and buffer (appendix 1).

### **Peter's Mosaic**

Peter does not appear to have many non-verbal strategies to aid his word-retrieval difficulties. At one point in the interview, I ask him if he would like to try and write the word he is struggling to find. He intimates, however, that he has similar linguistic difficulties in the written modality, so that attempting to write does not help his expressive success:

S: Does it help to write?

P: No, because the first word that I...will be using..I erm...if I...er...I....er...I (*pause*)...the...say we did focus on it but not very far...er...er...what happened...erm (*pause*)

He does use some gesture (although this is often quite undifferentiated and vague) or tapping his leg as a way of cueing himself in to the target word or phrase, but this is not always successful:

“what I was I was erm (*slaps right thigh, looks away and smiles*)”

However, just as his fluency and ability to retrieve a target word seem to increase when he talks about his garden, the place and activity which, as we shall see, gives his life meaning and provides happiness, so his gestures also become more specific and communicative:

“then that’s all good (*gestures hoeing*) erm hoe round the plants, hoe off the weeds and they’re better as well”

He also uses some non-speech sounds to convey meaning. For example, when he is relating the events of the day he had his stroke and he was alone, collapsed in his front garden, he expresses the emotion thus:

S: Could you ask him for help?

P: Erm (*sharp exhalation*) I don’t know erm I really don’t know erm...

Peter is aware of his errors, which lends his output a veneer of frustration but also enables him to self-correct successfully on many occasions:

“Er...and the and the erm people that I was in charge...er (*pause*) er no, (*looks away, searching for the words, moves left hand and shakes head slightly*) the people, the people that (*under his breath*) not in charge (*shakes head*)”

As the listener, I try and employ a number of strategies to aid his word-retrieval, as well as to foster a relationship of trust and patience. I give him time and space for the elusive words to come. I try and cue him in by paraphrasing what he has just said. I provide encouraging fillers, such as “aha, mm” and my non-verbal communication is open and encouraging (head-nodding, leaning forward, eye contact, smiling).

## Trauma of the stroke

Lindy had suggested I begin by asking people about their experience of stroke. Peter's story is a traumatic one and also one that feels as if it has been told often; events are remembered in detail, and added to the narration to create a rich and enduring image of the catastrophe:

S: Then you went to hospital?

P: Yes, I...it took erm because there's an accident in the erm on the [kontʃəflɔʊ] (contraflow) on the bridge

S: Uhuh

P: It took...took...three quarters of an hour to get an ambulance erm they had the one band...one band...one man [ambəsens] (ambulance) but obviously I...they had to...erm...they couldn't do anything with me so I had an ambulance and then I went off to {paraphasia – name of hospital}

He explains how, eighteen months or so prior to our meeting, he had suffered a stroke in his front garden. Living alone, no one missed him (he is separated from his wife and his two daughters had left home a few years previously) and he lay in the garden in the cold of a November day for many hours.

In talking about this traumatic experience, Peter uses understatement, as if the full horror of it cannot be fully acknowledged. So, he explains how, if his temperature had gone down by one more degree, it would have been “awkward”, when what he presumably means is ‘serious’ or even ‘fatal’. Whilst waiting for the ambulance, he was “out of it”, as opposed to maybe ‘unconscious’ or ‘very seriously ill’. It strikes me that this, as I perceive it, understated lexical choice may be less a feature of his aphasia and more a reaction to the chaos narrative (Frank, 2013) of this part of the stroke story; in order to contain the chaos, he chooses milder vocabulary.

Peter's word-finding difficulties are particularly marked when he describes the events of that day:

“Er...erm...I d..d..spoke about what had happened erm but then I didn't really feel erm what we weren't I think we weren't er (*looks away, frowning, taps thigh*) I think (*long pause, taps thigh*)”

This contrasts markedly with his word-retrieval and expressive abilities when he is talking about his garden:

P: All in the (*gesture*) erm (*gesture*) erm...what happened was I came from a garden that was a hundred and forty foot...the garden in {name of local town}

S: Right, so you downsized! (*laughs*)

P: (*laughs and smiles broadly*) yes, {name of street} and er what I did then, I [ɒlk] out some of the plants anyway, others I erm cut them in two. I bought one half so I had six hundred plants erm erm erm but then I bought them with me so

S: That must have been quite a lot of work, to have gathered all that

P: (*smiles broadly*) yes, it was I mean...erm...I was at home...I've been at home for eleven, twelve years erm so I er (*gesture*) I had plenty (*conduite d'approche*<sup>7</sup>) of time to do that...erm..I think my wife...I think my wife would have...erm...would have er I think she thought that I would stay there.

I ask if he was able to articulate this trauma whilst recovering in hospital, in an effort perhaps to make sense of what had happened to him, but he explains how his aphasia was so severe that he “really couldn’t use the words”. Frank (2013, p 115) talks about “the suffering [being] too great for the self to be told” and Peter had to contend with the double pain of also not having the language to express his angst. He also intimates that perhaps medical and hospital staff did not attempt to facilitate or encourage him to talk about what had happened to him:

P: Er the people in charge...way above them (*gestured “above”*) they wouldn’t talk me like a...er...they wouldn’t talk to me about (*hand gestures*) what happened because they were...er... (*pause*) erm no because then as I say I really couldn’t talk to them anyway, so.

S: Are these like doctors and consultants and that sort of person?

P: Yes, that’s what I think, yes

When I suggest the possibility or usefulness of being able to communicate his illness/ disability narrative to another person such as a hospital chaplain, he is candid about his lack of religious belief. However, it appears he would have been open to discussing events with a minister, but his aphasia precluded this anyway:

S: What about someone like a chaplain?

P: Er, no because..er...I...er because I er because I was an atheist

S: Oh, OK

P: So...

---

<sup>7</sup> Several attempts at the target word

S: That wouldn't have been the right person?

P: No...I would talk to 'em...er...but not knowing what I had erm I couldn't talk to them anyway  
(*nods*)

### **Relationship**

Two years after his stroke, he now finds relationship and communion with people in a similar position to him, people who attend his local stroke group, about whom he says:

“we tend to just talk about anything”

In fact, he seeks out relationship with stroke group members, neighbours, friends and family, and indeed views socialising as the next step in his therapy:

P: Yeah erm but it erm when I got the car erm I... I...erm this was only March...April...first of April when I got the car, I told I said to her {his speech and language therapist} I didn't really think I needed erm anything I thought I would do better le...getting on with talking with people  
(*gesture with both hands*)

S: Yes, I can understand that, going to the group and stuff

P: Yes, yeah going off to do the shopping and going round people's houses (*nods*) that sort of thing

S: Yes, good for you

Perhaps this is an illustration of Peter's disability narrative moving into what Frank (2013) would term “quest”, living with and coping with the illness/disability as it presents now. He is perhaps sharing his stroke story – his life story – with what Schweitzer called “the brotherhood of those who bear the mark of pain” (Schweitzer, 1998).

Despite living alone, Peter derives pleasure and meaning from relationships with his daughters and, indeed, his ex-wife:

“So but erm that's what it is with me. I go out and visit people er my daughter, she live in {name of local town} er and and my wife she [l+d] in {name of another local town}”

I perceive a relationship between participant and researcher also developing over the course of the interview. Despite the fact that this is only our second meeting (our first being at the stroke group, where I introduced my project), there are various moments of connection during

the interview. For example, when the cat descends from the back of Peter's chair to take centre stage, we both laugh, and he picks up on my irony when suggesting he has downsized, when he explains that he has gone from a garden of one hundred and forty feet, to a still very lengthy one of one hundred feet.

By the end of our hour together, he is also sharing quite intimate information with me, such as disclosure of mental illness, and his recent diagnosis of cancer. It is interesting to consider the overlap in qualitative interviewing between researcher and therapist; is it possible (or desirable) to separate the therapist from the interviewer? I wonder, too, if the subject matter of spirituality actually lends itself to disclosure or candidness; does an open "unfettered" researcher stance (Moustakas, 1994, p 85) regarding issues of a slightly unusual or unconventional nature and a non-judgmental mien and attitude foster in turn a readiness to disclose and to confide, on the part of the participant? I hope I have become what Moustakas (1994, p 39) identifies as the "enhancer", who "creates an atmosphere of freedom, openness, and trust, and is willing to respond and disclose his or her own thoughts and feelings."

### **Garden**

It is clear that Peter derives life meaning and purpose from his love of the garden and gardening. I am invited to view his garden before I am invited to sit down or to have a drink. Although he talks during the interview of a close bond with his children and with his ex-wife, and a good support network of friends and other stroke group members, when I specifically ask him what gives his life meaning, his answer is unequivocal:

S: What's important to you?

P: (*with energy*) what's [iɪmptət] to me is getting on with the garden (*smiles*)

He conveys the pivotal role the garden plays in his life through animated delivery of speech, facial expression, choice of vocabulary and gesture. He smiles broadly when discussing his garden as if his spirits are lifted:

S: So, what do you get, working in the garden? What does it do for you?

P: Ah (*shakes head, shrugs shoulders – as if to say "so much!" – smiles*) er...pause...I do [lʌb]...I love my garden...I like the flowers but I also like the birds and the bees and everything else erm...erm...(*gesture – animated*)

His enthusiasm is also conveyed by the complexity and detail of information he gives:

“what I did then, I [dʌk] out some of the plants anyway, others I erm cut them in two. I bought one half so I had six hundred plants erm erm erm but then I bought them with me so”

His expressive abilities (both verbal and non-verbal) are markedly better when he is discussing the garden as opposed to the story of what happened on the day of his stroke. For example, he is able to convey quite complex information about what appears to refer to grafting of one plant onto another through use of accurate gesture and good choice of vocabulary:

“I did erm this was three different plants and I (*gesture with both hands, finger of left hand crossing fingers of right*) then er er created plants er er and then erm oh they would just small bits of erm they were just small bits of garden and I joined all of the things together and made it what I did was er if I can hoe (*gestures hoeing*)”.

Passion, enthusiasm and importance seem to lend the utterance clarity and eloquence. Indeed, so important is the garden to Peter’s life that his mental health is affected if he is unable to get into the garden either because of the weather or because of his physical health:

“Oh, yes, yeah...erm...this...this...the best time of year when it’s it [bɔm] and when it’s warm...I don’t...I erm...live...I live a bit...I get...(pause) (*shakes head, sighs*) (pause) when it’s not nice out there, I get a bit low”

Having endured both a stroke and cancer, he craves life in the garden, away from illness:

P: So now I really think that I don’t...I can’t I can’t do do it anymore...I think I’ll get on with me garden and er that’s...and that’s (*gesture*) that’s because I don’t want to I don’t want to er...I don’t want anything I don’t want anything er...(pause – *shakes head*)

S: You’ve had your fill of being ill

P: Yes, I don’t want anymore

S: You, you just want to get on with the garden?

P: Yes

### **Peter’s definition of spirituality**

Despite the church order of service on the coffee table, Peter describes himself early on in the interview as an atheist. I am interested in what his definition of spirituality might be – after all, he expressed an interest in taking part in the study and I am intrigued as to his interest in and opinion about the subject matter. Of all the participants living long-term with their aphasia in

the study, Peter struggles the most in putting his understanding of spirituality into words, or into expression of any kind, verbal or non-verbal:

S: Mmm, yeah...so if I say the word spirituality to you, what does it...can you think of other words that it brings to mind, or other feelings, or...

P: Er... (*long pause*) I can't think of anything (*takes hand to mouth*)

S: Difficult concept, isn't it?

P: Yes, er... (*shakes head*), no, I can't think of anything

Is this a problem associated with his aphasia, or is this the universal problem of verbalising the numinous? Peter knows what spirituality is to him because he is able to claim that adjective in relation to himself, but he finds it difficult to express via any modality, not just speech. It seems to be his aphasia which renders the word "spiritual" difficult to produce, and Peter makes many unsuccessful attempts at producing the word and self-corrects many times before it is articulated correctly. His assertion that he definitely would consider himself a spiritual person, and that he believes "in something but what it is I don't know", feels more an inadequacy of language per se rather than of his language system in particular:

S: Would you describe yourself as a spiritual person?

P: Yes, yes, I...I could (*pause*) when I thought about that but I couldn't (*many attempts at word 'spiritual'*) (*shakes head*) spiritual person like that erm...I don't believe that...I do believe in something but what it is I, I don't know

When Peter is relaying the story of the day he had his stroke, I ask him twice what was going through his mind during his time alone in the garden, getting colder and colder as the day progressed ("they did say that if my temperature had fallen one degree (*gesture*) I...er...it would have been awkward"), and I think I have in my mind the notion of prayer. Ill and alone in the cold, I would have prayed, but Peter did not do so, and this is a lesson for me in listening to the other's story, not overlaying my own.

### **Disability narrative**

Frank's (2013) three illness (or disability) narratives are all revealed at various different points in our interview. Peter's retelling of his stroke story is couched in chaos terms – he is outside alone, in freezing temperatures, unseen by neighbours and the ambulance is delayed in both getting to him and conveying him to hospital. However, a restitution narrative is evident in his relaying of improvement in his speech, thanks to the input from a healthcare professional:

S: So, while you were in hospital, what was your talking like?

P: I couldn't (*shakes head*)

S: At all?

P: No

S: So, it's really improved?

P: Oh, yes. I couldn't, no, I couldn't talk at all and er then {name} at the...er..*(cat descends from back of chair behind P's head and we both smile and laugh)*

S: Is she your speech therapist?

P: Yes erm she was and she was very good because erm erm she taught me how to speak erm (*pause*) erm

In the restitution narrative, "for every ailment, there is a remedy" (Frank, 2013, p 86), and at this point Peter views his SLT as the 'healer' of his language.

After his cancer diagnosis, Peter also looks to the medics to cure his disease, so that he is able to return to what is important to him – his garden:

P: So, I just, I just I had it done...I had...er they...I had cancer of the stomach and they...they took it all off

S: Uhuh

P: and now I'm er I'm...the now I only have to go every...every (*looks away, slaps thigh as if to cue word*) every six months, so

S: Right, oh that's good

P: They had two lots of three months and when they got that they said six months...that's only last week. Obviously my girls were very concerned erm but (*shrugs*) just thought "ah well" get rid [əbɪt] and I'll get on with me garden (*smiles and laughs*)

Finally, a quest narrative is also established in Peter's story, as he shows acceptance of his disability, even indicating that he feels lucky to have preserved physical abilities after his stroke, recognising that this is lacking in some of his stroke "brothers", to use Schweitzer's (1998) language:

"but, because of that erm I didn't feel all I got in (*touching right hand with left*) in my hand is those...those fingers and the thumb that's all I got and going to the Stroke Association meeting I realised that I lucky because a lot of people there can't use an arm or leg or..."

Quest is epitomised for Peter by being able to "get on with me garden."

## Interweaving the aphasia stories

**“Stories are an important means of expressing and affirming who we are, inevitably influencing how others interact with us. Telling, constructing, revisiting, and developing stories are also an important way of understanding changes to life’s biography and incorporating disability into evolving identities. But how does one shape and share stories of identity without language?”**

**(Pound, in Swain et al (eds), 2014, p 164)**

### **The stroke stories**

Lindy gave me good advice early on in my research, before I had interviewed any of my participants. She suggested I just encourage each person to tell me what happened to them, in order to hear their stroke experience. It is a striking fact that all eight people with aphasia with whom I spoke told very different stroke stories. Their experiences were all unique and their memory of that day also differed. Some gave no, or very little information, suggesting a lack of memory of what happened or perhaps a difficulty in formulating the language to express it, or perhaps an unwillingness to give such personal information to a stranger, particularly a stranger with an audio recorder. Others gave factual accounts of what happened when and for how long: these narratives are peppered with times, places and people – the bare facts. Others ascribed a spiritual essence to their experience, relating events of a supernatural nature. The participants who were still in hospital related more limited stroke stories than their counterparts who had been living with their aphasia for months or years. Amy was the only person who was unable to relate virtually any detail; she seemed more concerned with the here and now, particularly the pain and discomfort she is in:

S: Yeah? So what happened to you? Why are you in hospital?

A: I don’t know...over that way

S: Over that way? So you were at home?

A: Yeah

S: Do you remember what happened?

A: No

S: No. So you just woke up and you were in hospital? Right

A: Yeah...I got pain...neck

S: Pain in your neck?

A: Yeah

S: Right

A: I don't know (*said in a despairing fashion*)

S: Been hard?

A: It hurts

Rosemary related a story which included reference to driving (possibly drink driving, although this might just be a type of word association, cueing her into a common, learnt phrase (Papathanasiou, Coppens and Potagas, 2013, p 146)). Liam described being at home by himself at the time the stroke happened and "stroke people" banging on the door in an effort to rescue him.

By contrast, participants in group 2 who had been living with their aphasia and disability for longer, by and large produced more elaborate stroke stories. There were a greater number of details, and the participants seemed to have started making meaning of the experience, perhaps through multiple narrations over time of what happened.

Peter gave a very factual account of the day he had his stroke. Although it is a narrative full of trauma, he chose non-catastrophising vocabulary to tell it. For example, he described how he fell in his front garden, and was lying there, unnoticed, for eight hours on a cold, November day; he explained how it would have been "awkward" if his temperature had fallen any further, even by one degree. David used vocabulary in a similar way, as if containing the catastrophe by diluting the language; he, for example, described how he was "slightly concerned" when he found he was unable to move.

Peter's narrative contained facts and timings, which lent it a cinematic quality; he described the ambulance taking 45 minutes to reach him because of an accident and a resultant contraflow system. He talked about living alone, not having the front door key on him, trying to alert his neighbours, about a delivery boy who did not attempt to help him.

Peter's stroke story was vivid, and felt as if it had been told often, either aloud or to himself. Lindy's story, too, felt as if it had been mulled over often, but her narrative was much less concerned with facts. Although she told me the day her stroke occurred (Christmas Day), and the fact that she was at the time walking in London with a friend, the rest of the story is about what she experienced and felt. Lindy's stroke was "massive" and she was in a coma for three days. Of all the participants, it is Lindy who ascribed a supernatural element to her physical situation. Rather than the facts and figures of Peter's narrative, she described the emotions

she felt – the calm and peace - experienced whilst in coma. She unselfconsciously described the benevolent visions she saw whilst in coma, of angels promoting peace, and of her (long dead) parents acting as a barrier between her and death. She gave herself a new post-stroke identity of survivor – “I am Lazarus”.

Joel’s stroke story was similar to Peter’s, Lindy’s and David’s in as much as he detailed where he was and with whom. The emphasis of his story, however, was that everything happened suddenly and that there was a sense of loss (he said the word “gone” and made a sweeping gesture over his body and head). Lindy described the “desperation” of waking from the coma and finding that she was still alive, whereas Joel corrected me when I suggested he was frustrated by his lost language skills; Joel’s belief in a resurrection body appeared to offer him hope.

Francesca’s stroke story was told with little emotion but, again, felt like it had been told often. Like, Peter, Francesca was alone when she had her stroke, and lay on the bathroom floor unconscious for thirty-six hours before being discovered by concerned work colleagues. Her stroke story was linked to her work and her identity, in that she situated the event around the completion of an important governmental initiative; perhaps the stroke occurrence was put into the work context and diary to normalise it, or to contextualise it.

### **Definitions of spirituality**

A perennial discussion in studies of spirituality is the relationship between religion and spirituality (for example, Tacey (2012, p 473)). Does one have to be religious to be spiritual? What does spirituality look like if it does not equate to religiosity? This question was mirrored in the responses of the participants when they were asked the question “what does spirituality mean to you?”.

For some, notably Joel, Lindy and Amy, spirituality and religion seemed to be inextricably linked. It became obvious as I got to know each of them better during our conversations that their faith was intrinsic and central to their identity; for Joel it was “all in all”. For Amy, her spirituality was expressed through prayer; she not only said this but also gestured, as if to give the word – and the concept – emphasis. For Lindy, God was at the centre of her spirituality, but she saw and felt his presence not only during formal prayer and liturgy, but also within nature. Joel’s spirituality was epitomised in his battered and much-used Bible, which he used as a constant referent. He found the verse in Ephesians which lists the fruits of the spirit (love, joy, peace, long-suffering, gentleness, goodness, faith) in order to illustrate what his definition

of spirituality comprised. He located the verse in his Bible, I then read, and in this way he was cued into the word “spirit”; so, although I verbalised the fruits of the spirit, he in fact instigated the idea non-verbally through finding and showing me the Bible verse, and indeed he completed it verbally.

For others, there is an emphatic lack of overlap between spirituality and organised religion, although they still profess to a faith. Both David and Francesca were adamant that their spirituality is completely divorced from the Church of England or any other religion. For example, Francesca says:

S: OK...so would you consider yourself to be a spiritual person?

F: Yes (*with definite intonation*)

S: You would, yeah

F: Yes, yep yep

S: Interesting

F: Yep but...erm...Christian, Muslim, Jewish, no

David is of a similar mindset:

D: Yeah...Church of England (*shakes head*)

S: Not Church of England?

D: No

S: Right

D: But I would go to any place

However, they do both claim a belief in a higher being. David believes in Jesus Christ, and Francesca says “Jesus maybe, maybe not” although it is unclear whether she is referring to her own beliefs or those of her parents.

For all participants who were able to formulate a definition of spirituality (Liam did not respond to this direct question, and my conversation with Rosemary did not progress to it), the concept of spirituality seems to evoke overwhelmingly positive feelings. For example, Lindy equates spirituality not only with God but also with nature and peace:

“Me...um...walking the fields and God um...angels or God...um, oh, God...it’s peaceful”

David, too, employs positive synonyms to define spirituality:

“erm...(latency) it means...er...comfort...it means...er...blessing...it means...er...it means good things, yeah”

For Francesca, the concept of spirituality appears to be all-encompassing and perhaps inextricable from other facets of life:

“Life (*with definite intonation*) yep”

Peter, like Francesca, considers himself to be a spiritual being, but is unsure how to put that into words, or of what he believes in:

S: Would you describe yourself as a spiritual person?

P: Yes, yes, I...I could (*pause*) when I thought about that but I couldn't (*many attempts at word "spiritual"*) (*shakes head*) spiritual person like that erm...I don't believe that...I do believe in something but what it is I...I don't know

Just as David “struggles” to express his spirituality, so Peter is also at a loss and “can't think of anything” when I ask him for his definition of spirituality.

### **Meaning-making**

Despite the evident difficulties of explaining what the term spirituality may mean to them, participants do express the spiritual aspects of their lives in a number of ways. When I ask what gives their life meaning, they are all able to give a response. “Meaning” is one of the terms used in Murray and Zentner's (1989) definition of spirituality:

“A quality that goes beyond religious affiliation, that strives for inspirations, reverence, awe, meaning and purpose, even in those who do not believe in any good.”

In my conversations, I tended to ask the question “what gives your life meaning”, as a prelude then to asking the more numinous “what does the term spirituality mean to you?”. These are difficult concepts to define with intact language – many have tried and some believe that it is a reductive and meaningless task to do so (Bash, 2004) – and it is made even more difficult by the addition of aphasia, as well as the emotion of serious and life-changing illness.

Telling me about their meaning-making activities animated a number of the participants. Peter told me definitively that it was his garden which gave his life meaning. In his case, his speech output became more fluent, with an increase in vocabulary and complex sentence structure,

when compared to his attempt to define spirituality, a concept with perhaps less resonance for him. Compare, for example, this description of working in his garden:

“I did erm this was three different plants and I (*gesture with both hands, finger of left hand crossing fingers of right*) then er er created plants er er and then erm oh they would just small bits of erm they were just small bits of garden and I joined all of the things together and made it what I did was er if I can hoe (*gestures hoeing*)”.

with his definition of spirituality:

er... (*long pause*) I can't think of anything (*takes hand to mouth*)

In his description of working in the garden, the utterance is considerably longer, and includes accurate and intricate gesture to convey meaning. As listener, I was captivated by his verbal and gestural description, and sensed his enthusiasm and delight. In contrast, vocabulary deserts him when trying to define spirituality, and the gesture he uses serves to reinforce the paucity of his output; by his gesture, he is almost gagging his mouth, or perhaps it is an attempt to coax the words from his mouth. Similarly, Francesca is able to retrieve the names of many opera composers (Donizetti, Wagner, Puccini, Verdi) – opera being her main meaning-maker - in the context of her expressive language being characterised by severe word-finding difficulties.

Nature also gives meaning to Lindy's life, although for her it would seem that nature and God are inextricably linked; God is revealed to her in nature, and by engaging in nature, she is able to commune with God:

L: Erm...erm...nature um um um um God...me and God (*laughs*)

S: Mm (*laughs*)

L: Talking (*gestures talking with left hand and smiles wryly*)

S: Yeah?

L: Why...er (*gestures talking again*) yeah (*smiles*)

S: Yeah, so you can talk to God when you're walking

For Francesca, it is the arts – and specifically music and opera – which give her life meaning. She describes the wonder of the words and music, and is also cued into the word “emotional”; it is clear that opera taps into a facet of her being which is not necessarily body or mind, but may be construed as spirit.

Although David is a fine artist, he eschews art as his meaning-maker and instead mentions his children. However, he does not elaborate, and I am left to ask questions to find out more:

D: Having kids, yeah

S: How many kids do you have?

D: I...[grɛ] two

S: Two

D: Two...they're both brothers and er...

S: How old are they?

D: They're eight and seven...er...six

Why the limited response? Is the concept of children so emotive that he is unable to express his feelings, or is it that I am a relative stranger and that rapport has never really become established between us? Perhaps it is just a truism that children give our lives meaning, and the statement therefore needs no further explanation or exegesis.

Both Lindy and Francesca mention their parents in our conversations. For both, parents represent protection and comfort. Francesca's father held her hand (she uses speech and gesture to express this) as she went into the CT scanner, just after her stroke. She also compares her mother's love of ballet to her own love of opera; it is not without a hint of pride that she tells me her mother was not of the social class one might associate with ballet-lovers, but was "working class but yep yep yep." She also self-corrects the tense ("loves" ballet becomes "loved" ballet, with intonational emphasis on the morphological ending), perhaps suggesting that the death of her mother was recent, or feels recent. Lindy's parents feature in a vision she had whilst in a coma directly after the stroke; she saw them form a protective barrier, preventing the Angel of Death from taking her soul to God, that is, saving her from death.

The meaning-makers in the lives of Amy, Liam and Rosemary may seem on the surface to be more prosaic: Liam loves his motor sport and his cat, Amy derives purpose and meaning from household chores and her pets, and the thing Rosemary misses most about home is her television. These three participants have all very recently had their strokes, and perhaps it is what gives them the most physical and emotional comfort that also provides the most meaning in their lives, whilst they are in the midst of the chaos of new illness (Frank, 2013).

### **Faith after stroke**

Of those participants who professed a faith, some indicated that their faith had not been altered by the advent of the stroke and their subsequent disability. Joel and Lindy both appear

steadfast in their faith and in their beliefs. Joel uses facial expression, intonation and definite head shaking to emphasise the fact that God is the most important aspect of his life, and that his faith has not changed from before the stroke:

J: Important is God (*lots of left hand gesturing and animated intonation*) other things, no...no

S: Hmm...and has that changed since the stroke?

J: (*Shakes head*) Not at all. (*More emphatically*) not at all. Yes, so, yeah, hm...

S: So, your faith is as strong now as it was before?

J: Yeah, yep...yep

He believes that “God will be glorified”, so perhaps he sees his disability as a testimony of faith. Lindy, too, uses intonation and head nodding very effectively to convey that, despite her illness and subsequent disability, she still believes in God, and in his goodness:

S: And then you said “God is good, benevolent God”

L: Yeah yes

S: So even after everything you’ve been through?

L: Yes (*nods*)

S: That’s still what you believe that...

L: Oh yes (*intonation = definitely*) yes

S: That hasn’t changed your attitude?

L: Oh no! No

Joel and Lindy’s unwavering faith may be linked to their belief in a “resurrection body”, that is, that they will receive the gift of eternal life and inhabit a new body in heaven.

### **Religion and liturgy**

Lindy, Joel and Amy all profess a faith and indicate that they take part in organised religious activities. Amy uses gesture and speech to talk about prayer and blessing. Joel uses artefacts to cue himself into half-remembered liturgy; for example, looking at and touching a communion wafer enables him to express the words “body”, “blood” and “testament”, and the pertinent snippet of liturgy “in remembrance of me”.

Both Lindy and Joel still take part in services at their respective local churches. They both admit that speaking prayers aloud is no longer possible, but that they are able to pray “without words”. Joel has an element of surprise in his voice, as he tells me that he still participates fully in liturgy and worship, as if to say ‘of course – why ever not?’. Lindy says at one point that she

is able to recite well-known prayers such as the Hail Mary, but is unable to engage fully in, for example, confession. When I ask Lindy if she is able to recite liturgy, she graphically gestures her lips being zipped shut.

### **Visions**

Both Lindy and David report seeing visions as integral parts of their spiritual stories. David reports seeing a vision of someone whom he intimates is Jesus when he was a young child:

D: Erm...yep...I had a...I don't know if you need to know...I had a very strange event happen to me about when I was about four which was...I've had it...you know...know that it tells people and they go 'my God just ring the child [æfjʊs] or something (*laughs*) but er this person...all right...someone came to see me...I remember it being of the [drait] frame of mind and I just thought 'I wonder why you're here' and he this man took my hand and...er..and said 'don't worry, it's all right, you're gonna be all right'.

S: Really

D: Yeah

S: And who do you believe that was?

D: Well...the guy had a beard, so I wasn't (*laughs*) certain it was him

This is a "positive" experience for David, and conveys comfort and protection. Similarly, Lindy relates two stories involving visions. One, when she sees her parents forming a barrier between herself and the angel of death, and another when she experiences angels surrounding her whilst in a coma after her stroke. Her parents shield her from the frightening vision of Azrael, and the angels bring a sense of peace and beauty.

### **Meaning-making being taken away post stroke**

Although all the participants report diverse meaning-makers in their lives, from pets to opera, God to gardening, many of them also report a common loss of or change to that meaning-maker post-stroke. They report no longer being able to engage in the activity as they might have done prior to the onset of their disability. What effect does being deprived of meaning-makers have on one's psyche? Is part of the rehabilitation process – part of the move into Frank's (2013) quest narrative – the ability to accept the loss of meaning-makers and to discover new ones? For example, Lindy is perhaps the participant who has progressed the most into a quest narrative. Formerly a published novelist but now no longer able to construct art of that length and complexity, the new post-stroke Lindy is now a poet, often drawing on

her stroke and aphasia experience as subject matter. For Lindy, although one meaning-maker was taken from her through aphasia, another has taken its place.

Neither Lindy nor Joel are able fully to engage in church services. As a Roman Catholic, Lindy is not able to participate in confession, for example, and Joel is no longer able to pray aloud.

Both, though, claim still to be able to communicate with God via silent, unspoken prayer, or through nature. The loss of the ability to engage fully in church and liturgical life was not explored with either of them during our conversations. I catch a glimpse of the frustration in Joel, as he tries to tell me about a particular verse in the Bible which he is unable to find; he instructs his wife to find it, too, and when she flicks further back in the Bible, he physically stops her and says “no, no”, with an air of exasperation. I write in my notes that his wife “drifts away as he continues to search”; this feels like a common occurrence, with Joel knowing the verse from scripture he wants but not being able to find it.

As well as finding life meaning in opera, Francesca talks about her love of photography, but her physical disability now precludes her actively taking photographs:

“erm, before the stroke I like...erm...erm...erm...pic...pictures no photography er no photos...no I like photography, yep. Before the stroke, two hands”.

Peter admits to the fact that his not being able to work in the garden in the winter negatively impacts on his mental health; being deprived of his meaning-maker has an obvious effect on his wellbeing and health.

### **Chaplains and churchmen**

What seems to be clear from all the interviews is that most participants were either not visited by a chaplain whilst in hospital, or they do not remember being visited. Despite Lindy and Amy being professed Christians, neither of them relates visits from a chaplain whilst an in-patient; Joel explains that although he was visited by the hospital chaplain, he was only able to express his spiritual needs “slightly” because of his language difficulties.

David talks about being visited at home by someone from the church – I wonder if this was instigated and encouraged by his church-going wife. Lindy and Amy also receive pastoral visits from their priest, and Joel attends church.

This is perhaps an indication of the inherent difficulty of ministering to people with very significant communication problems, and chimes with some comments made by the chaplain in group 3, who confesses to “moving on”, when a patient is unable to engage in conversation (see next section – The Lay Chaplain’s Story).

## **Stoicism**

A number of participants demonstrate a type of stoicism post-stroke, despite function (and sometimes meaning-makers) being compromised. Lindy explains how she tries to counteract the prevailing sadness at a drop-in centre she visits for people with aphasia:

L: Yes, um...sad...me jolly (*facial expression of happiness*) come on come on!

S: You try and chivvy them up?

L: Yes

S: Does that work?

L: Slowly slowly

What is it in Lindy that enables to her act in such a positive fashion and provide encouragement to others in a similar situation? Francesca, too, is an encourager and enabler at her local stroke support group, and her mantra is that one must “forward march”.

## **Post stroke identity**

Identity and subsequent perceived loss of identity has been discussed and explored in the aphasiology literature (Shadden, 2005; Bronken et al, 2012). My narratives also have a story to tell about the importance of identity for people whose language and communication skills have been affected by stroke. To each of the stories I have given not only a name to the person whose interview I was relating but also the identity that was conveyed to me whilst speaking to them. Thus, Joel became the evangelist, because he conveyed so eloquently and so fervently his love of God and the Bible. Peter became the gardener, because his garden and the joy it brought him seemed so manifestly intrinsic to who he was. Ethical considerations meant that I gave pseudonyms to all my participants (bar Lindy, who had given permission for me to use her real name); perhaps I, too, was guilty of stripping away their true identities because of research convention.

Issues of identity were most starkly thrown into relief for me in my discussions with Lindy and Francesca. They seemed to convey the essence of their identity not only in what they said but also in their choice of vocabulary, their environments and the labels they gave themselves.

In answer to my first question (“it would be really nice just to know a bit about you”), Francesca immediately tells me she studied accountancy at Bath University. There is no preamble about where she was born, where she lived, her family – the first pieces of information she wants me to know about her are that she is a graduate and what she did for a living. It almost feels as if she is saying to me ‘don’t write me off as someone who is unable to use language – I am an intelligent human being, for whom language was crucial in my career.’

She emphasises her erudition by alluding to perhaps more unusual associations of Bristol (“camera obscura”), in response to my rather prosaic observation “nice city”. Her ability to retrieve the names of several of her favourite opera composers is also a reflection of this erudition and her desire to convey it.

Lindy’s identity, too, is woven into the vocabulary she chooses. As a poet, she employs poetic language and imagery to convey meaning, such as Azrael and Lazarus. One wall of her small flat is comprised entirely of book-laden shelves, and open books are lying on the sofa, mid-read.

Whilst Francesca has seemingly lost a facet of her identity in terms of her job, Lindy’s career has shifted to accommodate her aphasia; although still a writer, she now writes poetry rather than novels, and still identifies herself as a wordsmith (“me, writer”). Francesca’s involvement in support groups for people with aphasia may be a reflection of her desire to assume a new role.

### **Physical needs**

Groups one and two – people with a newly-diagnosed aphasia and people who have been living with their aphasia for a while (from nine months to fifteen years) – presented quite differently and narrated very different stories of spirituality. Although of course all the stories were distinct and unique, there was a commonality in the group 1 stories of physical needs taking precedence over discussions of the numinous. It is perhaps intuitive, and reminiscent of Maslow’s (1954) hierarchy of need, that people in the acute stages of illness and new disability have to have their basic needs met, before they can concentrate on self-actualisation. This is illustrated in the group 1 stories by Amy not always being available for a conversation, because she is seeing a therapist as part of her rehabilitation programme. She is also often preoccupied with mealtimes and drinking, satisfying her physical needs before the numinous can be tackled. Liam, too, has many physical issues with which to contend, including a nasogastric tube, swallowing issues and a productive cough. Small wonder, then, that his need to defecate into his incontinence pad is overwhelming, and far outranks social etiquette or participation in any conversation, let alone a conversation about issues other than the physical. Rosemary is not available for us to get to know each other better in subsequent meetings, and perhaps have the opportunity for deepening the discussion to include spirituality, as she is transferred to another unit to continue her (physical) rehabilitation.

### **Communication difficulties of the participants**

Although all the participants present with aphasia following a stroke and all have good receptive skills in the context of poor expressive abilities, nevertheless they all present very

differently both in the effect of the aphasia on their communication skills and in their use of augmentative communication (total communication) strategies.

All participants presented with word-finding difficulties to a greater or lesser extent. Some participants demonstrated the typical “telegraphic” (Halpern and Goldfarb, 2013 p 46) or “agrammatic” (Marshall, 2013, p 198) quality of expressive aphasia, most notably Joel, Lindy and Francesca. Others showed more complex sentence structure in their expressive language, such as David, Peter and Amy.

Lindy, Joel and Francesca all showed a reduction in complexity of syntactic structure, most notably a dearth of function words. They typically produced short utterances, containing some content words (nouns, verbs, adjectives) but few function words (for example, pronouns, conjunctions). Morphology<sup>8</sup> was also limited. Several of them use favoured fillers, for example Francesca often said “exactly” and “yep”. By contrast, Amy, David and Peter employed more complex sentence structures, which included morphology and function words.

Liam and Amy (and to a lesser extent, Francesca) all use expletives, which may or may not be of pathological origin, and Liam’s output is also characterised by latency of response (perhaps indicative of a processing problem), palilalia and echolalia. Echolalia is often a sign of a lack of comprehension (Christman, Boutsen and Buckingham, 2004), so it may be that Liam’s receptive abilities were more compromised than first thought by the SLT.

### **Participants’ Mosaics**

To a greater or lesser extent, though, all participants were reliant on a mode of communication other than speech to convey their stories of spirituality. Some interviewees, such as Lindy, had a very rich Mosaic (Clark, 2001) of expression, comprising the written word, gesture, intonation, facial expression, email, Facebook and poetry. The mosaics of other participants were more limited in scope; for example, David used predominantly speech, with some use of intonation but otherwise no other total communication strategies. It is possible that, as he was closer to his stroke event, he was not yet ready to embrace non-verbal strategies, preferring to rely on his (improving) speech.

Joel was the only participant to whom I introduced artefacts in an effort to expand his Mosaic and therefore his range of expression. Because we had met before and he had been open about his faith (a faith I share), I was able to bring objects with me on the second meeting that I felt might prompt him in his story-telling. This strategy may perhaps have therapeutic importance which I will discuss later in Chapter 6.

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<sup>8</sup> In grammar, morphology refers to affixes to the root of a word to, for example, create tense

## **Researcher's strategies**

I used a number of facilitation techniques in listening to these stories of spirituality. All interviewees needed time and space in order to frame their stories. I hope I gave them this time and space to formulate their ideas and to convey those ideas via whichever modality they chose. I tried to be non-judgemental but at the same time always congruent, laying my prejudices aside before the conversation began.

Undoubtedly rapport, even friendship, occurred with some interviewees (Lindy, Amy, Joel, Peter), whereas with others I would say there was little connection (Liam, Rosemary, Francesca, David).

Lindy, Joel, Amy and I all shared a Christian faith. Given that the interviewees were talking about their spirituality, this seemed to lend a natural connection to our relationship. These relationships seemed to go deep quickly, perhaps again because of having something important in common. With Peter, the sense of connection is a little harder to define or explain. He was introduced to me at a stroke group by a mutual friend, which perhaps was a good basis for our relationship. He also confided in me details relating to health issues, possibly because he saw me as a therapist more than a researcher.

Liam recognised me when we met for the second and subsequent times, even remembering my name, but I never felt that we connected. Perhaps this was due in part to the clinical environment, lack of privacy on a hospital ward, and also his understandable preoccupation with physical over relational needs. Rapport-building with Rosemary was also probably affected by the clinical environment, as well as by our meetings being cut short by her move to another rehabilitation facility. Meeting these patients with acute aphasia only on a few short occasions also did not enable me to ascertain the most effective forms of facilitation, which again may have impacted on the quality of our interaction and therefore the depth of the relationship.

Of the three participants with acute aphasia, it was only Amy with whom I felt I had established a relationship. We met on five occasions in total (four interviews were recorded), which gave us more opportunity to get to know one another. By the end of our last meeting, she had invited me to visit her at home, and she referred to me as her friend when she introduced me to her neighbour on the ward.

With Francesca and David I felt there was very little rapport. They had both been recruited by my visiting and giving a presentation to a stroke group. Although they enthusiastically volunteered to be a part of the project, I wonder if they felt almost duty-bound to accommodate researchers in aphasia. As two professionals themselves, I wonder if they were altruistically helping me out, rather than keen to have a discussion about spirituality per se.

My behaviour and reactions also helped to foster or stunt rapport during the interviews. With David, for example, I found myself making assumptions (such as about the stroke experience being a frightening one), which he was quick to correct. I also asked leading questions sometimes, a fact I only recognised once I had listened back to the recording and transcribed what was said and how I had said it. For example, when I am talking to Liam, about his cat, I say “bet you miss him, do you?”, to which Liam predictably answers “yeah”. The subsequent occurrence of possible echolalia “miss...miss him” demonstrates the danger of using a leading question, particularly with someone with aphasia.

Immersing myself in the interviews also reveals other faults in my interviewing technique. For example, I sometimes give feedback which is totally out of tune with what the participant is attempting to convey:

S: What a fascinating experience

L: (*laughs*) yes, well...scared

It is at times like this that I become acutely aware of the sensitive nature of some of these spiritual stories, and I recognise that a high level of interviewing skill is warranted.

With all participants, I often give a non-committal sound, such as “uhuh”, in an effort to convey that I am listening, I have had my conversational turn, and they are free to continue or to expand that point. I also employ active listening strategies, such as leaning forward, maintaining eye contact, nodding and showing positive, encouraging facial expression. Shared knowledge allows me to understand references that might be impenetrable to someone without that knowledge. So, for example, Joel cues himself – and me – into a discussion about the twelve apostles by counting:

J: Yes, er...four, five, six, seven, eight, nine, ten, eleven, twelve (*with emphasis on last number*)

S: Twelve...? Ah! Are you talking about the twelve apostles?

### **Illness narratives**

When looking at the aphasia stories, one can start to see how each participant at different times uses slightly different narrative typologies. For example, Liam and Rosemary narrate stories of chaos; they are both still in the midst of changed circumstances where coherent narratives are impossible, and physical needs seem to outweigh the spiritual. Lindy, Joel and Amy all demonstrate aspects of a restitution narrative at times. Lindy, for example, at one point describes how she is like a child, gradually developing back into an adult. She relates how her language skills have improved hugely over the years since her stroke, and how she has a dream that she will be fluent by 2019. Joel also reports that his language skills are “better

now...[vatli] better", and he propounds a spiritual restitution, whereby he will live again with a new body. Amy, too, is seeking restitution, and this is illustrated in her asking to go home on many occasions.

Lindy, Francesca and Peter all show evidence of attaining or getting close to a quest narrative. Lindy has embraced a different style of writing to accommodate her aphasia, and Francesca has shifted her work from accountancy to helping to run a support group for people with aphasia. Peter is content in his garden, and tells me he is one of the lucky ones, because he has not been affected physically by the stroke, and is thus still able to participate in his passion. Of all the participants, perhaps David is the person whose narrative is less clear to me. Like Lindy he, too, is adapting his art to accommodate his changed circumstances, by moving from fine art drawing to sculpture. Yet his humour and toned down language perhaps belie a still chaotic state.

# **The stories of the multidisciplinary stroke team**

## **Sacred work: The speech and language therapist's tale**

I meet the speech and language therapist (SLT) in a quiet room at the University. I had already sent her the topic guide for the group 3 interviews (appendix IV), at her request. The guide follows a structure of talking in general terms about the work the multidisciplinary team (MDT) member does and then specific challenges of working with people with aphasia. It goes on to explore whether the team member ever discusses issues of a sensitive, spiritual or existential nature with clients, and if they see it as part of their role. Team members are also asked if they could give their definition of spirituality. The topic guide is just that – a guide – and, as interviewer, I am not rigid in sticking to these questions. Indeed, at the end of every interview, including this one with the SLT, I make a point of asking whether the interviewee has anything more they would like to say. In almost every instance, they did.

The SLT is a very experienced, highly specialist SLT (band 7), who has extensive experience of working with people with stroke and, in particular, those with aphasia following their stroke. She works on a 24-bed acute care and rehabilitation unit, where people are admitted 2 days or fewer after their stroke. She treats a spectrum of patients in terms of the severity of their stroke, from those who have good mobility post-stroke but have aphasia, to those for whom the stroke has been profound and “death is pending”. Severity of aphasia can also differ significantly, from those with mild word retrieval difficulties to those with profound global (expressive and receptive) aphasia.

The SLT's role is to assess and manage the swallowing and communication issues of patients on the stroke unit:

“swallowing and dysphagia assessments are an important part of my work, but then with people who have aphasia or cognitive communication impairment...I try to ascertain the best way to communicate.”

She sees herself as an integral member of the MDT, and considers communication with the other team members of vital importance when it comes to holistic and client-centred care for the patients on the unit. Details of patients' communicative and swallowing abilities are conveyed to the team via MDT meetings:

“and I will make a note of these things and write in the medical notes and share with my colleagues during handover”

Part of this role of MDT member involves both signposting patients to other members of the team, as necessary, or indeed acting as the communication advocate in interactions between patients and other staff members. So, in terms of addressing the spiritual needs of patients, she gives the example of using her skills in facilitating communicative competence in people with aphasia in interactions between the patient and their spiritual advisor (vicar or chaplain):

“and sometimes...vicars will come on the ward and I will ask them if they want me to facilitate or I will show them what works”

But she is also very open to discussing issues of a spiritual nature herself with clients, if that seems appropriate:

“I do think it’s part of our role because sometimes you will stumble upon it, you know, and I would have to say that in my experience people with aphasia, I would have to say about a quarter of the time to about half the time, they will bring it up”.

### **Specific skills of the SLT**

So what is it about the specific skills of the SLT which might enable patients to communicate freely about spiritual issues? She discusses the fact that often her role necessitates close physical proximity and that it is perhaps this physical closeness which engenders trust and openness:

“the work we do, it’s personal. I mean it might be oral care, it might be examining a person’s mouth for a swallowing assessment and in the course of that, you know, are you comfortable, you know, you may need to be transferred...here, I’m just going to give you a bit of a cuddle while we get you upright in bed”

Interestingly, she talks about what the SLT does “between the technical bits”, that is, whilst she is carrying out one SLT assessment or procedure, conversations of a deep or important nature can take place:

“you are doing the technical bits, you know, looking in a person’s mouth, asking them biographical questions and so on but then in between that having a meaningful conversation, yes, yes.”

The SLT obviously has comprehensive knowledge of aphasia in general, and of an individual's communication skills in particular following in-depth assessment, and she also has skills in therapeutic and facilitative techniques:

“yes, OK, with treatment I try and make it meaningful to the person, and assessing the communication ramps that will work, is it yes/ no questions...written choice communication...”

She is also adept at recognising and harnessing patients' non-verbal communication skills:

“I mean, as soon as you see a person, it speaks volumes”

She speaks very movingly of one particular patient who presented to her with a “grieving body posture”. He was a man in his fifties, with profound aphasia, to the extent that he found all language extremely difficult to understand. He was effectively cut off from the rest of the human race in terms of verbal communication. The SLT posits that this loss, not just of language but all the associated losses such as of identity, role and so on, was so great that he was grieving and this grief manifested itself non-verbally but graphically:

“he closed himself off in his room, he had a private room, he drew the curtains, you know, if you open his door, his curtains were drawn, he drew the curtains from the outside, the lights were off, he had his hoodie on and his legs were crossed...”

The SLT is also adept at creating a therapeutic environment and engendering trust:

“communicating with them so that...in a way where they feel safe, but not demanding anything of them, yes”.

### **Dignity**

Promotion and maintenance of dignity also seems to be a recurring motif in the work of the SLT. She strives always “to create an environment that says you matter”, by giving the client enough time to process information and to express themselves. She will ensure privacy and take patients to a day room for conversations, to make it “feel normal”.

### **Reinstating identity**

The SLT made several references to specific patients during our interview, in order to illustrate points or to clarify something. In doing so, it struck me how she actively tried to reinstate or emphasise their identity, something that often is compromised post-stroke (Ellis-Hill and Horn

2000; Shadden, 2005), with profound changes in functioning. She would, for example, tell me their profession:

“I am thinking of a retired professor – all walks of life”

“I’m thinking of one aphasic man, he was a pharmacist, he tried to take his own life”

It is as if she is saying – I am not just dealing with a person with aphasia; I am dealing with this professional person, who now also has aphasia.

She talks about the threat to identity post-stroke and the profound effect this can have on personhood:

“when identity is threatened, a person’s ‘intactness’ is threatened. And that can result in suffering” (private text)

Conversely, the SLT also recognises that stroke can strip away all vestiges of previous power or status (she gives the example of President Nixon, who became aphasic after a stroke), and therapists are left with the person beneath:

“a person who is in crisis and indeed they are, it really is a life and death event here, those external things fall by the wayside”

“it’s life, it’s life you’re clinging to, and those masks and those things that we wear, they really do fall to the wayside, yeah”

So, on the one hand, part of creating a therapeutic environment and alliance is acknowledging the identity of the client, but on the other there is the understanding that at times of crisis, masks that go to create our identities may fall to one side. As the SLT says in relation to President Nixon:

“and when I heard on the radio at the time I thought oh, I can tell you that he wanted to be treated as a man who was in crisis and not the former president of the United States, I am sure”.

## **Time**

Time was a recurring leitmotif during the interview with the SLT. She places supreme importance on allowing the patient time and space to communicate. Indeed, she goes so far as to maintain that this is a motto she lives by:

“it’s a rule of mine, I do not rush, I take time. It’s yeah...and I think to myself ‘OK, this is what I am doing now,’ and I put everything else on hold.”

So in being given time and space, the patient gets the message that they are important, that they matter.

## **Spirituality and “spiritual” conversations**

In response to my comment “what about this term, spirituality”, the SLT says the following:

“I think of the word ‘inspiration’, ‘inspire’, ‘to breathe’, ‘to come alive’”.

Although she recognises religion as one manifest example of spirituality, she implies that spirituality is broader than that and is an intrinsic aspect of being human:

“I think that by default of being a living/ breathing human being, there’s an element of spirituality, yes. It’s what makes you come alive and what’s meaningful.”

She gives several examples of times when she, as an SLT, has entered into what could be termed spiritual discussions with patients. Sometimes issues about death need to be discussed, for example with a patient who has to make the decision about whether they want an enteral feeding tube or not. She says she keeps her questions “very straightforward”, so as to avoid ambiguity. She also uses non-verbal communication strategies, in order to facilitate comprehension, expression or both:

“so then, if you give me the go ahead, I may present pictures of say a headstone and rest in peace, or bring an actual feeding tube...”

Several times, the SLT states that she is “a pair of ears” when listening to patients’ spiritual concerns. She listens in a non-judgemental and accepting way, as patients with a faith in God question what has happened to them, with reference to God:

“if a person does...they give some indication that they wish to speak about their faith, you know, like ‘why didn’t God take me?’ or what have you, I am a pair of ears and they may tell me how they feel about their stroke and their religion/ faith, and sometimes people don’t wish

to speak about it, they do have a particular religion but they feel abandoned by God and, you know, 'where is God in all this?'"

Equally, she listens attentively to "non-religious" patients, as they struggle with existential and painful issues post-crisis:

"And then there are people who...they are non-religious...they will ask questions, they might be asking questions such as, you know, 'what did I do to deserve this?'...I am a pair of ears."

### **Sacred work**

The interview concludes with the SLT describing her work as "sacred":

"I feel like the work I do is...is sacred work because I think if you need to see me you are obviously having a bad day...I try to make my work an act of kindness."

This is a fascinating term to use in relation to secular therapy. If one looks at a definition of sacred in the dictionary, it is very much concerned with God and divinity:

"exclusively dedicated or appropriated (to a god or to some religious purpose)" (Oxford Dictionaries, 2011)

When I asked if she could expand on this concept of "sacred work", she gave me the following explanation:

"one of the reasons I believe it is sacred or holy is because when people are admitted to hospital with stroke they may be confronted with a major disability where important decisions need to be made and their established values can be challenged. People may or may not be religious, but everyone I have met has a code of values, ethics, or core beliefs that guide their behaviours...And another thing, people are not "just a body". CT scans, taking blood, knowing your cranial nerves, meeting our targets are necessary, BUT there is more to healing than just that. That is not what is going to save the day." (personal text)

This seems to chime with the idea of sacredness or spirituality being a facet of the holistic work of the therapist; there is *more to healing* than the biomedical.

## **The human being it's not just the physical: the physiotherapist's tale**

I meet the physiotherapist (PT) in the relatives' room, just off the busy, bustling stroke unit. He has just come from seeing patients on the ward, but appears happy to sit and answer some questions. He is quietly spoken and gentle in his manner.

The PT has worked with people who have had strokes for a total of 14 years. He relates how seven of those were abroad, and seven in the UK. He is a clinical specialist, band 7.

We begin by talking about what his job on the stroke unit involves and there is immediately a predictable emphasis on the physical dimension of his patients:

“so, we generally look at...it can be balance from sitting, are they oriented in lying and sitting, and in standing? Then how is their dynamic balance? Then looking at their walking.”

It is interesting that, as the interview progresses, he appears to become more and more open to ideas related to the numinous:

“so I think yeah, now it's time to move forward and add the other dimension as well because yeah, the human being it's not just the physical”

From what the PT says, patients seemingly do sometimes bring up issues of a spiritual nature in their physiotherapy sessions, and he is willing to discuss such things “if they initiate it”. He suggests that the trust and therapeutic alliance between PT and patient make for a situation conducive to addressing meaningful issues:

“so as they get confident that *yeah, I think...I have got someone who understands me*, I think they communicate better their fears”

Earlier in the interview he explains how he would answer existential questions (such as “why did this happen to me?”) by giving medical answers related to the body and reasons for impairment:

“as a physio, I am going to explain it from the medical, yeah...”

However, as the interview progresses, he concedes that when a patient asks such a question, it may not be a medical answer that they are looking for; it may be that they are searching for deeper truths:

“are they asking me about the organic causes of stroke, or is it something else? They are thinking *if I have done everything right, I have lived right, why is this happening to me?* So there might be again a spiritual question there”

When asked how he would define the term “spirituality”, the PT initially equates it to religion, but also recognises that it is a concept that maybe can encompass more than just religion:

“The first thing that comes to mind is religion because obviously spirituality has always been associated with religion and then it encompasses...but I think it...there is a lot more than just religion”

and that perhaps every human being has a facet of self which could be termed spiritual:

“Some people think they’re not spiritual but when you speak with them you realise that they are spiritual but they don’t see it as being spiritual...”

He identifies how aphasia can be a barrier in therapy in general, and that communication difficulties in the therapy session can lead to changes in mood and motivation:

“can lead to frustration and yeah, if not handled properly then make the person feel like they are not doing well so they start to feel that they are worthless”

He acknowledges, too, that for a person with aphasia as a result of their stroke, tackling the abstract nature of the concept of spirituality could be problematic:

“someone with communication sort of difficulties will find it a bit difficult to convey that abstract nature of spiritualism [sic]”

Interestingly he does not proffer any mitigation to these communication barriers; he does not discuss liaison with the speech and language therapist for advice, for example, or the use of non-verbal communication facilitation techniques. I, as interviewer, also do not prompt him to think about facilitation of communication with patients with aphasia; this is an oversight on my part, I think.

The PT identifies a number of interesting objections or at least caveats to discussing issues of a spiritual nature with patients. Although he says he will discuss such issues at the patient’s request:

“if someone willingly sort of brings up the topic I discuss it with them”

he is wary of overstepping the mark, of venturing beyond his remit:

“it’s not knowing where are the limits and how far should you discuss”

He seems very aware of the importance of spirituality to people and is anxious not to minimise its importance by perhaps handling the subject matter in the wrong way, or in an inappropriate way:

“I think there is a danger of trivialising other people’s sort of journey as well, and their spiritual views which they may hold very dearly and are part of their identity and I always feel like yeah, I don’t want to sort of trivialise someone’s beliefs and spiritual wellbeing, especially if they are having to struggle with a stroke as well, so yeah, I am always cautious of not making things worse”

He is also wary of the danger of healthcare professionals proselytising or forcing their own opinions about spirituality and religion onto patients:

“maybe they could be seen as trying to influence people into their own religion”

The PT seems to imply that the spiritual domain is not accepted within the healthcare paradigm, that it would be “politically incorrect” to talk about spiritual issues with patients:

“I thought *hmm, in the health sector religion is not talked so much about* and I think again it’s that...people are trying not...avoiding not being politically correct”

On the other hand, he is obviously an holistic practitioner, seeing and managing all facets the patient:

“So I find it’s important otherwise then you may...I may try just the physical and find I am losing my patient, they are not participating/ engaging and if I don’t go back into why and try and sort of untangle all the little bits...”

He also acknowledges that perhaps the landscape of healthcare has changed over the last few years and continues to do so. He talks about how healthcare used at one time to be very

concerned with body and impairment, then progressed to encompass the mind and psychosocial aspects of patients; perhaps now it is ready to embrace the spiritual:

“it took a while to sort of get psychology in, involved in...because it used to be quite a medical concept, isn't it? ...Now we are there, so I think yeah, it's now time to move forward and add the other dimensions as well”

He is the only healthcare professional interviewed who considers NHS Trust policies and procedures, and whether addressing spirituality in his sessions is permitted:

“I am happy to discuss it, but in terms of policies and procedures I think yeah, it's the fear of treading that thin line.”

However, he also ends the interview with the fact that perhaps we as professionals should be starting to consider more the spiritual in our clients, even possibly including it in our Trust procedures, such as an agenda item in multidisciplinary meetings:

“I think it's worth...it's worth putting on our MDM agenda.”

## **It's part and parcel of someone's life: the occupational therapist's tale**

The occupational therapist (OT) greets me enthusiastically on the stroke unit and we go into the relatives' room, where it is relatively quiet. The OT is chatty and informative; her interview is comprehensive and detailed, covering the many facets of her work, a reflection of the all-encompassing work of an OT. Her conversation is peppered with concepts such as holism, function and meaning.

The OT is a clinical specialist on the stroke unit – a band 7 – whose role is to support the OT team, providing second opinions on complex clients when needed. As with all the multidisciplinary participants, a topic guide has been provided; the loquacious OT, however, tends to veer off the topic guide, creating much more of a “conversational interview” (Kim, 2015, p 262).

### **Role of OT and rapport-building**

The OT maintains that she deals with “the basics”, such as “washing, dressing, toileting, eating, drinking, getting in and out, on and off furniture, making decisions, problem-solving, safety”. However, she also points out that OTs “look at all areas”, including how patients “see the world”. Hers is a truly holistic role, and this holism includes attending to all aspects of the individual. She posits that because of the intimate nature of some of their work, OTs are ideally placed to create a relationship with clients:

“I think because we end up doing things like personal care, you do really get to know somebody in that way because you can't not”

This rapport and “sensitive conversations” then mean that the OT is open to exploring spirituality with her patients:

“it really is about getting to know that person and understanding them and what they think and what they believe and how they see the world really and I think that's what spirituality is for me, is what it's about, it's how you see things, yeah, definitely.”

She is clear that discussing spirituality is not necessarily a core role for the OT, but that because of this holistic and all-encompassing approach to client care, she finds that the subject can be intrinsic to that care:

“So quite often we can get very involved in that, so yeah, and not necessarily wanting to, it's just that we get drawn into that... the discussions and the looking at life”.

### **Stroke as disruptor**

The OT employs vocabulary which evokes the destruction stroke can wreak on a person's life. For example, she talks about “that knock from the stroke”, and the fact that normality can be “all whooshed from under their feet”. She sees her role as an OT to imbue the situation with positivity, and to encourage function, even if this is different to pre-morbid function:

“But even people like that, they then get knocked down and we have to bring them back up again and look at ... not how negative it is, how can we work and improve on what they are doing”.

### **Time**

The OT identifies that in her role she has the privilege of being able to spend time with her patients, which in turn makes for more opportunity for discussion and possibly for enriched relationships:

“we get lots of time with the patients and lots of in-depth stuff, quite personal stuff sometimes as well”

With patients with aphasia, she recognises that perhaps even more time is needed, in order to ensure messages are understood and conveyed:

“I think we do allow more time. I think we... because obviously we spend quite a lot of time with our patients anyway but with aphasic patients we do need to give them more time”

She intimates that more time is needed with patients with aphasia, because rapport-building is not quite so straight-forward when language is affected:

“sometimes it means we have to spend more time with people because we have to get to know them better because they can't just verbalise and say ‘Well I don't like this, I don't like that, I don't want to do it this way.’”

Time is viewed by the OT as a precious commodity, which can be eroded by busyness, to the detriment of relationships with patients:

“And then obviously when we are really busy, that impacts negatively because we haven’t got the time to spend which is a shame”.

### **Personhood and identity**

In line with person-centred care, it is important for the OT to recognise the person behind the stroke, the person the patient once was:

“we go ‘OK, so what did you do before you had a stroke, who are you?’ you know, so it's about them as a person, not just well you’re that patient that’s had a stroke, so you have got all this information.”

This gathering of information to formulate a picture of the patient pre-stroke is made more complex by the presence of aphasia:

“I don’t think you have the same in-depth conversations as we do with people because we can’t... I think personal issues... it’s so personal, people need to... it needs to be a two way conversation, and you can’t do that with somebody with aphasia... “

### **Getting to know the patient**

Getting to know the patient well, their past, their interests, their goals, is obviously important for the OT but is problematic when the patient is unable to verbalise these things directly:

“I would say it almost restricts a little bit how, how you know what they do and what they like”.

She reports that the process of getting to know a client with aphasia is “slightly skewed” because of the restrictions on normal conversation. She acknowledges that the person does not intrinsically alter in character post-stroke, but that it can be difficult to gain access to that prior identity if language is missing or compromised:

“they are still there, they are still that person, they still want to do these things they enjoy and they still want to be part of the world and enjoy what they do, but they just... it’s limited and they can’t verbalise that to them. It's very difficult I think to get that true feel of a person, it really is, when you can’t get that from themselves, yeah.”

Therapists are then reliant on family members to provide the information required, which the OT sees as information somehow diluted, that may not tell the complete or accurate story:

“Again we quite often have to rely on the relatives in order to tell us ‘Oh, they love going in their garden’ or ‘they like sewing’ or ‘they go to church every week’ or they ‘believe in this, or they believe in that’ and you sort of think we don’t get that direct from the patient and I think unless you do, you don’t get a full picture of that person”.

### **Aphasia**

The OT has a good understanding of aphasia and the effects of aphasia on her assessment and management of patients. Problems with comprehension pose a particular risk of danger for her, when a patient’s safety could be compromised away from the protective rehabilitation environment:

“quite often if it's the receptive problems, following what we’re asking them to do, so if we are asking them to show us can you move your limbs, can you get up from your chair, can you come to the kitchen? – all these sort of things - it's then their understanding of what we’re asking them to do, and so if we can’t get them to understand that in a therapy session in a very safe protective environment, how do we then expect that to translate into going home and how are they going to manage there?”

She identifies that direct information-gathering can be difficult and that time is needed to enable messages to be conveyed and understood in conversations with people with aphasia: “so when you are asking a person and yeah, they’re aphasic and you go up to them and you say ‘How are you?’ and you introduce yourself and we can’t get that information from them, sometimes it's nice to spend some time to see what they can give us and...”

She refers to the process of “deciphering”, as if because the client is not able to give the information needed themselves, it is conveyed in a coded way by a third party, never quite giving the information as accurately as if it had come directly from the patient themselves: “So the first challenge is, you walk up to them and you think you can’t tell me this information so it's then deciphering that from a different source or a next of kin, a relative or wife/partner whatever, so that’s definitely our first challenge”.

Her language at this point is quite negative and definitive (for example, “they can’t tell us”), and the resultant information is seen by the OT as perhaps not as valuable or accurate:

“that information doesn’t necessarily always come from the patient so I don’t think we always get a clear idea of actually what makes that patient tick, what do they enjoy, what do they believe in, what do they get a lot out of, you know, that sort of thing? “

The OT recognises that she and the other members of the stroke rehabilitation team have to have special skills of noticing when working with people with aphasia. They need to be alert to body language and other non-verbal methods of communication:

“we have to be more perceptive I think with people with aphasia, yeah, if they can’t communicate to talk to you, and when they are trying desperately to tell you something...I think there is a real skill in actually reading that person.”

She illustrates how a misunderstanding by members of the team of someone who is having difficulties communicating can result in loss of dignity, by telling me about a real episode which had recently occurred on the ward:

“the example that I gave is that the gentleman who needed the toilet desperately and all he kept saying was ‘Come on, come on, come on.’ Not knowing him at all, I just thought he wanted us to get him up, because he wanted to get up, and then we found out that wasn’t what it was about...and even if we get there on time he can’t tell us ‘Do you know what? I really need a wee’ and we can’t then get there necessarily quickly enough to do it properly with him.”

She accepts that patients with aphasia can therefore become very frustrated:

“and yet we are expecting this person who can’t verbalise to us, to go and sit in front of a sink and they are probably going ‘I don’t do this at home, I go in there, that shower over there,’ and sometimes that’s when their frustrations can come in because they can’t say to us... they can indicate to us”

The OT concedes that conversation – particularly about more sensitive issues – is compromised with a person with severe aphasia:

“I don’t think you have the same in-depth conversations as we do with people because we can’t... I think personal issues... it’s so personal, people need to... it needs to be a two-way conversation, and you can’t do that with somebody with aphasia.”

She alludes to conversations – which are quite common on a stroke ward – about death and dying, and how much more difficult these can be if the patient has lost their ability to formulate language in the way they used to:

“they have had a stroke and they can see this is the end, this is ... you know, that’s it, end of my life, can’t do any more, and quite often a lot of our sessions will be very emotional and we’re talking through, you know... and obviously if they’re aphasic it can be more difficult but talking through the impact of the stroke, what that then means for them in terms of what they have done in their life”.

### **Non-verbal Communication**

Despite this, the OT seems, of all the healthcare professionals other than the speech and language therapist (SLT), the most familiar with non-verbal, total communication strategies. This is no doubt a feature of her holistic stance and eagerness to facilitate function. Although she does not explicitly discuss liaising or working with the SLT, possible joint-working is suggested by her knowledge and use of photos, communication boards and pictures to facilitate conversation with people with aphasia.

She also stresses several times during the interview the need to know a patient well and become familiar with their non-verbal skills, in order to understand them more fully:

“You have to sort of figure out what their gestures are, like John, the gentleman we were saying about, I am very aware of when I first met him, I didn’t really know what his words meant when he was trying to tell us something, but it was a desperate plea to tell us something, and once he had done the thing that he did I went ‘Oh that’s what you were telling...’ but I had never met him, but now I know, if he would say that to me, that is his way of communicating, that’s his way.”

### **Skill of the therapist**

The OT sees the whole person and thinks about all areas of their life, and this is reflected in the specific skills the OT brings to dealing with spirituality in her patients with aphasia:

“I think it is just very individual, spirituality, and I think a lot of ... we as a profession, I think, think more about it than others because I think it’s part and parcel of somebody’s life and that’s what we ask about.”

She explains that OTs discuss the whole gamut of human activity and occupation from family and work to sex and relationships in the course of their management of a client, and that a person's spirituality would be no different in terms of its inclusion in these discussions:

"I mean because we talk to people about all sorts of things, we can talk to them about sex, we can talk to them about ... that's often a question they will ask us because we have asked them very personal things about toileting and things, so we are the obvious person to talk to. I think we do ask them about their hobbies and a lot of people will say they enjoy going to church or they enjoy meditation or they enjoy any sort of activities that they consider really important to them and that's part of their life, that can be gardening, that can be anything that sort of fulfils them and makes them happy."

For stroke patients with aphasia in particular, she sees the OT as having honed skills in understanding non-verbal responses:

"and that's I think where we pick up on and things, you think 'Well why are you reacting like that?' and perhaps a nurse wouldn't pick up on that"

She contrasts the OT approach – where the professional would allow the patient to have a go at a particular activity, and the approach of a nurse – who, because of the busyness of the day and the need to make sure things are completed – may carry out the procedure for the patient. In this way, the OT has the time and is able to observe and learn from the client's response.

The OT acknowledges, however, that all members of the stroke team possess skills of understanding and facilitating communication skills of people on the ward with aphasia:

"And I think as a stroke team generally, not just as a therapist myself, but I think we are more aware of that. It's that understanding isn't it, it's understanding that that person can't communicate, so how can they get their point across and how can we meet their needs fully."

Team members – and specifically OTs – can act as the bridge between a person with aphasia and their family members, because of this acquired skill of interpretation and facilitation:

"quite often we have to be a bit of an advocate for them in that sense because they can't verbalise that or not in the way they would perhaps want to if they can verbalise, but it's not, not clear to the family sometimes".

## **Loss**

As well as the vocabulary of destruction noted above (“whooshed away”, “knock by”, “the stroke sort of throws that”), the OT also describes the loss experienced by her stroke patients, and those patients with aphasia in particular. She describes the catastrophe of loss of language, and its impact on a person’s ability to function:

“We use our voice for everything, we do, you know...we would be lost without it, so when somebody has lost it, that in terms of function is massive so yeah, it impacts greatly.”

Dignity can be lost if a person is unable to communicate their basic needs (as exemplified in the example of John, cited above, and his inability to articulate the need for the toilet). The OT saw her role in this instance as instigating management strategies that would mitigate the need to communicate verbally:

“and so we were aware that actually that’s something that then really frustrates him, is that he’s then not getting to the toilet on time, so we put in a 2 hourly toileting regime so that we know that his needs are met, because otherwise if he is left uncomfortable he then gets very distressed and upset, and even if we get there on time he can’t tell us ‘Do you know what? I really need a wee’ and we can’t then get there necessarily quickly enough to do it properly with him.”

The OT views the loss of function post-stroke as a type of bereavement; the patient is grieving for what they used to be able to do, whilst facing a future with changed abilities:

“so I think it becomes very spiritual because everything that they think they can’t do any more, they have just lost that so it’s like a bereavement process really”.

## **Definition of spirituality**

The OT views this loss and bereavement process as “spiritual”; in fact, her definition of what constitutes the spiritual is broad. She defines spirituality as “anything that guides them”, which may include God or Buddha, but also includes sewing and gardening, pets, exercise or the sunrise. Spirituality is about how people “see the world” and her role vis à vis spirituality as an OT, is in knowing all facets of her patients:

“it really is about getting to know that person and understanding them and what they think and what they believe and how they see the world really”

Interestingly, even with this broad definition of spirituality, the OT does not consider herself to be a spiritual person, or at least not a religious one:

“I would say... I am not particularly religious, I am not... you know, I don't believe in anything really myself, but I think ... it's very individual and I think it's about what guides people's lives”

She begins to conflate religion with spirituality in this excerpt, so it is unclear whether she is claiming a lack of religiosity or a lack of spirituality.

### **Referral on to other professionals**

It is clear from the OT's frequent references to other professionals that she works closely with other multidisciplinary team members. In the area of spiritual needs of patients, she cites the chaplain, neuropsychologist and stroke liaison nurse as the key professionals to whom to refer, as well as the patient's local minister. Like the SLT, she sees herself as the mediator between the chaplaincy team and patients requiring spiritual support:

“we quite often have the chaplains down here. We have a nice relationship with them, then quite often if people indicate that they would like to see them or that we... if someone has got aphasia we will ask them and we indicate somehow...”

For the OT, spirituality is “part and parcel” of the whole person, and therefore comes within the OT's holistic remit.

## **Warmth and comfort: the nurse's tale**

Of all the healthcare professionals working with people with aphasia post-stroke in the acute setting, the nurse was the most problematic to recruit. I initially approached the nursing team of the stroke unit where the other members of the multidisciplinary team worked, but their workload was such that none of the nurses was able to commit time to be interviewed. This, sadly, is a reflection of current healthcare working, where professionals often feel overworked and too stressed and stretched to contemplate anything extraneous to their normal working day. Of course, the opinion of the nursing manager on this unit was respected and understood, and I sought instead to recruit the nurse for my study from a neighbouring hospital, belonging to the same Trust but in a different town.

Although the manager of this second stroke unit was willing to take part in the project and a mutually convenient time and place was agreed, it was still a short, rushed interview, during which I was always aware of the nurse's need to get back to her patients and the running of the ward.

Our meeting takes place half way through the morning on the stroke unit; the time and place has been agreed as the most convenient and least likely to cause disruption. When I arrive, the nurse is busy in a six-bedded bay, conversing with other members of the team about patients. Already I feel like I am imposing, taking her away from the important business of direct patient care.

The nurse, however, is insistent that she can spare some time to chat with me, and we go to her small office just off the ward. I never quite shake off the feeling that my being there is a slight inconvenience, and the resultant interview is short, with questions and answers left unexplored or not expanded upon. The nurse herself has difficulty articulating issues relating to spirituality; this is certainly not a difficulty exclusive to the participants with aphasia:

“Sorry, I am trying to think where I am... What was I going to say?”

The nurse's title is “stroke liaison sister”, and she tells me she has worked in the area of stroke care for six years. She sums up her role as liaising with the rest of the stroke rehabilitation team, meeting patients and relatives, providing information on stroke and being involved in discharge planning.

### **Nurse's definition of spirituality**

The nurse defines spirituality thus:

“I would say it's believing in something else that's not physically here and kind of ... it's giving you that warmth and comfort to help you get through things in life”

Although she says towards the end of our discussion that she does not consider herself to be a spiritual person, she nevertheless says she believes in something that “gives comfort”. She is also open to other people's spiritual needs. However, she intimates that often patients come into her care who do not require any spiritual help or special consideration:

“But we haven't really had that many to be honest of patients that have required anything extra in that sense really.”

She also suggests that spiritual concerns are not necessarily included when a patient is clerked into the ward by the nursing staff, apart from explicit information about belonging to a particular religion:

“...but very often it's not expressed in the form, whether there was any religion, religious beliefs, unless there was an actual religious belief.”

The nurse gives an example of a patient who had been on the ward. She was not necessarily a religious person, but the nurse identifies her as someone with spiritual needs:

“we have had a patient in the past that was very spiritual... so she would express how she was feeling or what she was seeing and saying... describing things in colours as well, so ‘I am feeling red today,’ ‘I am feeling....’ Yeah, that was quite a while ago though that patient.”

I wonder why this patient (who was on the ward “quite a while ago”) has stayed in the nurse's mind as an example of a patient with spiritual needs? Is it that hers was an unusual manifestation of spirituality, or is it that the nurse comes across patients with overt spiritual needs infrequently?

### **Nurse's role in terms of spirituality**

The nurse's role is one very much of supporting the patient and it is clear that this also applies to supporting their spiritual needs:

“Yeah, if it is someone's choice to talk about those things and obviously we are there to support patients”

However, time constraints often make supporting spiritual needs problematic:

“the difficulty obviously is with the times in the NHS and having less staff and having more of a workload to do as well, it does make things like that more difficult.”

She recognises the benefit of working within a team in order to address the emotional and spiritual issues of a patient:

“and we find that hard as nurses to be able to support someone going through that and that’s when we would call on other people to ... you know, it’s a multidisciplinary team, to try and help and support them even if it’s just sitting with them or if their family come in at any time”

The nurse seems tentative in her understanding of her role in addressing spiritual needs, and would value more explicit guidance:

“It’s something that I think we are always going to be learning with because there’s nothing really out there to help ... there’s no guidelines, it’s kind of how you interpret it isn’t it?”

### **Team working**

As her title suggests, the stroke liaison nurse’s role involves bringing in other professionals at different points in the patient journey, relaying pertinent information between professionals and patients and their carers. She mentions the speech and language therapist (SLT) as being the key team member on whom to call when she and other team members need to know the best method of communicating with a patient:

“We normally ask the speech and language therapists for support within that area so they would let us know what is reliable communication”

and the SLT also offers support to nursing staff and other team members when the patient is showing frustration because of communication difficulties:

“you can see their frustration so that’s when, you know, speech and language [sic] comes in very well, if they are able to help support us with that then it’s very beneficial”

She also mentions the neuropsychologist as being another key team member for supporting team members and patients, particularly in relation to patients' expressing existential angst post stroke:

"Yeah, yeah, so you would have some patients that are expressing, you know, 'Why has this happened to me, have I done something wrong, is it because of this?' you know, and thinking about things in their past life that 'I have been a bad person, and this is why this has happened' – that's why it's quite helpful that we have neuropsych going as well because it may be something more underlying going on than what we know."

The nurse also views her role as one of supporting the medical team in breaking diagnostic news to patients; the doctors would talk to the patient about their medical diagnosis, and then the nurse, with other team members, would be there to help the patient understand and come to terms with the news:

"So generally things like that are normally broached by the doctors because they are discussing the medical side of things more often when they do their daily rounds, and then obviously after that, then obviously we are kind of the fallback from that, so if they had any questions or if they are getting more frustrated we would... if we were struggling we would speak to the language therapists [sic] for support or say neuropsych if they are able to come into play as well."

#### **Referring on to other members of the team**

The nurse sees her role vis à vis spirituality as one of referring on when appropriate to the chaplaincy team. She mentions referral of a dying patient to chaplaincy for administration of the last rites:

"whether it's getting a chaplain in, or, you know, if they were a patient that was dying and they needed their last rites and anything like that really"

She acknowledges that the role of the chaplain is perhaps made more difficult with the person whose communication skills are compromised:

"sometimes we have had chaplains come in but obviously that makes it difficult because if they are not able to communicate..."

However, she is also able to see the value of chaplains using facilitative communication strategies, as well as of the possible comfort of familiarity:

“but they would use the communication aids as well and see if they are able to help and establish what it is that they are wanting to know, they read prayers as well with patients even if they are not fully understanding, they still do that because it's a process that they are used to doing.”

Interestingly, the nurse discusses referral to palliative care for patients requiring spiritual support at the end of life. It of course makes intuitive sense that those professionals who are very used to spending time with the dying and their families would also be able to support other team members with issues of spirituality, and yet she is the only member of the team to mention them:

“It's more difficult if the patient is coming to the end of their life in a way because it's what are they understanding of that... Palliative care as well, we often speak to palliative care and they'll help us with that.”

### **Challenges of working with people with aphasia**

Not unsurprisingly, the nurse has a good understanding of aphasia, and the different ways it may affect a person's ability to communicate:

“whether they are understanding (because some patients may be understanding but are not able to express that they understand) so it just depends on what type of ... whether it's receptive or expressive as well”

She recognises the challenge of discerning the patient's needs if they are unable to communicate, and the benefit of spending time with patients in order to get to know their likes and dislikes:

“until you know someone it's difficult to know what they would prefer and that's what makes things a lot more interesting.”

She also understands the limits of the nurse's remit in terms of communication. For example, in assessing a person with aphasia's ability to give informed consent, the nurse would call on a

speech and language therapist to determine the patient's capacity to understand and to express consent:

"Sometimes they [the speech and language therapists] support with the capacity assessments as well just to help us really to establish whether what we are understanding is reliable."

### **Emotions encountered**

The nurse recognises a number of emotions encountered by people with aphasia following stroke, such as frustration, anger and being "uptight". She explains how some people following stroke may experience periods of existential angst, when they are asking questions about why they have become ill:

"yeah, so you would have some patients that are expressing, you know, 'Why has this happened to me, have I done something wrong, is it because of this?' you know, and thinking about things in their past life that 'I have been a bad person, and this is why this has happened'"

She talks about the particular fear people may experience at the end of life:

"It's more difficult if the patient is coming to the end of their life in a way because it's what are they understanding of that, and I think it can be quite frightening for them because it's frightening for anyone to be facing that."

One can only surmise that this fear may be even more marked in those patients who are unable to voice this.

### **Non-verbal communication**

The nurse has some understanding of total communication strategies:

"We have a communication booklet that we use; also if there's certain things that patients understand that the family have, then they can bring them in – photos, anything that helps trigger things really, that's the main... the non-verbal commands, sometimes people are able to gesture but not able to speak"

However, there are some practical barriers in the way of communication aids being used routinely:

“Yes we have communication aids. We did have some up on the wall but they have taken them down when they were painting, so... We are just waiting for them to be put back up again.”

Like many of the participants in this study, when the interview is coming to an end (and in this case, the recorder has been switched off), the nurse reveals a nugget of information about spirituality which she subsequently gives me permission to share. She tells me that she does not consider herself to be a spiritual person, but that she believes in something that “gives comfort”. She describes a beautiful picture that her grandmother relayed to her as she lay dying in a hospice; her grandmother saw daffodils and knew she was going to a good place.

## **To listen and love: The lay chaplain's tale**

The lay chaplain and I meet for our interview in the hospital chapel, a quiet area but one where people would come and go freely. The lay chaplain is a Christian and has many years' experience in this capacity of working with people who have had strokes:

"at the {named hospital} going back 15 years"

He is not ordained but is a volunteer with the chaplaincy team. In line with the other qualified members of the multidisciplinary team (MDT) interviewees, I had intended to interview the chaplain herself, an ordained minister. However, in consultation with her, it was decided that the lay chaplain had much more experience of ministering to people post stroke and that he would therefore be the most appropriate member of the chaplaincy team to be interviewed. Again, the interview loosely followed the MDT topic guide and finished with the question "is there anything else you want to say about this topic that I haven't covered?"

### **Listening**

The lay chaplain begins by outlining what his job generally entails. He explains that his is a listening role, one that provides support and help through talking and listening:

"I says 'I am here to talk to you and listen to you, to help you in what is happening to you'."

He values this listening role as perhaps the most important part of the interaction:

"also at the end they have thanked me for listening to them".

### **Relationship**

His role is also one of relationship. He laments the fact that, in the hospital in which he currently works, throughput of patients is much faster than it was in his previous hospital, and thus he is not able to see patients as often, and forge such strong relationships:

"form a very big relationship with them, and seeing them every day, it did help"

"It's awkward in this hospital now because I only see a patient once"

The relationship he does forge with patients, however, appears to be mutually beneficial:

“so, I’m getting something out of it as well because I listen to people’s lives”.

### **Being comfortable in his presence**

He stresses the fact that he wants patients to feel comfortable in his presence and wants to avoid obstructions to interaction appearing because he has the title of ‘chaplain’, and therefore perhaps the reputation of someone who is going to proselytise:

“and I think when you say you’re a lay chaplain people sometimes put up a barrier and I say ‘I am not here for chaplaincy, I am not here to preach to you.’”

He wants to provide ministry to patients who desire it, regardless of their faith or lack of faith:

“there has been a couple of times when I have met patients and they have said ‘I am sorry, I am not a Christian, I don’t believe.’ I say ‘I’m not here for that,’ “

On the other hand, he will pray with people who explicitly request that ministry:

“a few of them have turned round and said ‘would you pray for me?’”

### **Love**

At the heart of what he does is love and compassion:

“I don’t know, encompassing them in that love that we have all got and if they can feel that, I think it must help a hell of a lot”.

### **Holism**

The lay chaplain views his input as holistic, not just benefitting the patient from a spiritual perspective but also contributing to body/mind restitution:

“ and also by doing that [patient talking about family, hobbies etc] I think it helps their minds to work, so it’s helping all the way through the body”

Just as the other professionals involved want to include the spiritual in their rehabilitation of mind and body, so the lay chaplain is cognisant of the need to include the mind and body in his spiritual ministry.

## **Evasion**

It seems that the majority of the lay chaplain's role is based around the verbal; being able to talk to and listen to the patient, to pray with them. When asked about ministering to people with little or "no talk" (McVicker, 2007), the lay chaplain appears less confident in his response. Indeed, he does not actually answer the question "do you find people who have had a stroke and have communication problems, are they sometimes still wanting to talk to you about ... spiritual issues?". He instead, perhaps, stays in his comfort zone, of reassuring people that they do not have to be church-goers to be loved by God. Or perhaps he misunderstood the question.

At times, he candidly admits to shutting down the conversation because verbal communication is so limited:

"But some I...you get that blank look and so you say 'well thank you very much, I am happy to be here with you but as we cannot communicate I will say a prayer and I will move on'"

This is at odds, however, with his assertion that "I try and make them feel at ease just by sitting there".

He alludes to the "awkwardness" of interacting with someone with little or no verbal communication, and to the fact that he does not want to put "too much strain" on the patient. Is it that he is wary of causing stress to the patient, or is this "awkwardness" felt as keenly by him?

I broach the concept of "ministering without words" and, although he is initially puzzled by this idea, he does then take on board what it could mean:

"...just by our faces and the way we look at people and just actions".

## **Non-verbal communication**

When it comes to ministering specifically to people with aphasia post-stroke, the lay chaplain has a rudimentary understanding of the fact that non-verbal communication strategies may be helpful. He uses written cues, gesture and facial expression to try and facilitate expression and understanding of language:

"I ask them if they want to write it down. I always carry a pen and paper...if they can't talk to me then I will do language [sic], and you know, I will say 'are you happy?' (*gesturing*) and smile, and do different things like that to try and see whether I can get recollection from them"

When I ask him what would help when having conversations with people with aphasia, he says:

“different cards, ones that have got photos on them...visual aids, I think that would help quite a bit”.

### **Definition of spirituality**

When asked for his definition of spirituality, the lay chaplain first laments that this is a difficult concept to define. He then goes on to say:

“I would say to try and actually do what the Lord asks us to do, as he asked his disciples, to go out to teach, to heal, to listen and love”

So, his initial definition, not unsurprisingly, is based on Christian, biblical teaching. However, he later goes on to broaden out his definition of spirituality, veering away from the overtly Christian, or even religious:

“I think it’s everything, you know, in all we do”.

### **Personal experience**

At the end of the interview, as I have done in all the interviews, I ask the lay chaplain whether there is anything else about the topic that he wants to say, anything I have missed. He takes this opportunity to tell me his personal, and immediate, experience of stroke; his aunt had just suffered a stroke and had subsequent aphasia. He gives his take on what aphasia is:

“because with a stroke I think people, their brains sometimes...they can hear the words we are saying but they’re jumbled and sometimes we need to let them have that sort of...to un-jumble it”

and how best to communicate with someone with aphasia:

“It has affected her talking side more and I was just allowing her to talk slowly and I think this is the main thing we have got to look at, if a patient can’t talk to you properly, allow them to take their time”

I wonder why he has alluded to this personal experience? Is it that he just wants to use a specific patient as an example of someone with aphasia, albeit a relative? Perhaps he sees me as an interested party, as someone with inherent interest in a situation currently very close to his heart. Maybe he is looking for my professional SLT opinion. Can the qualitative interview process become a therapeutic one?

What strikes me about the lay chaplain is his very definite desire to help and to offer love to the patients with whom he engages. However, it is also clear that he has limited understanding of aphasia and the multifarious effects of aphasia on an individual's ability to communicate. Perhaps the "awkwardness" he identifies in his interactions with people with aphasia could be mitigated by being better informed about the different types of aphasia, and the different facilitation strategies which may enrich his interactions with stroke patients.

## Chapter 5: Making sense of the stories

**“There are more things in heaven and on earth, Horatio, than are dreamt of in your philosophy”**

**(Hamlet William Shakespeare)**

If phenomenology is “the art of bringing truth into being” (Merleau-Ponty, 2002, p xxii), then this research has attempted to bring the truth about the participants’ spirituality to the fore. Spirituality for them, as for me, encompassed myriad facets of life - including but not exclusively - religious belief. The stories of the participants in groups 1 and 2 have been an attempt to discover what it is like to express one’s spirituality, when one has aphasia. Their myriad comments, gestures, intonation and facial expressions all create a rich Mosaic (Clark, 2001) of spiritual matters communicated. People with a professed faith were able to convey complex religious concepts; Joel and I, for example, were able to have a conversation about the Christian concepts of the Holy Trinity and the fruits of the spirit. Other participants were able to express the complexity of supernatural occurrences; David shared a vision of Jesus he had experienced as a young child, and Lindy eloquently and beautifully described the appearance of angels at her bedside during her stroke coma. Others equated spirituality with meaning-making, and were able to convey what gave their life meaning and purpose. In order to help build a framework from which to view these stories, I have used some concepts propounded by Merleau-Ponty (2002), namely ambiguity, language and thought, lived body, the body as expression and wonder. These concepts enabled me to make sense of the stories. Aligning each story to Frank’s (2013) illness narratives added a further framework, which has particular pertinence when I come to discuss clinical relevance of the study (chapter 6).

The second research question asked what is the lived experience of the multidisciplinary stroke team when discussing spirituality with their clients with aphasia? I found it helpful to look at the MDT interviews through the lens of Merleau-Ponty’s (2002) ideas of ambiguity and wonder, in order to dig deeper into this experience.

In order to make sense of the stories, I had to again consider Gadamer’s fusion of horizons (2013, p 316), as I had when carrying out the interviews. My prejudices (or “fore-meanings” – see chapter 2) formed part of my horizon, as this horizon met those of my participants. So it was that I felt able to become an “enhancer”, creating “an atmosphere of freedom, openness, and trust”, enabling participants to “respond and disclose [their] own thoughts and feelings” (Moustakas, 1994, p 39).

## 5.1 Frank's illness (disability) narratives

As I listened to the spiritual stories of people with aphasia, I also contemplated the three illness narratives propounded by Frank, namely restitution, chaos and quest (Frank, 2013, p 52). Some participants with aphasia expressed a restitution narrative, claiming experienced or hoped-for improvement in their language impairment, or their body function (World Health Organisation, 2001). Some participants were still deep in the wreckage of the chaos narrative, unable to navigate a way through. Some, however, seemed to have attained a state of quest, and were embracing a new life with new, changed communication skills. Some stories of spirituality revealed more than one illness/disability narrative. Participants expressing a predominantly quest narrative seemed to be the most able or willing also to engage in a spiritual narrative.

### 5.1.1 Chaos

The “anti-narrative” (Frank, 2013, p 98) of the chaos story is epitomised in the efforts of some participants to convey the utter devastation and distress of the stroke event. Peter talks about the fact that he “really couldn’t use the words” immediately after the stroke, chiming with Frank’s notion that “the suffering is too great for the self to be told” (p 115). Of course, these participants were not only in a state where narrative may fail, but were also deprived of their linguistic abilities per se; most participants explained how their aphasia was far more pronounced immediately post-onset than at the point of interview. Peter intimates that hospital staff in the acute setting were not able to hear or listen to his illness narrative soon after the stroke:

“I really couldn’t talk to them anyway”

and for some participants, like Lindy, the aphasia was so severe that telling any kind of narrative was impossible; “me, mute”, she says and I write in my notes after the second interview that she *draws fingers of left hand across mouth – like a gag?* Language and narration is literally stalled, by both the aphasia and perhaps also because these individuals are in this state of chaos.

Other participants demonstrate this annihilation by their choice of vocabulary. Joel says “because you have gone”, and he, too, makes a sweeping gesture with his left hand as if to emphasise this. David talks about his preferred hand being “buggered”, so that writing (and, for him, art) have become difficult.

Both Peter and David use peculiarly mild vocabulary to convey the events surrounding their stroke. Peter's severe dip in temperature after spending several hours collapsed in the garden is described by him as "awkward", and David relates how he was "slightly concerned" at waking up in the night and not being able to move the right side of his body. Perhaps they are trying to contain the chaos by tempering their lexical choice.

The related stroke stories themselves all inevitably carry a chaotic theme, none more so than Peter's, where the ambulance is delayed by a contraflow system, with cars driving on the opposite side of the road – perhaps the epitome of chaos. Aspects of these narratives are very frightening; Joel was driving with a passenger in the car when he experienced his stroke, and Francesca was alone in her flat and not found for 36 hours. Lindy experienced her stroke on Christmas day whilst out for a walk with a friend; here the catastrophe of the stroke experience seems to be heightened by the contrast with festivities going on around her.

Of all the participants with aphasia, it is those in group 1 who have recently had their strokes who display the most evidence of still living a chaos narrative. Although David in group 2 still appears to blame his sister-in-law for giving medical and nursing staff erroneous information relating to his insulin, thereby prolonging his hospital stay, he nevertheless does also demonstrate other narratives now that he is nine months on. Liam and Amy, however, both seem lost in a "narrative wreckage" (Frank, 2013, p 53), where physical needs take precedence over everything. For Liam, all identified meaning-makers have been stripped away – he has few visitors, he is not able to care for his cat, he is physically unable to engage in the sports he loves, and he has a real lack of control over his physical functioning (for example, his swallowing difficulties necessitate a nasogastric tube, and his lack of bladder and bowel control means he is reliant on incontinence pads). For Amy, too, physical discomfort and pain are at the forefront of our discussions, and satisfaction of physical needs is paramount.

The participants in group 1 were less inclined to talk about spiritual or existential issues than their group 2 colleagues; perhaps this is due in part to their being deep within the chaos narrative, where all their energy is consumed by trying to satisfy the base of Maslow's hierarchy of need pyramid (Maslow, 1954); the pinnacle of self-actualisation can perhaps only be voiced as individuals approach and enter a quest narrative. All participants in group 1 were relatively passive in their communication, perhaps another indication of the "narrative wreckage" which finds expression difficult:

"Lived chaos makes reflection, and consequently storytelling, impossible." (Frank, 2013, p 98).

Interestingly, neither of the two participants with a strong Christian faith – Lindy and Joel – blame God for their situation or lose their faith. God is not lost in the chaos.

### 5.1.2 Restitution

The aphasia stories of spirituality from group 2 are peppered with restitution narratives. All the participants bar Francesca report that their expressive language is better now than it was immediately post-stroke. David says “well, hopefully it’s [his speech] a bit improved” and Joel exclaims how his language is “[vatli] (vastly?) better”. Some attribute this to the speech and language therapy input they have received. The SLT is seen by some as the ‘curer’, the medical expert who takes responsibility for improving the impairment; “she taught me how to speak”, says Peter. SLT is seen as the restitution remedy.

Lindy reports that she is always reading and writing and “striving” to make improvements in her language abilities. Joel and Francesca also both show this stoicism, perhaps illustrated best in Francesca’s exclamation of “forward march”.

For two of the Christian participants, restitution has a religious overlay. Lindy’s comment in a private email of “I am Lazarus” suggests that she feels saved from death, in fact that she was dead but was brought back through miraculous and divine intervention. Joel’s stoic attitude of accepting what life has dealt him seems rooted in his belief that this phase is transient, and that he will receive a new, healed body when he rises again after death. This religious restitution does not rely on the medical model of intervention but rather on divine healing.

### 5.1.3 Quest

All the participants in group 1 seem a long way from finding a quest narrative. Although Amy voices often during our conversations that she wants to go home, thereby perhaps intimating that she is searching for normality, she nevertheless remains dependent on nursing and medical care which necessitates her staying in hospital. Liam and Rosemary also appear far from being able to express a quest narrative, notwithstanding their expressive language difficulties.

By contrast, all the participants in group 2 display some evidence of a quest narrative at certain stages of their stories. The artists – David and Lindy – are both starting to embrace artistic expressions close to but different from their original forms; published novelist Lindy now writes poetry, and fine artist David is now experimenting with sculpture. Francesca, who from the beginning of our conversation makes it clear that employment is of huge importance to her, is no longer able to work as an accountant but has a role within her stroke group which she refers to as “work”. Joel is content with his lot, almost chiding me for assuming that his word-finding difficulties are a source of frustration. Peter is thankful that his stroke did not result in physical disability: “and going to the Stroke Association meeting I realised that I lucky

because a lot of people there can't use an arm or leg or..." , as this means he still has the physical ability to "get on with me garden", a perfect representation of quest.

All the participants with aphasia in groups 1 and 2 express one or more of these illness narratives throughout their stories, testament to the fact that telling the story of one's illness is possible, even when language is severely impaired.

## 5.2 The influence of Merleau-Ponty

Relating the stories to the phenomenology of perception propounded by Merleau-Ponty (2002) helped to root them in a framework, which in turn enhanced my understanding. Much of Merleau-Ponty's work is concerned with the so-called "third dimension" which, he claims, exists between empiricism and intellectualism, between "physical reality" and a "spiritual or mental realm" (Lewis and Staehler, 2010, p 164).

Merleau-Ponty's philosophy demands that we go back to the Husserlian things themselves, to look at things pre-reflexively, before we have objective knowledge of them:

"To return to things themselves is to return to that world which precedes knowledge, of which knowledge always *speaks*, and in relation to which every scientific schematization is an abstract and derivative sign-language, as is geography in relation to the country-side in which we have learnt beforehand what a forest, a prairie or a river is" (Merleau-Ponty, 2010, p x).

In the thinking of Carel (2008), a philosopher herself undergoing serious, life-limiting illness, phenomenology in the health sciences can be used to create a framework that "gives precedence to the experience of illness and to the embodied nature of human existence" (p 103). So it is that phenomenology and the concept of "lived body" (Lewis and Staehler, 2010, p 161) fits the study of a particular facet of what it is to be human – namely spirituality – with a client group for whom the body has altered and a normal function of the body is changed – namely the ability to communicate in people with aphasia. In fact, for Merleau-Ponty (2002, p 229), the act of expressing – whether via speech or another modality – is a transcendental, spiritual act:

"speech or gesture transfigure the body"

which further lends congruence to the use of phenomenology – and specifically the phenomenology of Merleau-Ponty - to investigate spirituality with those who are challenged in their communication.

The success of intersubjectivity in this study varied from participant to participant and from story to story, success or otherwise being largely governed by my ability truly to 'be with' my

participants. This, in turn, was influenced by multifarious factors, including time pressures and lack of shared cultural reference, but also, undeniably, communication breakdown.

Hinckley (2013) states that the “phenomenological” emphasizes the “sensory and perceptual experiences” (p 93) of individuals, which tallies with Merleau-Ponty’s emphasis on perception, which he divides into, amongst other concepts, bodily sensation, association, attention and, importantly for this study, speech (Merleau-Ponty, 2002). Much of Merleau-Ponty’s philosophy is concerned with ambiguity – or the so-called “third way” between empiricism and intellectualism – language and thought, the lived body, the body as expression and wonder. Each of these elements of Merleau-Ponty’s philosophy has been used in order to look at the participants’ stories, and to make sense of the emergent themes.

### **5.2.1 Merleau-Ponty and Ambiguity**

Merleau-Ponty’s philosophy deals with the space between. To ‘do’ phenomenology, one must always begin with the lived experience, but that experience may be hazy, ambivalent or undefined. Within this study, a light was shone on the ambiguous concept of spirituality, expressed in the ambiguous language of people both with and without aphasia. Ambiguity revealed itself in language used and roles adopted, but it was also at times mitigated by careful listening and skilful non-verbal communication.

To enter into an exploration of the spiritual stories of people with aphasia is to enter into a world of ambiguity. Merleau-Ponty (2002, p 30) recognises that between the worlds of intellectualism and empiricism, or idealism and realism (Dorfman, 2005, p 25), or perhaps even mind and body, lies the morass of ambiguity. Spirituality is itself a topic fraught with ambiguity, often seen as a nebulous concept, unwilling or unable to be confined in human-made verbal definition. Attempts have been made to define spirituality; indeed, examples were quoted in chapter 1, and all the participants in this study have given their own, disparate ideas as to what spirituality means to them. Yet it remains a concept which defies reductive definitive definition, being perceived differently by each person.

People with aphasia produce expressive language that may be pregnant with neologisms and paraphasias, latency and fillers, palilalia and automatic speech; in short, the expression of people with aphasia can reside in an ambiguous land, where it is incumbent upon the listener to attempt to create certainty through facilitative techniques and listening skills. The person with aphasia may themselves try to navigate this land of linguistic ambiguity, by creating their own landmarks in gesture, writing or drawing.

As the majority of people have their language areas in the left cerebral cortex (Schoenberg and Scott, 2011, p 159), an infarct affecting the left cortex may result in aphasia. In his book, “The

Master and his Emissary” McGilchrist (2010) posits that there are marked differences in the ‘character’ of the right hemisphere (the ‘master’) and the left hemisphere (its ‘emissary’), which may be pertinent not only to the ambiguity of aphasic language, but also to the ambiguity inherent in the study of a subject such as spirituality.

The right hemisphere, says McGilchrist (2010, p 52), is “more global and holistic” than its left brother. The larger left hemisphere is concerned with the concrete, with categorisation, with focussed attention, and has traditionally been referred to as the dominant hemisphere “since it did all the talking” (McGilchrist, 2010, p 23). He argues that the right hemisphere is better at mediating emotions, seeing the whole rather than the parts, and that “intense emotional responses are related to the right hemisphere and inhibited by the left” (p 27). Little wonder then, perhaps, that the preserved right hemisphere in people with aphasia might actually thrive in an atmosphere of ambiguity, whereas their left hemisphere might balk at a lack of cohesion and certitude:

“the right hemisphere’s interest in language lies in all things that help to take it beyond the limiting effects of denotation to connotation; it acknowledges the importance of ambiguity.” (p 80).

Does the enforced dominance of the right hemisphere in patients with aphasia and damage to their left hemisphere mean that they are better able to cope with ambiguity? Be that as it may, the language of aphasia is nevertheless a potentially ambiguous one. In this study, I asked people with the ambiguous language of aphasia, to voice their understanding of the ambiguous concept of spirituality.

Congruent with this ambiguity of both concept and its transportation to the listener is a phenomenological methodology. Positivism has in the past always striven for certainty and sureness, where there are right and wrong answers, and no room for grey areas of ambiguity: “positivism offers assurance of unambiguous and accurate knowledge of the world” (Crotty, 1998 p 18).

Merleau-Ponty (1964, p 160), however, urges us to eschew such “vagabond endeavours” and instead try to perceive the meaning of a phenomenon as it is given to us, in all its uncertainty and ambiguity, even if, as Heidegger (Lewis and Staehler, 2010, p 71) believed, in some instances, “the ultimate meaning of phenomena may *never* be fully revealed to consciousness”. Lewis and Staehler (2010, p 190) acknowledge that “a phenomenological investigation discloses an essential ambiguity at the core of our existence”, and this is perhaps particularly apposite when one is endeavouring to disclose a facet of a person such as their spirituality, which is necessarily individual, unique and nebulous.

There exists in this ambiguity a liminal space. Just as Merleau-Ponty’s philosophy occupies an area between the two extremes of empiricism and intellectualism, so this study occupies a

space between normality and pathology, between body and spirit, between speaker and listener. It speaks into ambiguity and a liminal space, where lines and definitions are blurred. Within this study, ambiguity exists in the methodology, the subject matter, the methods whereby the stories were collected, and in the way the stories were told.

### **5.2.2 Ambiguity in language**

Predictable aphasic errors abound in the samples of language of participants in groups 1 and 2, such as word retrieval difficulties, paraphasias, neologisms, palilalia, overuse of fillers (such as 'ah' and 'um'), reduced syntactic complexity, latency of response and favoured automatic words/phrases (such as "exactly" (Francesca)). David's output is characterised at times by lack of content words, or erroneous word choice, so that responses are unclear in relation to the subject at hand: "we don't really love really", he says, in response to whether he is currently able to work. He also sometimes produces unintelligible strings of phonemes, and 'empty' speech, with good preserved syntactic structure which belies his inability to retrieve the target word at times. David wryly repeats my word 'struggling' as he attempts to offer his definition of spirituality, a reflection perhaps both of the complexity of the concept, but also of his word finding difficulties. Joel confuses gender and pronouns in his word selection, which lends part of our conversation a confused and ambiguous tenor:

S: You were driving?

J: Yes

S: Wow, OK, OK. And were you alone in the car?

J: No, no...boy, well girl

S: Your girl?

J: No, boy

S: Your boy?

J: No, no, no...man

S: Do you mean your wife?

J: No no no because it was a female, no no, male

S: Male – right. A male relative?

J: No no no

S: A male friend?

J: There...er yes and

Joel is also the only participant in group 1 or 2 who habitually uses neologisms, particularly the phrase [məʊ məʊ]. He seems aware of this neologism, aware that it is incomprehensible and not the word or phrase that he wants, and so it is often accompanied by an embarrassed laugh. In all the ambiguity of language and non-language, there is the added confusion of embarrassment. Francesca and David also use laughter which seems to serve the role of camouflaging word finding difficulties. Similarly, Joel uses the phrase “for now” when he has attempted to convey something but the words elude him and his listener is not able to facilitate. It seems to signify ‘let’s leave it, as I can’t find the right words, and you can’t help me’; perhaps another indication of ambiguity in the world of aphasia.

Ambiguity present in aphasic output during the interviews seems to be exacerbated by emotive content, and mitigated by meaning-making content. When Peter describes the traumatic day of his stroke, his language is lacking in content words (nouns, verbs, adjectives) and his gestures are indistinct:

S: No. So what were you thinking during that time?

P: (*hand movement, pause*) I was thinking about trying to get back in but obviously I wouldn’t be able to...erm...I don’t really know (*shakes head*) erm no

Contrast this with the clarity of conveying information, both verbally and in gesture, about plants and grafting of plants in his garden:

“I did erm this was three different plants and I (*gesture with both hands, finger of left hand crossing fingers of right*) then er er created plants er er and then erm oh they would just small bits of erm they were just small bits of garden and I joined all of the things together and made it what I did was er if I can hoe (*gestures hoeing*)”.

Gesture in this excerpt is specific and aids understanding by the listener, as does his increased use of nouns and verbs.

Similarly, Francesca has significant word finding difficulties in general conversation, and her responses often comprise only one or two words, but when I ask her about opera, she is able to name several favourite composers. Proper nouns are often problematic for people with aphasia (Beeson, Holland and Murray, 1997), so this is perhaps testament to the importance opera and composers hold in her life; the target words – or names – are triggered in the phonological output lexicon, despite the reduced semantic information inherent in proper nouns.

Ambiguity in aphasic language lies not only with the speaker, however. Seemingly conflicting statements, such as David's claims about being religious or not, and Lindy's comments about her ability to remember and express learnt liturgy, may also be in part due to my inability as facilitator:

"Communication difficulty belongs equally to those with the impairment and those who struggle to communicate with them." (Hewitt and Pound, 2014, p 181).

When David tries to explain who the person visiting the house after me is, I make several attempts to clarify but to no avail; by the end of the interchange I am still not quite sure of this person's role:

D: Yeah, and she's quite in church actually she's very into it and...er...I don't go to church at all. I...actually the person who's last there was a someone who is...er...a spiritualist – not a spiritualist – a...erm...yeah he looks after me. He [gʌns] me everything

S: Like a sort of spiritual adviser?

D: No, no, he's...er...he's not a spiritualist, I meant...erm...yeah...he er...he's trying to take me [dʒɛn] (?gently) er be a...Oh, I don't know...trying to embrace the church like the way he does

S: Oh, OK, so he's sort of mentoring you?

D: No, he's purely just there to help

S: So, he's from the church?

D: Yeah

S: So he's just come to...

D: Yep

S: to talk to you and...

D: Yep. An hour after you!

S: Oh, right, OK (*laughs*)

Amy in group 1 also gives what appears to be conflicting information about whether or not her grandchildren have visited recently. This discrepancy may again be a reflection of my inability to grasp fully what she is conveying, or perhaps it reflects her wanting to see them more, a feeling that often is just not often enough.

This inability of the listener sometimes to understand the message is not confined to me. Joel's wife at one point is summoned by Joel in order to help him find a specific Bible verse. She is unable to understand which verse he is alluding to, and I later note in my reflective log:

*J's wife tries to help, flicking further back in the Bible. J physically stops her and says "no, no". She drifts away as he continues to search.*

A glimpse is offered into their day-to-day existence, where ambiguity of meaning abounds. The ambiguity of aphasic output is compounded by overlaid motor speech difficulties of some of the participants; Amy presents with unilateral upper motor neuron dysarthria, and Rosemary with possible apraxia of speech and dysarthria.

There is no clear cut distinction in clarity, however, between the aphasic output of the people in groups 1 and 2 and the non-aphasic participants of the multidisciplinary team in group 3. The MDT members are also hesitant in their speech and use many fillers. They, too, can be non-fluent and lacking in clarity at times, using ambiguous non-specific vocabulary and needing facilitation from the listener:

“Sorry, I am trying to think where I am... What was I going to say?” (Nurse’s interview)

The participants with aphasia attempt to mitigate the ambiguity in their aphasic output in a number of ways, many of which are successful. Francesca’s speech output is limited and telegraphic; she tends to use single words or short phrases. To augment this, she uses gesture on a number of occasions; for example, the word for a CT scanner eludes her, so she is able to gesture leaning back. She also gestures her father holding her hand, a gesture which is arguably more evocative than the spoken message would have been. She is able to cue herself in using sequences, particularly with numbers, for example, when she tells me how old she was when she had a her stroke: “yes, thirty...forty...fifty-one”.

Lindy also uses gesture to good effect, such as when she ‘zips her mouth shut’ when I ask her if she is still able to recite liturgy in church. She also uses facial expression and intonation to great effect; perhaps her being a poet means she has a natural affinity for prosody. Writing, though, is her most used and most efficacious augmentative communication method; she writes key words when the spoken form eludes her, which sometimes cues her into uttering the spoken form, or sometimes simply enables her interlocutor/reader to understand. Ambiguity is averted by this written record, which also acts as a referent to come back to during the conversation.

Joel uses a form of circumlocution in order to cue his listener into elusive words. For example, when he is unable to find the word ‘apostle’ or ‘disciple’ in his lexicon, he ingeniously counts to twelve, which, along with context, is enough to alert me to the intended word. At various times he uses intonation to convey the message; at different times in the interview he expresses lack of equivocation (when I suggest his word-finding problems must be frustrating), emphasis (such as when he asserts that he is still able to pray) and enthusiasm (for reading the Bible, for example). Although he occasionally reaches for pencil and paper, writing is less

successful for Joel than for Lindy; starting the word in written form enables me to guess at, and for him to eventually achieve, the name of his church (appendix VIII).

Peter uses physical prompts to try and cue himself in to words he is unable to retrieve; he often taps his thigh as if coaxing out the target word. He also pauses, giving himself time to find the word. The written modality does not help Peter; it may be that he has a similar word-retrieval deficit in the written modality to the spoken.

David, too, eschews the idea of writing to help convey the message, but for him writing is not possible because of hemiplegia of his right side and, therefore, his dominant hand.

Interestingly, David is the person in group 2 closest to the stroke event, and he is the participant who uses augmentative, total communication strategies the least. This may be because he is not yet at the rehabilitation stage needed in order to contemplate methods other than speech.

Amy, Liam and Rosemary in group 1, who are even closer to their stroke event than David is to his, also use little total communication, or, to use Clark's (2001) terminology, limited communication Mosaics. Amy's use of the occasional gesture (such as hands together for 'prayer', or hand on head for 'blessing') is effective but infrequent. Rosemary uses excellent eye contact and facial expression in the context of severely reduced verbal output which, although they help in forging relationship and connection, do not facilitate language comprehension and expression per se. Of all the participants, Liam is the least able to mitigate the ambiguity of his aphasic output with any attempts at total communication. Our interview is peppered with pauses, as he struggles to process what was said to him and/or to formulate a response.

Perhaps the participants who *are* able to utilise non-verbal clarification methods do so because they have enforced dominance of their right hemisphere, and therefore, as McGilchrist (2010) intimates, "allow the 'silent' right hemisphere to speak" (p 155) by using more 'right hemisphere' functions, such as the musicality of intonation. If the emissary (left hemisphere) is the "paint box" of language (p 99), providing the utensils of lexical items and syntax, the master (right hemisphere) paints the whole picture. So, McGilchrist surmises, "following a left hemisphere stroke, the right hemisphere painter has lost his materials." (p 100). However, using total communication strategies, the person with aphasia can learn to paint (or, perhaps, create Mosaics (Clark, 2001)), with other materials.

As a researcher and as a speech and language therapist, I attempt to use learnt skills to mitigate the ambiguity in the participants' output. I check back to make sure I have understood correctly, sometimes paraphrasing, sometimes mirroring. I try cueing in participants by starting off a sentence for them, hoping they will be able to complete it. I allow time and give non-committal responses (such as 'uhuh'), to show that I am still listening. I also use questioning

intonation to encourage further output or elaboration of what has been said. Throughout the interviews, I try and keep an interested demeanour, and employ active listening strategies, such as leaning forward, maintaining eye contact and nodding. Using a “phenomenological attitude” (van Manen, 2016, p 32), I listen attentively and non-judgementally to equivocal episodes (for example, visions), to allow them to be voiced, noted and accepted.

For my second interview with Joel, I bring artefacts which I hope may stimulate some more discussion about spirituality and, in his case, Christianity. Nebulous and difficult concepts could be tackled when Joel and I had objects in front of us to refer to and to prompt conversation. Some objects even seemed to stimulate remembered liturgy (such as the communion wafer). Occasionally, ambiguity within interaction between participants with aphasia and me as researcher remains; between us, we are unable to repair it:

S: Yeah, so you have a quite a positive attitude?

L: I don't know, I don't know

S: No

L: I don't know

Most, but not all, of the MDT members were also well used to incorporating strategies into their conversations with clients with aphasia which helped mitigate the ambiguity of their communication. The occupational therapist refers to “deciphering” aphasic speech, and explains how she and the other members of the team are perceptive to non-verbal attempts at communication. She also, however, uses some reductive phrases regarding people with aphasia, such as “they can't tell us” which suggest she is under-confident in the communication capacities of people with aphasia. The lay chaplain is similarly dismissive of the non-verbal communication skills of patients he sees with aphasia, a stance that is doubtless due to a lack of knowledge or training: “but some I...you get that blank look...”. The physiotherapist speaks of the client's confidence in him creating a conducive relationship for expression and for comprehension of that expression.

Aphasic language, then, is an ambiguous language, where errors and misunderstandings abound. If the language of the dominant (left) hemisphere “brings precision and fixity” (McGilchrist, 2010, p 114), the communication of the right affords a certain lack of clarity, where both communication partners have to work at interpretation.

### 5.2.3 Ambiguity of identity

It is a well-documented fact (Ellis-Hill and Horn, 2000; Shadden, 2005; Simmons-Mackie and Damico, 2008; Corsten et al, 2015) that people who have aphasia following a stroke may experience a feeling of lost or changed identity. In this study, participants exhibited some ambiguity in their role but were successfully finding new ones. So, for example, Lindy the novelist becomes Lindy the poet. The first thing that Francesca tells me about herself is that she is an accountant; her identity is formed through her profession. The SLT in particular tries hard to preserve the identities of the patients she mentions, usually by telling me their age or occupation. Throughout the stories, I have given the participants titles reflecting the identities they conveyed to me during our conversations, in an effort to solidify changing roles and identities.

I find that my role, too, is at times ambiguous throughout the project. Am I researcher or therapist, professional or friend? As a researcher, I needed to be concerned with correct process; I needed to set up the recording equipment, read through the information sheet and ask the participant to sign the consent form. As a therapist, however, I wanted to create a therapeutic space, to nurture and to encourage, to facilitate and to empathise. I felt a certain ambiguity of role; was I there to collect information, or to provide therapy? Was I intending to be a “miner” digging for nuggets of research interest, or a “traveller”, accompanying the co-researchers as they navigated my prompts and questions, their opinions and feelings (Kvale and Brinkmann, 2009, p 49). My role as I perceived it changed in relation to how I recruited or met the participants. Lindy and Joel were both introduced to me by mutual acquaintances, and our relationship therefore started out on more of a friendship footing. This was enhanced by continued interactions via email and social media. Francesca and David were very much ‘recruited’ via a stroke group, following a presentation of the project, and so our relationship felt like more one of professional researcher and research participant. For the participants in group 1, I was entering the ward with a Trust research passport which gave me free rein as an employee to come and go as I needed to. This, combined with my six years’ experience of working on acute wards as an SLT, made my role feel more like one of professional therapist. All these variables meant that my role could feel different from participant to participant, from interview to interview, and even within one interview. I wonder if my own perception of role also impacted on my behaviour, which in turn influenced how each participant viewed me, and therefore how they reacted to me.

During interviews where I felt more like ‘researcher’, I was not able to react in as much of a therapeutic way as was perhaps natural for me. When David explained that his dominant hand was “buggered” which had effectively put paid to his art for the moment, the therapist inside

me wanted to pursue this, yet I was there in my capacity as researcher, and the necessary therapeutic rapport had not been forged. Therapeutic interviewing is, however, possible in the research context; the lay chaplain divulged to me the fact that his aunt had recently had a stroke with resultant aphasia. However, therapeutic rapport within the research setting is needed in order for therapy to happen. I felt powerless when Amy asked me if she could go home, as if I were not a researcher but a member of hospital staff with influence to bear on her discharge date. Just being in a hospital setting made me feel I should be helping more. Friendship began to form between me and some participants. Amy introduced me to a fellow patient as her friend; at the end of our time together, I gave her a parting gift of a holding cross, thinking that, following our conversations about prayer, this might be a helpful adjunct to her prayer life. She invited me to visit her, once she was home from the hospital. Visiting Lindy again, it felt right to take her some flowers, as a friend would. Shared experience, history, faith or culture created relationship bonds; even something as simple as laughing about the antics of a cat with Peter allowed us to connect, as did looking at a symbol of the Trinity with Joel. Peter seemed at times to view me as therapist and divulged some intimate mental and physical health issues. Often participants responded to the final question (which always took the form of 'is there anything else you would like to talk about?') with a confidence; the lay chaplain shared his experiences of an aunt who had recently had a stroke, and the nurse spoke about the death of her grandmother. A lack of connection, or even therapeutic alliance, such as in the interview with Francesca, resulted in a less successful interaction, an interaction that became more like an interrogation – the antithesis of therapeutic. What difference did the ambiguity of relationship make to the research process? Were participants more or less likely to 'open up' to a researcher they regarded as a friend? Was friendship more likely to be forged because of the nature of the research subject? Was there something in my demeanour as interlocutor which spoke of therapy, or was it the subject matter of spirituality which had created in that space the permission to talk freely and candidly?

Moustakas (1994, p 39) speaks of the "enhancer" within the research environment, encouraging participants, in a quasi-therapeutic way, to communicate their thoughts and feelings. Perhaps this enhancer is a hybrid of researcher and therapist.

The members of the MDT seemed on the whole to be clear about their roles and identities within the team, both in terms of their normal duties, but also in terms of their remit vis à vis spirituality. The nurse is clear when a patient's communication difficulties necessitate discussion with the SLT, and also when emotional issues might best be addressed by the neuropsychologist. The OT, SLT, nurse and physiotherapist are all clear that the lay chaplain is the expert in spiritual matters, and the team member to whom they should refer:

“we quite often have the chaplains down here. We have a nice relationship with them, then quite often if people indicate that they would like to see them or that we... if someone has got aphasia we will ask them and we indicate somehow... there’s a nice team here.” (OT interview)

The chaplain is keen to explain his role to me, that it is not one of proselytising but that he is there to listen, not to preach or to pray – he will visit Christians and non-Christians alike.

Perhaps he often has to clarify this ambiguity for both staff and patients.

The majority of participants with aphasia did not see (or did not remember that they had seen) a chaplain whilst in hospital. Neither Lindy, a committed Catholic, nor Amy, a woman of faith, saw a chaplain after their stroke. I am struck after interviewing both a chaplain and an SLT that perhaps the one has the ministry skills, whilst the other has the facilitative skills; a sharing of expertise between team members may result in an increased confidence in lay chaplains to facilitate conversation with people with aphasia.

#### **5.2.4 Ambiguity and altered states of consciousness**

Confusion around the stroke event also seems to have created an atmosphere of ambiguity for some participants. Liam, for example, does not remember (or at least is not able to convey) what happened on the day of his stroke, other than “stroke people” banging on the door. David admits that he did not know what was happening to him as he had his stroke: “I had nothing. I did no idea”.

Altered states of consciousness that often surround the stroke event lent their own ambiguity to the participants’ stroke stories. David recounts that he was conscious during the trauma of the stroke happening:

D: No, erm...I remember it all. I wish it wasn’t

S: Do you? Right, so you weren’t unconscious at all?

D: No

S: Right, so you remember it all

but then his memory becomes hazy because the drugs he was on “make you feel really knocked out”. Lindy was conversely unconscious for three days, and during this time she saw graphic visions of angels and of her dead parents.

If, as McGilchrist (2010, p 115) posits, “whatever can’t be brought into focus and fixed, ceases to exist as far as the speaking hemisphere is concerned”, perhaps if the speaking hemisphere is

damaged and the so-called non-dominant hemisphere comes more into play, more nebulous, less “fixed” concepts are allowed to be entertained by the brain. During the interview, even Lindy herself appreciates the unlikeliness of the reality of these visions, or the identity of the beings depicted:

“....angels? (*questioning intonation*) I don’t know...um...um...God? (*questioning intonation*) I don’t know”

However, in a subsequent email, she is sure of their existence and identity:

“Angels: intense compassion and androgynous. The most real thing I have ever felt”.

Possible ambiguity of the existence of these visions is, for Lindy, clarified.

### **5.2.5 Windows of clarity**

Although ambiguity is a recurrent leitmotif in the stories, windows of absolute clarity also exist, and these are thrown into sharp relief by their contrast with the ambiguity. For example, most participants are able to give their definition of spirituality, and are often clear what it is and what it is not for them. David and Francesca, for example, are clear that spirituality for them is not about organised religion. It is the opposite for the two Christians, Lindy and Joel, who equate their spirituality with their faith tradition. Joel demonstrates a complete absence of ambiguity when I ask him what is important in his life, and he conveys this very successfully through emphatic intonation, gesture and repetition:

“Important is God (*lots of left hand gesturing and animated intonation*) other things, no...no God God God God (*emphatic*), so...”

There also exists a distinct clarity in the telling or retelling of the stroke story; the impression gained from asking the group 2 participants to tell me what happened to them is one of rehearsed or practised telling. In line with Frank’s (2013, p 53) view that “stories are a way of redrawing maps and finding new destinations” for people who have suffered or are suffering from illness, it is as if through the telling and retelling of the catastrophe, these participants are somehow able to start to make sense of what happened to them. Developing Frank’s (2013, p 53) wreckage analogy, it is as if telling the story of the illness anchors the storyteller as she navigates the chaos.

## 5.2.6 Ambiguity and liminality

The participants with aphasia have a pathology; an illness event has resulted in aphasia. Yet they continue to be thinking, feeling human beings, with all the desire and need to communicate that they possessed prior to the stroke. Therefore the normal/abnormal dichotomy is made null and void; people with pathology may have lost a route to communication but they have not lost the desire and need to communicate per se. With or without aphasia, participants struggle to convey the meaning of an abstract and personal concept such as spirituality; the ability to access language skills easily and barely with a second thought does not automatically allow for easy and fluent definitions of nebulous concepts. Areas of liminality existed, then, for all participants, yet these liminal places may prove to be areas of development:

“Undoing, dissolution, decomposition are accompanied by processes of growth, transformation, and the reformulation of old elements in new patterns” (Turner, 1964, p 49). Some participants occupied a liminal position between the shoreline of intelligibility and fluency, and the waters of not being understood. Within the conversations, that liminal space was filled by non-verbal attempts at communication, as well as listener intervention (prompt questions, use of artefacts, accepting demeanour). It seems in these interchanges that the liminal space is often occupied by both speaker and listener, both engaged in the pursuit of understanding and being understood:

“in a shared world, another human being can still see the intended direction and the goal of the entire movement, the meaning of the movement.” (Hjelmlink et al, 2007 p 95).

Participants in the study occupied various liminal spaces. Firstly, there were the physical ‘shorelines’, where participants found themselves stranded; Peter was semiconscious in his front garden for many hours before being discovered, and Francesca was unconscious in her bathroom for a day and a half before work colleagues raised the alarm. Lindy also reports occupying the physical liminal space of coma, in which she is visited by benevolent beings who bring her a sense of peace. Little wonder that in this hazy, blurred world, “meanings emerging from reflecting on lived experience are always ambiguous, enigmatic, and ultimately unfathomable.” (van Manen, 2016, p 42).

The word retrieval difficulties of all the participants with aphasia lend a liminal essence to our interactions; it is as if meaning is at the edge of the interchange, sometimes not fathomable. Consider this interaction with Rosemary:

S: You could walk to the sea?

R: Yeah

S: Ah that's good. Do you like the sea?

R: Yeah

S: Yeah

R: But...erm...wouldn't go too far away to (*unintelligible*)

S: Mm

R: So, er...

Her limited output, and my inability to facilitate, result in a hint of understanding of the essence of her meaning but no more. In contrast, being a wordsmith, and perhaps because she is further down the line of recovery, Lindy uses her gift gloriously to evoke her feelings in poetry, and to enable the reader/listener to catch a glimpse of her lifeworld:

“by each memory  
elusive brain,  
so much still

frustrating,  
me here  
limbo-land-aphasia” (Usher, 2011)

Here she conveys so eloquently and beautifully the intangibility of words and expression in the lifeworld of someone with aphasia; expression eludes her, and leaves her in a liminal space.

Just as loss of language creates a liminal space of misunderstanding, so, too, may grief and loss which can accompany stroke create a liminal space for some of the participants, partially cut off from the rest of the human race. This is perhaps illustrated best by the SLT's description of the man with a “grieving posture”, distanced from those around him by the severity of language difficulty and reflected in his physically distancing himself from others; he is described as being in a side room with the curtains drawn, the hood of his sweatshirt pulled up around his face. His is a liminal existence, where interaction with others is so difficult and the grief of loss of function so intense that he physically creates separation from the world.

Social liminality is also hinted at in some of the stories. The OT recognises the difficulty of ‘normal’ interaction with a person with aphasia, where traditional turn-taking and information sharing is not always possible: “it needs to be a two-way conversation and you can't do that with someone with aphasia”. I am struck, when going to visit Joel for the first time, by the fact

that he is unknown to his immediate neighbours, when I inadvertently knock on their door instead of his. This may of course be a reflection of post-modern lack of community and contact with neighbours, but it might also indicate the social isolation that can accompany language impairment.

Spirituality as a concept in the therapies may occupy a liminal space in the professional remit. Amongst the members of the MDT, opinions varied as to how much spirituality did or should be addressed with patients within clinical sessions. All the professionals interviewed agreed they would be willing and able to discuss some issues related to spirituality with their clients. The SLT felt able to address spiritual or existential issues “between the technical bits”; these sensitive discussions were able to take place around other (more traditional?) SLT procedures such as an oral examination, helped in part, she says, by having time and being in close physical proximity.

The physiotherapist was the most vocal about not wanting to overstep the mark. He was also concerned about being sensitive to individuals’ religion and mores, especially if he knew little about them, and he was cognisant of Trust policy and procedure and was anxious not to infringe these. However, like his OT, SLT and nurse colleagues, he is holistic in his approach and recognises that impairment and disability may not be just in relation to the body, that “there is more to healing than the biomedical” (SLT interview). Just as other MDT members see spirituality as part of their input (albeit on the periphery at times), the lay chaplain sees his spiritual input as also benefitting mind and body. For him, a client’s physical and psychological health is on the liminal edge of his mainly spiritual intervention.

Merleau-Ponty’s concept of ambiguity in the lived world, then, is certainly reflected in both the stories of the people with aphasia and of the multidisciplinary team, and is also present in the liminal spaces identified.

### **5.3 Thought and language**

Merleau-Ponty’s understanding of aphasia may be disputed somewhat by modern aphasiologists and speech and language therapists. He posits that the person with aphasia has lost “the manner of using words” (Landes, 2013), which in the cognitive neuropsychological era of the post-1980s may seem a simplistic stance. However, his particular theory of aphasia also perhaps helps us to appreciate his understanding of thought and language, why thought might “tend[s] towards language as to its completion” (Merleau-Ponty, 2002, p 206). For Merleau-Ponty, language “is not the ‘sign’ of thought, if by this we understand a phenomenon which

heralds another as smoke betrays fire” (Merleau-Ponty, 2002, p 211); my understanding of this is that language is not just a physiological representation of a person’s thought. Rather, that language – and perhaps communication in general – is an imperfect representation of our thoughts, open to interpretation, temporality and nuance, perhaps even more so in the individual with disrupted language skills:

“there are no conventional signs, standing as the simple notation of a thought: pure and clear in itself, there are only words into which the history of the whole language is compressed, and which effect communication with no absolute guarantee, dogged as they are by incredible linguistic hazards.” (Merleau-Ponty, 2002, p 218).

So it would appear for Merleau-Ponty that there is no one perfect language, comprising words which convey perfectly the meaning for every object or every experience of the human condition. Rather, language is imperfect, as we stutter to convey our thoughts and feelings; whether one has aphasia or not, expression of concepts is not always precise.

However, Merleau-Ponty (2002, p 206) also posits that thought is somehow incomplete or unrealised if not put into language:

“A thought limited to existing for itself independently of the constraints of speech and communication, would no sooner appear than it would sink into the unconscious, which means that it would not exist even for itself.”

It is as if the act of speaking or formulating language solidifies the notion and realises it. For people with aphasia, this concept is problematic. People with aphasia continue to function as cognate, intelligent individuals. As can be seen from the stories, they convey complex ideas, thoughts and feelings. Fedorenko and Varley (2016) showed through complex experiments and neuroimaging that cognitive function such as arithmetic processing, logical reasoning, theory of mind, music processing and spatial navigation can all take place separately from linguistic processing. They cite examples of people with severe global aphasia post-stroke still being able to play chess or compose music. It is clear, then, that other cognitive processes can and do take place separately from language. However, it seems possible that “language resources may often be deployed to scaffold performance on a range of problems without being a mandatory component of that reasoning” (Varley, 2014, p 242), so that cognitive tasks may somehow be completed or realised through language. In philosophical terms, Merleau-Ponty’s point seems to be that our thoughts are not properly formed or complete until conveyed via language to another.

Is it possible that Merleau-Ponty means communication, when he uses the word ‘language’ or ‘speech’? Is he in fact surmising that in order to give life to our thoughts, they need somehow to be moulded into some form of expression, ready to be received by another? “The word bears the meaning” for Merleau-Ponty (2002, p 206), but, as the stories show us, words are

not only confined to spoken language. Lindy uses the written word, Peter uses gesture, and so on. It is incumbent upon the listener to facilitate this conversion of thought into expression. This is the imperative of the communication partner, to coax clarity of expression from the ambiguity of thought.

Merleau-Ponty's philosophy, therefore, explores the idea that language and thought, though related ("as smoke betrays fire" (Merleau-Ponty, 2002, p 211)), are different. The word conveys the meaning of the thought but has no intrinsic meaning of its own. Words in and of themselves do not have the power of expression; rather, they are the system of transport from mind/thought to the other:

"The word is still bereft of any effectiveness of its own, this time because it is only the external sign of an internal recognition" (Merleau-Ponty, 2002 p 205).

Words become redolent with meaning, as they are habitually used, but the sequence of phonemes in the word do not of themselves convey meaning. There is no inherent 'catness' in the sequence of phonemes /kæt/. McGilchrist (2010, p 119) disagrees, citing the "kiki/ bouba effect ('kiki' suggesting a spiky-shaped object, where 'bouba' suggests a softly rounded object)". He posits that words are "not arbitrary but evocative, in a synaesthetic way, of the experience of the things they refer to." I would suggest a middle ground, where depending on their etymology, some words will have no intrinsic evocation of their meaning, whereas others possess a sort of onomatopoeia.

It seems to me that Merleau-Ponty's philosophy regarding thought and language has great import for people with aphasia, for whom words can become elusive. If "the word is not the bearer of its own meaning, has no inner power" (Merleau-Ponty, 2002, p 205), then the person with aphasia can be acknowledged as a still thinking being, and the onus is on the listener to hear their thoughts, however they may be conveyed, whether verbally or non-verbally.

Listening to the stories of people with aphasia – told through some spoken words but also gesture, intonation, writing and artefacts – can be seen as one way of enabling them to bring their thoughts into existence. Merleau-Ponty (2002, p 206) says, "language is but an external accompaniment of thought", just as gesture may be. "Speech accomplishes thought" (p 174) he also posits, implying that in order for the thought to be properly defined it must be expressed in some way.

This journey of thought through expression is a treacherous one, where words may be misconstrued and messages therefore misunderstood. This is true of the language skills of someone with no pathology, but has particular resonance in terms of understanding the thoughts of those with aphasia.

In unimpaired language then, thought is only imperfectly reflected or conveyed. Likewise, in aphasic language, thought is potentially conveyed imperfectly, with the listener needing to employ facilitation and interpretation.

Many participants, such as Francesca, for example, show latency of response. This may of course be a facet of her impaired language skills; she is struggling to find the correct words, and to construct the correct syntax. It might also, however, be a reflection of reduced clarity of thought, which because of its haziness cannot be brought to realisation via expression.

Some participants intimate that automatic speech is relatively preserved; Lindy gives conflicting information (or I have heard it as such) about her ability to say familiar, over-learned liturgy, but she does say at one point that she is still able to recite the Hail Mary and the Lord's Prayer, prayers that she would doubtlessly have learnt as a young child and have continued to recite throughout her life before the stroke:

S: Yes, OK, so things like...um...things that you would have learnt at an early age, I presume, like the Hail Mary or the Our Father

L: Oh, yes (*emphatic intonation*)

S: Do you remember those? Can you recite those now?

L: Oh, yes

S: OK so they're quite...almost automatic

L: Yeah

S: So they still come out fluently?

L: Yes

S: Right. That's really interesting

L: Yes

S: And what about hymns and songs?

L: [sim] no. Hymn no, no

S: Perhaps not as familiar as...

L: No

S: Or maybe there's something about those really familiar prayers like the Hail Mary that you've said so many times in the past become ingrained almost

L: Yes, yes

An ability to recite the Lord's Prayer or the Hail Mary, for example, would chime with the right hemisphere's apparent ability to produce automatic speech (Ferryhough, 2016, p 173). This ability arguably bypasses the thought process; one does not necessarily need to think about what one is saying. This contrasts with Lindy's ability to pray without words when she is with

God in nature; she has a direct link to God which does not involve speech but does involve thought, in the form of prayer:

S: So, were you able to pray?

L: No (*with intonation of puzzlement*) no, um...the...God...here (*points to head*)

S: Yeah

L: Faith yes, yes

S: So there were no words needed but...

L: Yes

S: Was there a connection to God?

L: Yes

S: But without prayer necessarily

L: Yes

S: OK, yes, that's interesting. And what about...um...praying now? Is that something – I don't know whether you can answer this or whether I should be asking it but is that something you do in words...praying?

L: No

S: Right

L: Me...um...walking the fields and God um...angels or God ...um, oh, God...it's peaceful

S: Yeah

L: Peaceful

S: Peaceful, yes. So, it's praying without words. Would you describe it as that?

L: Yes

Similarly, she is not able to take part in confession, as this would necessitate complex and lengthy novel expression, rather than automatic speech. Presumably she is able to think about her sins but is not able to voice them.

Joel, too, is cued in to very familiar liturgy, so that showing him a communion wafer prompts not only the contextually-related word 'blood', but also the associated liturgical reference:

J: Blood, yeah

S: Yeah

J: Drink

S: Yep

J: In remembrance of me

However, the automatic speech and the thought or concept are surely linked in this example.

Thought is definitely “realised” or “completed” by conveyance, inasmuch as it is heard or perceived by another and it therefore has existence outside of the thinker. Despite Merleau-Ponty’s notion that it is *speech* that “accomplishes thought” (2002, p 174), however, my contention is that expression of thought via any modality realises it in the same way. Take, for example, Lindy’s description of her experience whilst in coma. Using speech augmented by gesture, nodding, intonation, facial expression and writing, she is able to convey a complex array of ideas about emotion, death, beauty, Satan, God and visions:

L: Yes...um...angels

S: Uhuh

L: Um...joy...um...me...er...dying

S: Uhuh

L: Um...(writes)...er three days coma

S: Yeah

L: Yes...er...beautiful (*intonation – simply beautiful – what more can I say*)

S: Beautiful vision, or feeling, or...

L: No...er...beautiful (*gesture of hand sweeping*)...um...beautiful (*nods*) yes

S: So when you woke up...

L: (*nods*)

S: You had that feeling of beauty and...

L: No...um crying

S: Right

L: All the time crying (*gesture*) um...um...l...um...um...um...weeping...I don’t know...I don’t know (*gesture with left hand and intonation/ facial expression*)...um...um...um (*writes*)

S: (*after reading what L has written*) So that was the 4th day?

L: Yes

S: You woke up weeping?

L: Yes yes...um um um um (*starts to write*) Satan...or...um...God...um (*tries to write again*) the one (*gestures with left hand as if using a scythe*) um...death

S: Yeah

L: [s] death...er...um...Oh God

Members of the multidisciplinary team instinctively understand how to nurture this conveyance of ideas. The nurse talks about getting to know her patients, so that she can

understand their preferences better. The OT says that she and other members of the MDT are particularly attuned to listening to people with aphasia:

“we have to be more perceptive I think with people with aphasia, yeah, if they can’t communicate to talk to you, and when they are trying desperately to tell you something...I think there is a real skill in actually reading that person” (OT interview)

The OT, lay chaplain and the SLT identify time as one of the key elements in enabling people with aphasia to express their ideas and thoughts.

There are several examples throughout the interviews with the MDT which suggest that team members assume their clients with aphasia are still thinking, possibly in language, but are struggling to convey this via speech. This is exemplified by the OT, who says:

“and yet we are expecting this person who can’t verbalise to us, to go and sit in front of a sink and they are probably going ‘I don’t do this at home, I go in there, that shower over there,’ and sometimes that’s when their frustrations can come in because they can’t say to us... they can indicate to us” (OT interview).

The nurse identifies the frustration which so often accompanies expressive aphasia; the client knows what they want to say but is unable to find the words:

“You can see it more in the frustration, and we have had a few patients where they can’t express things and they just get more angry and uptight and you can see their frustration” (Nurse interview)

The physiotherapist interestingly alludes to patients with whom he has worked who have had transient ischaemic attacks resulting in aphasia:

“Because that’s also important because if I heard it is a mini-stroke, I can’t communicate, or I am having difficulties and I am worried during that time ‘Am I going to survive this? And if I am going to give an effort, how long is it going to take me, and will it be worthwhile? And all those things are going through their minds but no essentially, it’s only when they recover that they start telling you backwards how it was and I find that quite interesting” (Physiotherapist interview).

He implies that these patients, who temporarily lost their language, report their thought processes once their language skills return. This stance is supported by the report of a

nineteenth century professor of physiology cited by McGilchrist (2010, p 109) who suffered an aphasic episode from which he recovered: “*the thought was all ready*, but the sounds that had to express it as intermediary were no longer at my disposition...I was unable to accept...the theory that verbal signs are necessary, even indispensable for thought.”

The SLT is adept at starting to read the non-verbal conveyance of thought:

“Definitely, even from the time.... It's funny you should say that, I mean as soon as you see a person it speaks volumes, you know, ‘Are they out in a chair and engaged and looking around?’ ‘Are they ... do they have a grieving body posture?’ ‘What is their facial expression like?’ You know, that starts... I would have to say that starts the moment you see a person.” (SLT interview)

This contrasts sharply with the lay chaplain’s rather dismissive attitude to patients who are unable to communicate with him via speech:

“But some I...you get that blank look and so you say ‘well thank you very much, I am happy to be here with you but as we cannot communicate I will say a prayer and I will move on’” (Lay chaplain interview).

It is clear, then, that humans do not need lexical items or intact syntax in order to think and perform other cognitive functions. Whether people with aphasia are still able to produce the “inner speech” of thought with which most of us are familiar remains a moot point (Ferryhough, 2016), but the fact that their powers of thought survive is indisputable:

“language is necessary neither for categorisation, nor for reasoning, nor for concept formation, nor perception” (McGilchrist, 2010, p 110).

How much more important that listeners to the stories of people with aphasia – stories about spirituality or of other issues – use every facilitation and support technique at their disposal? Merleau-Ponty had much to say about the nature of thought and language, and I have attempted to see the stories of the people with aphasia in relation to this. Do we think in language? How do people with impaired language skills think? Does aphasia affect the person’s ability to think, or does the non-dominant hemisphere (and its language areas) take over from the left, allowing the person with aphasia to think, but maybe think differently, with the “speaking hemisphere” silenced and the “master” hemisphere in charge (McGilchrist, 2010).

As previously discussed, Merleau-Ponty intimated that thought was realised by its expression. He talks about “speech” accomplishing thought, but I would like to contend that he is using the term ‘speech’ to suggest expression, be that spoken language, writing, gesture, sign language or any other non-verbal method.

## 5.4 Wonder

A phenomenological approach to shedding light on the subject of spirituality with people with aphasia demands a researcher stance of wonder, curiosity, awe and openness (Finlay, 2011, p 230; van Manen, 2016, p 36). To enter into phenomenological dialogue is to expose oneself as researcher to the essence of that lived experience, as told by the participant. In the “bountiful world of phenomenology” (Crotty, 1998 p 85) there is ample scope for wonder; within the accepting space of the research interview, fascinating insights were gained.

Through phenomenology, says van Manen (2016, p 31), “an ordinary experience may suddenly appear quite extraordinary: we become aware of the phenomenal phenomenality of a phenomenon!”. It is through adopting a “phenomenological attitude” (van Manen, 2016, p 32), of openness, curiosity and acceptance that we discover the wonder of what is being shown to us. Van Manen (2016, p 38) suggests that “any ordinary experience tends to become quite extraordinary when we lift it up from our daily existence and hold it with our phenomenological gaze.” In order to be fully present with the other, we need to listen and look and perceive them in an attitude of curiosity and wonder. In order to be fully present with the participants, I had to listen attentively with this phenomenological attitude. This tallies with Gadamer’s (2013, p 316) idea of horizons fusing; as I listened to the other, I attempted to acknowledge my own horizons, full of my fore-meanings, whilst meeting the horizon of my interlocutor with interest and awe. This is the naïve wonder of the phenomenological attitude, as opposed to the natural attitude (Finlay, 2011, p 47; van Manen, 2016, p 34), where opinions and stances have already been created. In phenomenological inquiry, we are open to novelty and new ways of seeing (Dorfman, 2005).

Merleau-Ponty likens phenomenology to art in its inquisitiveness and attention to detail: “phenomenology...is as painstaking as the works of Balzac, Proust, Valéry or Cézanne – by reason of the same kind of attentiveness and wonder” (2002, p xxiv).

He discusses Cézanne wanting to paint the white, snow-like table cloth described poetically, using simile, by Balzac. Cézanne knows he must not paint using the poetic images evoked by Balzac, but rather what is actually there; not the freshly fallen snow but the “napkins and rolls as they really are” (Merleau-Ponty, 2005, p 230).

The task in listening to the spiritual stories was to be open to what was being communicated, not hearing them through a filter of what I might have expected or what I thought might be conveyed. It was not difficult to be awestruck as researcher when listening to the stories. Both what the participants told me and the manner in which they did so often left me humbled. Such is the power of phenomenological research and “reflective wonder” (Hinckley, 2013, p 93) of new horizons being explored.

Merleau-Ponty’s method of achieving openness comes back to a certain extent to the reduction, and his and our ability to see phenomenon afresh, without the encumbrance of prior experience, belief or culture:

“in order to see the world and grasp it as paradoxical, we must break with our familiar acceptance of it” (Merleau-Ponty, 2002, p xv).

Members of the multidisciplinary team adopted a therapeutic “phenomenological attitude” within their work which is evident in how they described their encounters with patients with aphasia. The OT, for example, is curious about her clients and anxious to get to know them as much as she can in order to tailor her management. She inwardly asks “who are you?” when she meets a patient and strives to understand who they are, above and beyond a patient who has just had a stroke:

“we not only go in and go ‘Oh look, you’ve have had a stroke’ we go ‘OK, so what did you do before you had a stroke, who are you?’ you know, so it’s about them as a person, not just well you’re that patient that’s had a stroke, so you have got all this information.” (OT interview)

Her eagerness to communicate with people with aphasia is also reflected in her curiosity regarding total communication strategies and her willingness to employ them:

“quite often would use picture cards to try and communicate or communication boards to try and help with that” (OT interview)

The SLT also views her clients with a “phenomenological gaze” (van Manen, 2016, p 38), perhaps exemplified in her explaining to her clients that “you matter” and “I am a pair of ears”. For her, therapy is “sacred work”, an “act of kindness”.

A sense of wonder is evident in many of the aphasia stories, too, and is expressed in various ways by the participants. Lindy’s poetry illustrates this wonder beautifully and succinctly:

*“‘Happiness’,*

*I, sampling the word,*

happy-in-ness.” (Usher, 2011)

This speaks of being open to newness, to the novelty that old, well-used words have now become in her new world of aphasia. Merleau-Ponty (2002, p 174) understands the use of poetry as a means of expressing wonder:

“the poem uses language, and even a particular language, in such a way that the existential modulation, instead of being dissipated at the very instant of its expression, finds in poetic art a means of making itself eternal.”

He contrasts the use of poetry with non-verbal communicative methods such as intonation. Intonation, he posits, “no longer reveal[s] the speaker’s thoughts but the source of his thoughts”. Poetry, it seems, is between this and day-to-day speech or narrative, in that it expresses deep emotion but is more lasting than a non-verbal cry or sigh.

According to McGilchrist (2010, p 177), the right hemisphere of the brain’s understanding of the world includes “empathy and intersubjectivity...the importance of an open, patient attention to the world, as opposed to a wilful, grasping attention; the implicit or hidden nature of truth...the primacy of perception...creativity as an unveiling (no-saying) process”. People with a damaged left hemisphere, in which their language skills resided pre-stroke, perhaps make more use of this right hemisphere understanding of the world.

As well as poetry, Lindy uses non-verbal communication during our discussions in order to convey a sense of wonder. In particular, she conveys the wonder of the beings which revealed themselves to her in visions during coma, using facial expression and intonation to augment her speech:

L: Um...joy...um...me...er...dying

S: Uhuh

L: Um...(writes)...er three days coma

S: Yeah

L: Yes...er...beautiful (*intonation = what more can I say*)

She also expresses a religious awe of her God, using speech and intonation:

“Me...um...walking the fields and God um...angels or God ...um, oh, God...it’s peaceful”

Joel’s sense of wonder is also rooted in his religious belief, and it is his intonation above all that conveys this sense of awe. Peter’s sense of wonder is evinced by his garden; his language becomes more fluent as he talks about (and gestures about) hoeing and weeding and grafting.

## 5.5 Lived body and the body as expression

Heidegger (1962, p 27) propounded the concept of “Dasein”, and believed that we are bodies in the world (just as for Husserl, we are ‘being-in-the-world’), experiencing and perceiving phenomena. Husserl urged us to go straight to the things themselves (“zu den Sachen selbst”) (Lewis and Staehler, 2010, p 5; Finlay, 2011, p 3) in order to understand them. In order to go directly to the things themselves, we have to experience them, to perceive them. For Merleau-Ponty (1964, p 160), we have a ‘lived body’ that interacts with the world in order to perceive and be perceived:

“that actual body I call mine, this sentinel standing quietly at the command of my words and my acts.”

Merleau-Ponty’s (1964, p 163) definition of this body is one which chimes with the concept of tripartite being, or a person comprising body, mind and spirit:

“The body’s animation is not the assemblage or juxtaposition of its parts. Nor is it a question of a mind or spirit coming down from somewhere else into an automaton; this would still suppose that the body itself is without an inside and without a “self”. There is a human body when, between the seeing and the seen, between touching and the touched, between one eye and the other, between hand and hand, a blending of some sort takes place.”

The body is more than just a physical body; there exists a perfect amalgam of perceived and perceiving body, which Merleau-Ponty (1964, p 163) astutely recognises may be disturbed by illness or disability:

“when the spark is lit between sensing and sensible, lighting the fire that will not stop burning until some accident of the body will undo what no accident would have sufficed to do...”

For the people in this study with aphasia, this (cerebrovascular) “accident” has occurred, and they are striving to join together again the constituent parts of this lived body by using their total communication or Mosaic (Clark, 2001) strategies.

For Merleau-Ponty, to understand the environment we need to interact with the environment. In order to interact we need to both perceive and be perceived; he gives the famous example of a hand touching whilst simultaneously being touched. This could be seen as analogous to speaking and *being heard*, to being both storyteller and story-listener. In order truly to listen to a story, we must be perceptive, willing to see and hear communication in all its forms.

Merleau-Ponty suggests that we are able to perceive and communicate by using our whole lived body as expression. This philosophical premise also finds credence in the established speech and language therapy strategy of total communication, Frank’s idea of the “communicative body” (Frank, 2013, p 29), and the Mosaic approach (Clark, 2001). People with aphasia use all forms of verbal and non-verbal communication in order to convey their

message, whilst the listener perceives and acknowledges those attempts. Both Merleau-Ponty and Frank, then, appreciate that communication is not only verbal in form, but can, or indeed should, employ the body, too. Similarly, Clark's (2001) Mosaic approach propounds the use of any and all forms of communication to get a message across.

Participants in group 1 were less able to make use of these non-verbal communication techniques (such as gesture and writing) than those in group 2. One may surmise that they had had less chance to develop and practise non-verbal strategies, and there may have also been a reluctance on their part to relinquish attempts at the verbal so early on in the rehabilitation process. The hospital setting, too, was less conducive to these communication methods; it is physically difficult to use pen and paper when you are either in bed or poorly-positioned in a hospital chair. Strategies that were less reliant on props were used more with these participants; Rosemary, for example, made good use of intonation and laughter.

Participants in group 2, however, who were that much further down the rehabilitation path, were in the main adept at using their body as expression (such as gesture, intonation and facial expression) and other non-speech communication methods (such as writing key words, referring to objects).

Lindy used writing throughout her conversations with me, and supplemented these with emails, poems and Facebook messages. Joel often reached for his well-used Bible and used this to communicate specific religious ideas through selecting relevant verses. Peter used gesture to supplement his speech, and Francesca was adept at creating meaning by using words augmented by intonation, and gesture. David was the least likely of group 2 to employ total communication strategies; his Mosaic mostly comprised spoken words only. This may be a reflection of the relative recency of his stroke compared to others in group 2.

For Merleau-Ponty (2002, p 210), speech is "one of the possible uses of my body"; he uses speech as one way in which his body can interact with Husserl's *Lebenswelt* ('lifeworld') (Lewis and Staehler, 2010, p 34). However, it is not the only one. For him, there is authenticity in the expression derived via non-verbal means:

"One can see what there is in common between the gesture and its meaning, for example in the case of emotional expression and the emotions themselves: the smile, the relaxed face, gaiety of gesture really have in them the rhythm of action, the mode of being in the world which are joy itself." (Merleau-Ponty, 2002, p 217).

He contrasts the inherent meaning contained within non-verbal communication (facial expression, gesture), with the apparent arbitrariness of word labels:

"is not the link between the verbal sign and its meaning quite accidental?" (Merleau-Ponty, 2002, p 217)

Picture Lindy in your mind's eye demonstrating with her hand at various levels to the ground how, after her stroke she felt like a small child again: or hear the sigh which accompanies Joel's explanation that the stroke happened suddenly whilst he was driving:

J: and (*sighs*)...sudden...sudden

and one begins to appreciate Merleau-Ponty's point, that gesture and intonation can carry meaning as much as words can, in fact possibly more effectively.

Perhaps this vindicates and validates the use of non-verbal communication as the primary method of communication for people with aphasia; there is an innate authenticity to their expression.

Just as for Merleau-Ponty, the body can be the bearer of meaning, so Frank (2013) also emphasises the body's role in expressing meaning. He talks about a "communicative body" that "transcends the verbal." (p 49).

An extension of Merleau-Ponty's body as expression (2002, p 210) and Frank's communicative body (2013, p 49) may be the therapeutic method of total communication. People with aphasia – including the participants in this study – are encouraged to use all communicative methods at their disposal, be it gesture, drawing, writing key words, intonation, facial expression. All of these communication methods are used to a greater or lesser extent by the participants with aphasia, often very successfully to convey complex, abstract and numinous concepts. Total communication embraces Merleau-Ponty's (2002, p 230) concept of "the miracle of expression", and becomes an extension to the lived body. Just as the white stick of a blind person or a car to improve mobility may be regarded as an extension of self and body, so Lindy's pen and paper, or Joel's Bible may be regarded as extensions to their selfhood and expressive abilities:

"the automobile and the cane are no longer external objects for their possessors, but extensions of their bodies that have been incorporated into their bodily space. In driving or in walking with the cane, the wings of the car and the end of the cane have come to mark the boundaries between the embodied self and its world." (Lewis and Staehler, 2010, p 165).

In her article looking at the lived experiences of people closely related to someone with aphasia, Nyström (2011, p 7) discusses how relatives and carers become "an extension of the aphasic person's body and mind", thereby inadvertently contributing to the person with aphasia's feelings of loss of identity. The relative assumes new roles which may have at one time been the remit of the person with aphasia, or they may, with the best of intentions, speak for their relative, or supply missing words. Thus, people as well as objects may become extensions to our lived bodies, whether desired or not.

For Merleau-Ponty (2002, p 230) then, there is an “immanent or incipient significance in the living body”, a significance which can augment the expression of speech and result in conveyance of information, feelings and concepts that goes beyond the verbal. For him, there exist “several ways for the human body to sing the world’s praises and in the last resort to live in it.” (Merleau-Ponty, 2002, p 218).

Using the principles of the lived body being able to communicate in ways other than speech, participants were treated as expert voices, as competent, valued members of the research process, contributing to knowledge created. In terms of expressing spirituality, it is clear from the stories and from the methods used to tell these stories, that people with aphasia are able to express their spiritual needs, distress and well-being through multifarious and effective means.

## **5.6 Conclusion**

Frank’s illness narratives and Merleau-Ponty’s philosophy regarding ambiguity, thought and language, wonder and lived body, have provided a framework on which to view the stories of spirituality. Frank’s chaos narrative may be seen as illustrative of Merleau-Ponty’s ambiguity; participants living a chaos narrative demonstrated ambiguity of role, identity and language. As they approached or attained a quest narrative, participants were more able to realise their thoughts through myriad mosaics of communication, including use of what Merleau-Ponty termed “lived body” (2002, p 210), and what Frank (2013, p 49) called “communicative body”. Healthcare professionals demonstrated in their stories how a sense of wonder (Merleau-Ponty, 2002, p xxiv; Finlay, 2011, p 230; van Manen, 2016, p 13) allowed them to be open and curious about their patients’ spiritual stories. Being able to analyse some of the issues related to talking to people with aphasia about spirituality in this way has helped me to understand the stories, and also to consider possible ways of addressing spirituality with people with aphasia.

What follows is a final discussion, where I summarise the findings of this study and contemplate possible implications for clinical practice in speech and language therapy.

## Chapter 6: Discussion

**“ Phenomenology...enthrals us with insights into the enigmas of life as we experience it – the world as it gives and reveals itself to the wondering gaze”**

**(van Manen, 2017, p 779)**

In this final chapter, I will look again at the original questions asked and consider how these have been answered through the research. I will also summarise new knowledge gained about spirituality and people with aphasia, including ideas for how, when and if to talk about spirituality with our clients with aphasia. I will discuss practical implications for further developments of the topic, including recommendations for stakeholders such as commissioners of SLT services, and higher education institutions that teach SLT student practitioners. Finally, I will evaluate the research and explore ways in which this research may be developed in the future.

### 6.1 Introduction

Patient-centred care (Koubel and Bungay, 2008) – or relationship-centred care (Dewar and Nolan, 2013) – hinges on the ability of healthcare professionals to care for the whole person. Personhood may be viewed as tripartite in nature, comprising body, mind and spirit (Frankl, 2011, p 34; Narayanasamy, 2010, p 38). We may be relatively secure in what we mean by body (being the physical) and mind (being the psychological), but by contrast definitions of spirit and spirituality are multifarious, not just in the health literature but in general. This inability to be definitively defined, however, has not stopped a rich array of studies related to spirituality in healthcare appearing over the last thirty years. Indeed, it is perhaps this very “vagueness” (Swinton and Pattison, 2010) which lends the term its power. Nursing leads the way in terms of literature pertaining to spirituality and the nurse’s role, with the therapies – particularly speech and language therapy – lagging behind.

Although they consider themselves to be holistic practitioners, speech and language therapists rarely, if ever, consider the spiritual aspect of their clients (MacKenzie, 2015, p 132). Despite this, it is generally recognised that people undergoing serious illness or dealing with disability may benefit from being able to voice their existential questions (Burke and Neimeyer, 2012, p 127), that this telling of the illness narrative may actually lead to increased healing (Koenig, 2012) or an enhanced ability to come to terms with a change in function, or, to use Frank’s (2013) typology, to enter the quest narrative. What is it like to do this if you have aphasia? What is the lived experience of the stroke multidisciplinary team working with people with

aphasia, when discussing spirituality? The stories of spirituality give an essence of this, and as part of the gathering of these stories, I asked each participant what spirituality meant for them.

## **6.2 What is spirituality?: the perspective of the people with aphasia**

The participants' stories show that spirituality is a personal and unique experience for each individual, and is experienced differently by each person. This chimes with the definitions of spirituality first discussed in chapter one, and bears testament to the usefulness of a "vague" definition of spirituality (Swinton and Pattison, 2010) also proving "useful" when talking to people with aphasia.

All the participants (except Rosemary) in the study were able to give some form of definition of spirituality, or give the essence of what gives their life meaning, either through speech, or speech augmented by non-verbal means. For Joel, spirituality equated fully with his religious belief, and Amy, similarly, relates her definition of spirituality to religious practice.

For Lindy, also a practising Christian, her spirituality encompasses both God and nature, and she intimates that the act of walking in nature also has a positive effect on her physical wellbeing in terms of her neurology. The concept of spirituality does not resonate for Peter, but as soon as I talk about meaning and purpose, he is unequivocal, and he, too, relates this to nature in the form of his garden. David's thoughts on spirituality encompass both religious ideas but also positive qualities not necessarily related to religion. Life-meaning and purpose are exemplified in his being a father.

Although the relationship with her parents is alluded to several times within the conversation, Francesca's definition is far more general and all-encompassing and, because of her obvious love of the arts, and her erudition, I wonder if this is in fact her definition of spirituality, or whether her aphasia is limiting her ability to convey what spirituality means for her.

Liam does not respond at all when I ask the question 'what does spirituality mean to you?' As discussed in his story, this may have been related to the busyness and noisiness of the environment, or to the fact that he was unable to contemplate questions of such an abstract nature, when his basic needs were barely being met. He does, however, tell me that both his cat and sport are important meaning-makers in his life.

All these ideas of what constitutes spirituality resonate with Swinton's (2010, p 19) definition of "meaning, purpose, value, hope and love", as well as with Frankl's (2004, p 49) notion that relationship and love are integral to spirituality and spiritual freedom. They also illustrate the contention posited at the beginning of the thesis, that spirituality may encompass religion, but may also be separate from it (Egan et al, 2011, p 3).

### **6.3 What is spirituality?: the perspective of the multidisciplinary team**

The members of the multidisciplinary team were more likely than the participants with aphasia to mention religion in their definitions of spirituality. The lay chaplain's definition is predictably Bible-based, and completely rooted in his religious beliefs. The physiotherapist also begins his definition with religion, but then broadens this out to incorporate ideas about connections between the past and the future. The occupational therapist also immediately begins to talk about religion but then in a characteristically holistic way, she explains how a definition of spirituality can be very broad and mean many different things to many different people. The speech and language therapist considers other possible definitions of spirituality before mentioning religion, and, like Vanier (1999, p 97) she also believes it to be an integral facet of humanness. Of all the MDT members, only the nurse does not explicitly mention religion in her ideas of what constitutes spirituality. That said, she is very aware of her remit in terms of responding to patients' and families' religious needs, for example referring to the chaplaincy team.

There was clear understanding amongst group 3 participants that spirituality, although encompassing religious beliefs, was not confined to religion and faith; this reflects the literature, where spirituality may be seen as multiperspectival in nature, including the religious, but also the generic (pertaining to the "human universal" (Swinton, 2010, p 19)) and biological (Swinton, 2010, p 21). All professionals were cognisant of the need to treat the whole person in a client-centred way, and were therefore very open to include the spiritual.

Although all the MDT members expressed a willingness to engage in spiritual conversations with their clients with aphasia, speech and language therapists are one of the best-placed healthcare professionals to help those with communication impairment to express their spirituality because of their skills and training in facilitation and listening skills. People with aphasia can become adept at the use of so-called total communication, creating communicative "Mosaics" (Clark, 2001) in order to convey concepts, thoughts and feelings. Despite living with an altered communication method, people with aphasia are often able to engage in in-depth and meaningful discussions around spirituality through these Mosaics of words, pictures, objects and gestures.

Interviewing various members of the multidisciplinary stroke team provided a unique insight into how these professionals viewed their role, and how spirituality entered their work. None of the five professionals dismissed spirituality as unrelated to their day-to-day clinical work; I was surprised by the ease with which they spoke about their own spirituality and that of their patients.

All members of the team bar the lay chaplain describe the physical proximity necessary in the care of the patients as being conducive to sensitive issues being discussed. This then engenders a relationship where other sensitive and personal issues may be brought to the fore.

Getting to know the patient fully is highlighted by the occupational therapist, and this includes knowing about all aspects of them. The SLT, too, focusses on identity, both on how identity can be stripped away by a stroke but also on how a good therapeutic relationship can acknowledge and bolster a sense of identity. If we accept that spirituality is an intrinsic aspect of identity, these healthcare professionals are appreciating that aspect of their tripartite clients.

Similarly, the NHS core values of dignity and respect (NHS England) are upheld by the healthcare professionals' attitude to caring for the whole person. A person's dignity is maintained by recognition and appreciation of their personhood; that personhood comprises all of what it means to be fully human.

Time is identified by the OT and the SLT as vital to having in-depth conversations about personal and sensitive issues such as spirituality. They recognise that within their remit there is time to explore other issues. This luxury is sadly often denied the nurse; it is in the busyness of the clinical day that the biomedical model of care reasserts itself, as targets must be met and outcomes proven.

In line with Mathisen et al's (2015, p 2318) opinion on the importance of recognising and taking into account clients' spiritual needs, team members were cognisant of making therapy relevant and avoiding its becoming "superficial by not including religious or spiritual beliefs". Having listened to the stories of, in particular, Joel, Lindy, David and Peter in group 2, one begins to recognise how intrinsic spirituality is to the individuals' lives, and how ignoring this in the therapy room could be detrimental to overall, holistic care.

The OT explains how she and the other professionals on the stroke unit are particularly perceptive when it comes to communicating with people after stroke, especially those with reduced language skills. Without this facilitative help, Mathisen et al's (2015, p 2318) concept of clients not being able to access meaningful spiritual resources or practices which may help with the "restorative, healing or educational processes that would enhance or sustain therapy goals" may be realised.

As well as providing the therapeutic environment to discuss spiritual concerns by giving time, being a listening ear, and being involved with other personal aspects of care, the MDT members recognised their role as one of facilitating discussion between the patient and 'spiritual professional', such as the chaplain. The SLT described facilitating conversations between the client with aphasia and visiting priests, and the OT and nurse both describe referring patients on to chaplaincy once spiritual needs have been identified. The nurse

interestingly mentions patients not requiring spiritual consideration; I had naively thought that nursing staff always made a cursory assessment of a patient's spirituality on admission to a ward, but in her interview, the nurse intimated that only a question specifically about religion (as opposed to spirituality) was asked during clerking in.

The nurse is the only professional interviewed who mentioned further training and guidance in the area of spirituality in healthcare. Spirituality has become more of a core subject on pre-registration nursing courses over the last twenty years (The Quality Assurance Agency, 2001a), and has also been incorporated into occupational therapy training (The Quality Assurance Agency, 2001b), but is not so far a recognised prerequisite standard curriculum item on speech and language therapy (The Quality Assurance Agency, 2001c) nor physiotherapy (The Quality Assurance Agency, 2001d) pre-registration courses in the UK, so it is intriguing that the nurse is the only professional to suggest further training would be beneficial.

Team members were very aware of their remit and were sensitive about not overstepping boundaries. The physiotherapist, in particular, was mindful of treading roughshod over patients' precious beliefs, or of contravening Trust policy or professional remit.

Just as there is arguably scope for improving education of healthcare professionals regarding patients' spiritual needs, the MDT interviews indicate that knowledge and skills about communicating with someone with aphasia could be shared with the lay chaplain. Lay members of chaplaincy teams are volunteers from all walks of life, with multifarious experience. Communicating with people with speech and language difficulties may be outside their experience prior to volunteering, so it is incumbent upon trained healthcare professionals, particularly speech and language therapists, to offer advice and guidance, so that the chaplaincy team feels confident in ministering to those with limited communication skills.

The participants with aphasia, and those of the multidisciplinary team, therefore gave multifarious definitions of spirituality and what it means to them. In order to explore further what it is like to express one's spirituality when one has aphasia, or to be a professional working with people with aphasia expressing their spirituality, I used some ideas propounded by Merleau-Ponty.

## **6.4 The relevance of Merleau-Ponty**

Merleau-Ponty's exploration of the concepts of ambiguity, wonder, language and thought, and lived body have helped in the understanding of the participants' stories (see chapter 5). His philosophy provided a framework on which to hang various themes which emerged from the conversations, but also various ways of being which may have clinical relevance.

## **6.4.1 Ambiguity and its clinical relevance**

The concept of ambiguity in this thesis exists in the subject matter, the methods whereby the stories were collected, the methodology, and in the way the stories were told. The term spirituality is an ambiguous one, with myriad meanings to different people. The language of aphasia can present ambiguities of comprehension and expression, as concepts are misconstrued or expressed inaccurately because of impaired processing of language. As the chosen methodology, phenomenology also offered up ambiguity in the form of, for example, confusion over the epoché, and the role of researcher versus that of therapist.

### **6.4.1.1 Ambiguity and the concept of spirituality**

Spirituality may not be able to be definitively defined, yet the concept resonated with most of the participants in the study, so that nearly all of them were able to express what spirituality meant to them. Difficult, nebulous, partially formed ideas and concepts can be broached with people with aphasia, if we are prepared to dwell with the ambiguity. Spirituality may be at the liminal edge of SLT practice, but most of the participants (bar Rosemary and Liam in group 1) were willing and able to engage with the topic with an SLT researcher. The multidisciplinary team members – including the SLT - were also all open to discussions related to spirituality. This is in contrast to Spillers et al's findings (2009), where a minority (35%) of practising SLTs felt that addressing spirituality was part of their professional remit. A larger scale project to explore SLTs' perceptions of spirituality in regard to their professional remit is merited, in order to mitigate this ambiguity around role; the results of this could impact on future SLT pre-registration training.

### **6.4.1.2 Ambiguity and the language of aphasia**

Aphasia can create an atmosphere of ambiguity and misunderstandings. Salient features of expressive aphasia include word retrieval difficulties, which may result in neologisms, paraphasias, fillers or circumlocution. Syntax may be elusive, so that sentence structure becomes simplified or constrained. Receptive aphasia is characterised by impaired comprehension, even of one's own output, and language may become empty and non-specific. The inherent ambiguity within aphasic language, however, may be construed as a benefit when one is discussing hazy, unformed concepts, such as spirituality. McGilchrist (2010, p 83) speculates that the right hemisphere of the cerebral cortex is more comfortable with ambiguity and haziness than its left hemisphere cousin:

“the left hemisphere’s affinity for what it itself has made (here language), well-worn familiarity, certainty and finitude, and, on the other, the right hemisphere’s affinity for all that is ‘other’, new, unknown, uncertain and unbounded.”

In most individuals, language predominantly inhabits the left hemisphere of the cerebral cortex. Patients with aphasia following stroke usually have their site of lesion in the left hemisphere. There exists the possibility that people with an impaired left hemisphere, where certainty abounds, use their unimpaired hemisphere to embrace ambiguity and all that is uncertain and unproven. They may revel in the ambiguity of the master hemisphere, and therefore be more amenable to discussions of a numinous nature than their right-hemisphere-damaged counterparts, or, indeed, those with no impairment of the cerebral cortex.

McGilchrist further contends that in order to comprehend the whole in a narrative – that is, to understand not just the grammatical structure and lexical choice with which the left hemisphere deals, but also the nuances of prosody, inference and metaphor which are the preserve of the right (Bryan, 1988) – one is reliant on the master hemisphere:

“the understanding of narrative is a right hemisphere skill: the left hemisphere cannot follow a narrative. “ (McGilchrist, 2010, p 76).

The emissary (left) hemisphere “has a particular affinity for words and concepts for tools, man-made things, mechanisms and whatever is not alive” (McGilchrist, 2010, p 55), whereas for the right hemisphere, “its utterances are implicit” (McGilchrist, 2010, p 73), and therefore may be more adept at expressing the non-specific.

One might contend, then, that the right hemisphere and its propensity for the ill-defined and nuanced is better equipped to consider and communicate issues of a spiritual nature, perhaps not in words but through Mosaics (Clark, 2001) of intonation, gesture and facial expression. Lindy, in particular, has become adept at using her sometimes ambiguous aphasic language to express clearly her thoughts about nebulous topics.

Despite my intact left hemisphere, perhaps I am drawing on my right hemisphere, too, as I listen to the participants’ narratives, and attempt to understand their output. It may be that, as healthcare professionals, we need to dwell with this ambiguous output more, in order to understand our clients with aphasia. The chaplain who once reported to me that they habitually walked past the patients with aphasia on the stroke ward because of the inherent difficulty of ministering to people who have no words may be encouraged to dwell with that same patient by understanding more the ambiguity of aphasia.

### **6.4.1.3 Ambiguity and identity**

Throughout the study I have been struck by how identities were sometimes obfuscated. As people with aphasia often experience a change or loss of identity (Ellis-Hill and Horn, 2000; Shadden, 2005), I attempted to emphasise their identities by giving them pseudonyms as opposed to a number or letter, and I also gave their identity as I perceived it having spoken to them, albeit briefly (such as Peter, the gardener). My identity, too, was unclear at times. When visiting participants in hospital, I carried a Trust research passport which enabled me to come and go as I pleased as if I were an employee. However, staff members did not always recognise me, so I frequently had to explain who I was and what I was doing on the ward. I felt like the clinician I had once been at times, falling easily into the infection control procedures, or pulling curtains around the bed for privacy. At the same time, however, I patently was not a clinician; my remit was to talk to these patients, not to assess their language or plan their management. This ambiguity of my identity could be uncomfortable; I often felt I should be doing more, helping more. I remember feeling how utterly anachronistic it seemed to be talking to Liam (group 1) about spirituality when his basic needs were not even being fully met. My identity was equally nebulous when interviewing the participants in group 2. With some, such as Lindy and Joel, a friendship of sorts was forged. With others (such as Francesca and David), connection was lacking, and the interviews became less like a chat between friends and more like a formal interview. This must have had a bearing on how comfortable the participants felt in talking with me, and therefore on what they were willing and able to convey.

In clinical practice, clarity of role and identity in terms of spirituality may be beneficial. Professional and regulatory bodies, for example, could be explicit about the expectations, *vis à vis* addressing clients' spiritual needs, of the healthcare professionals that belong to them. Higher education establishments could impart clear guidance and training on addressing spiritual issues with clients.

### **6.4.1.4 Methodological ambiguity**

Chapter 2 demonstrates the journey through various epistemological stances throughout the study, finally arriving at phenomenology as my methodology. Phenomenology as a research approach has been used sparingly in the field of speech and language therapy to date, possibly because of its emphasis on verbal data, in the form of the spoken or written word. As a methodology, therefore, phenomenology also occupies a liminal, hazy space within speech and language therapy, untested and potentially untapped as a way of looking with fresh eyes at a

phenomenon. However, phenomenology's emphasis on looking at a phenomenon by, to paraphrase Husserl, going back to the thing itself, is congruent with a client-centred therapeutic approach, and enables the therapist/researcher to be fully present with the client. Full presence implies that the researcher or clinician also employs a sense of genuine curiosity and wonder.

This study employed both a descriptive and interpretive phenomenological approach, notwithstanding Finlay's (2011, p 120) assertion that the distinction between these two methods is somewhat blurred. Listening to and transcribing the data demanded openness, a readiness to embrace newness, and a lack of judgement, in a manner akin to descriptive phenomenology. Analysis of the stories, however, demanded a hermeneutic approach, where the tales were interpreted through the lens of some of Merleau-Ponty's ideas. The blurring of these two phenomenological approaches adds to the aura of ambiguity throughout.

#### **6.4.2 Wonder and its clinical relevance**

Part of viewing phenomena in this naïve way is the adoption of a sense of wonder, as propounded by Merleau-Ponty. To wonder at an object, or indeed a story, is to welcome it with eagerness and interest. Van Manen (2016) develops this idea of viewing phenomena with fresh eyes and with an attitude of awe and curiosity by encouraging practitioners to adopt a "phenomenological attitude" (p 32), as they look on their subject and their participants with a "phenomenological gaze" (p 38). I believe this phenomenological stance is beneficial to researchers and clinicians alike, as they strive to keep the client at the centre. A client or participant who is listened to with a sense of wonder is one that feels valued, acknowledged and heard. This is particularly apposite when one is talking to individuals with reduced communicative capital, where the power is often with their interlocutor (O'Malley, 2011, p 94), and where necessary time and space to formulate responses is sometimes not forthcoming. In common with other subject matter of an emotional nature, spirituality as a topic demands an accepting and open attitude which is conducive to allowing the client space to express herself.

A sense of wonder suggests curiosity, "an emotion excited by what is unexpected, unfamiliar, or inexplicable" (Oxford Dictionaries, 2011). During the interviews, allowing myself to wonder at the participants' stories of stroke and spirituality enabled me to accept and respect what was being conveyed with Moustakas' "unfettered stance" (1994, p 85) and an attitude of genuine interest. Some of the stories of spirituality contained supernatural occurrences (Lindy and David in group 2). Some participants (Amy and Liam in group 1) identified seemingly quite mundane meaning-makers in their lives. My opinion of the contents of these stories is

immaterial; the fact that they were real and meaningful to the storyteller demands that we, as researchers and clinicians, afford the narrator respect by listening with wonder to what might be, to us, inexplicable.

Adoption of a sense of wonder may have clinical application, as speech and language therapists listen to stories of the stroke journey, medical treatment, hope for recovery, and myriad other patient concerns. Acceptance and wonder may be even more of a therapeutic imperative when the patient's reduced communicative competence renders them less 'listened to' day-to-day.

#### **6.4.3 Language and thought and clinical relevance**

Listening with a sense of wonder and openness becomes of paramount importance when we consider Merleau-Ponty's ideas on language and thought, especially the notion that in order to realise a thought it must in some way be conveyed to another via language (2002, p 174). If thought must be realised through expression, it is incumbent upon healthcare professionals to do all they can to facilitate the expressive abilities of people with limited language. The stories in this study show how people with aphasia are able to convey thought via multiple Mosaic (Clark, 2001) means including, but not limited to, spoken language. They tell of their previous occupations, the stroke event, of their life meaning-makers. Speech and language therapists are very used to providing communication charts or apps to enable their clients to communicate their basic needs, but Merleau-Ponty's ideas on thought perhaps impel us to consider how we enable clients to express more than basic needs, including concepts which are emotive, difficult or complex, in order for them to be fully realised.

#### **6.4.4 Lived body and its clinical relevance**

Even complex ideas may be conveyed through many different communication means, not just speech, and this is borne out in the study. Joel (group 2), for example, is able to converse with me about the Trinity, and Holy Communion, through use of objects of reference, intonation, and a shared culture. Peter (group 2) is able to express the importance of gardening to him (even to the extent that being unable to garden affects his mental health) by not only speech but also creative use of gesture and intonation. Merleau-Ponty's ideas about non-verbal communication and aids such as the white stick of the blind person being an extension of their own body (Lewis and Staehler, 2010, p 165) chime very much with the SLT concept of total communication, and with Clark's (2001) Mosaic approach with young children. Just as very young, even pre-verbal, children are able to convey complex ideas through using, for example, photography and pictures, along with guided discussion with a professional, so people who are

essentially post-verbal, whose language is impaired through disease or accident, can be encouraged to discuss complex ideas, even nebulous ideas like spirituality, with a facilitative listener, who is willing and able to accept the lived body as part of a person's communication apparatus.

It appears from this study that there are many variables at play when one considers the use of communication Mosaics with people with aphasia. The participants in group 1, for example, were all close to their stroke event, and used very little in the way of total communication strategies. Liam, who appeared the most entrenched in a chaos narrative, as evidenced by the fact that he was in a hospital bed, with paraphernalia of hospitalisation very much in evidence (nasogastric tube, incontinence pads) used no communication strategies other than speech. Amy used some gestures very effectively, but also largely relied on her spoken output. Her dominant narrative seemed to be restitution, as she ached to be allowed home. Although a very small sample, these two participants and their use of alternative/ augmentative communication contrasts with participants in group 2, whose illness narratives had shifted away from chaos and come closer to quest, and who adopted myriad alternative and augmentative communication methods.

This is clinically pertinent, as practitioners strive to help patients come to terms with their disability, and embrace an altered method of communicating, in a new stage of life which could be termed the "quest" phase (Frank, 2013). Speech and language therapists can and do explore multifarious compensatory communication strategies with their clients with aphasia. The stories in this study re-emphasise the importance of these strategies, and confirm that they can be usefully employed to enable the person with aphasia to express not only basic needs but also issues of a less concrete nature.

### **6.5 The relevance of Frank's illness narratives**

Frank's (2013) ideas around specific narratives that seem to accompany various stages of illness could be adopted and adapted to apply to people with permanent disability as a result of illness (Couser, 2016), such as aphasia as a result of stroke. The narratives were familiar to me as I thought back to the different patients I had worked with over the years as an SLT. Often patients themselves and those around them would be in an initial state of confusion straight after the stroke had occurred. This was often followed by questions about prognosis, number of therapy sessions available and requests for exercises to improve speech or language, as a restitution narrative became dominant. Further down the rehabilitation line, patients might start to come to terms with the permanence – or at least longevity - of an impaired language system and begin to explore alternative/augmentative communication

methods and adapt to these new methods. These phases are not linear, and a patient may vacillate between stages; in this study, for example, Lindy in group 2 was adept at using written words to augment her spoken output (a sign of entering a quest narrative), but also talked in the interview about her aspiration to be fluent in her speech output in a few years' time (a restitution narrative).

Experience of working with people who had had a stroke also taught me that there is a need to tell and retell the illness narrative; patients (and carers) would often regale me with the details of the day the stroke occurred; where they were, who was or was not with them, the horror of the situation. Interestingly, Lindy had advised me to begin my conversations with the participants with aphasia by asking them about their stroke journey; this usually took the form of my saying "tell me what happened to you." Frank (2013, p 3) suggests that there exists "the need of ill people to tell their stories", in order to make sense of what has happened to them. Although not a question relating to their spirituality per se, Lindy was right to recommend this, as the stroke narrative provided a natural way in to discussion of spiritual and existential issues related to being a stroke survivor. Frank's illness (or disability) narratives proved a useful framework on which to view the participants' spiritual stories. Participants expressing a current chaos narrative were more likely to be closer in time to the stroke event. Other participants expressed having been through a chaos narrative at the time of the stroke and shortly thereafter, but were subsequently entering a different narrative. Several participants expressed having been through restitution, usually in the form of indicating that their language skills had improved. Participants who had been living with their stroke for the longest were the most likely to express their narrative in the form of quest.

Quest also seemed to be the state required for most participants to be willing or able to enter into conversations around spirituality. Lindy, Joel, Francesca, and Peter were all several years post-stroke, and were able to express their spiritual thoughts. David was nearer in time to his stroke than the other members of group 2; however, he, too, was showing evidence of entering a quest narrative (for example, by exploring art again), and he was also able to take part in a conversation about life meaning with me. Group 1 participants were far more likely to show a chaos narrative, where physical needs seemed to take precedence over self-actualisation, or "soul work" (Spillers, 2011, p 231).

Merleau-Ponty's (2002) thoughts on ambiguity, wonder, language and thought, and lived body also align with Frank's (2013) typology. Within the chaos narrative, ambiguity is rife; prognosis is unclear, physical health is compromised and aphasia is at its most severe. Frank (2013) explains how people locked in a chaos narrative are in such a state of confusion and despair that they are unable to narrate their story. This concept is even more poignant when we consider those individuals in a chaotic state whose ability to narrate their illness story is not

only compromised by the chaos but also by aphasia. Ambiguity is perpetuated when clarity of language and narration of events is denied.

Ambiguity is also evident in the restitution narrative, where individuals hope for complete resolution of language skills, even after many months or even years, in the midst of medical claims that despite some lost abilities being “rerouted through existing unimpaired pathways” (Papathanasiou, Coppens and Ansaldo, 2013, p 51), language levels may never reach pre-morbid levels.

Merleau-Ponty’s emphasis on viewing phenomena with a sense of wonder allows clinicians to listen to and acknowledge new ways of communicating using the lived body, and as thought is realised through communication, narratives are expressed and stories told. As other SLTs have discussed (Mitchell, Skirton and Monrouxe, 2010), narrative types can “assist people with reflection and may enable them to gain unexpected insights” (p 333), as they make their way along the stroke journey.

If speech and language therapy involves accompanying the client from chaos to quest, then embracing spiritual concerns constitutes an integral part of this journey, and embracing ambiguity and wonder, whilst facilitating realisation of thought using total communication is the SLT’s remit.

## **6.6 The use of narrative inquiry**

Despite the potential contradiction of using narrative inquiry with people with language difficulties, even the participants with the most limited expressive spoken language, such as Liam and Joel were able to create their own spiritual narratives. Kim (2016, p 73) talks about the “open-endedness” of stories, when “the real connection begins where the ordinary plot ends”. As far as these spiritual stories are concerned, the “ordinary plot” could be construed as the prosaic, the non-numinous, the everyday, but it might also pertain to ‘normal’ language, as opposed to the extraordinary narrative methods employed here. The term ‘narrative inquiry’ can and does include non-speech narratives, and can be a powerful method by which to gather data pertaining to experiences of people with communication impairment. Narrative within this study ironically encompassed the non-verbal; participants in groups one and two successfully told their narratives using not only their speech, but also their facial expression, intonation, writing, gesture and objects of reference. Narratives were constructed with communication Mosaics (Clark, 2001).

## 6.7 Spirituality in times of severe illness or distress

Although the literature suggests that individuals do tend to seek answers to existential questions at times of crisis and severe ill health (Burke and Neimeyer, 2012, p 127), this was apparent in only some of the current stories (Lindy and Joel in group 2). These overtly spiritual or existential accounts are unusual in the stories, however. Although other participants, such as Peter, David and Francesca, make reference to spiritual issues in the form of life meaning-makers, they do not explicitly relate their spiritual concerns to the stroke event.

It is clear, therefore, that some participants did not talk about their spiritual concerns in the face of the catastrophe of stroke – at least not to me. It is possible that no such spiritual concerns exist. It might also be, however, that such issues exist but cannot – or at least were not – expressed. Some people with severe expressive aphasia may be unable to put into words, or into any other expressive means, their spiritual issues. This may also be hindered by lack of skill in facilitation on the part of the listener.

People at the early stages post-stroke may be experiencing acute symptoms, such as chest infection, and they require their physiological needs to be met before self-actualisation can be broached, including asking or answering questions of existence and life-meaning.

For some participants, perhaps so much time had elapsed since the time of the stroke episode, those immediate existential questions no longer pertained. Francesca, for example, although she sighs and leaves a long gap before answering, insists that her stroke has not made her ask existential questions, but rather has given her a stoical attitude.

Participants in the study may have wanted and indeed needed to express their spiritual concerns but were unable to do so with me. Lack of trust in me, lack of a true relationship with me, the fact of being recorded, may all have contributed to a situation uncondusive to relaying issues of a spiritual nature. It might be that participants who did not convey much about their spirituality with me may have done so with another researcher, or with me if a longer period had enabled us to create a deeper relationship.

It is argued, then, that people facing serious illness seek answers to existential questions, and participants such as Lindy pay testament to this. However, is it possible that they may also have an enhanced *ability* to access these answers or the source of these answers?

## 6.8 Privileged access to the divine

Early on in the research process, I was introduced to the concept of the “privileged access to the divine” (Clark Power et al, 2008, p 375), the idea that people with disabilities or undergoing illness and suffering might in some way have this path to the spiritual that is not

necessarily granted to the well. Lindy mentioned in one of her emails the writings of Meister Eckhart and his idea that “one must be dead to see God” (private email). She asks why she had to suffer a stroke; it is as if she has concluded in order to be close to God, one has to suffer in this way.

Historical and literary figures have claimed to have found God in times of physical trial, from Dostoyevsky, who suffered from epilepsy, and maintained that he had “touched God” through his condition (Foster, 2010, p 54) to Julian of Norwich who experienced “supreme spiritual pleasure in [her] soul” (Julian of Norwich, 1998, p 14) during an acute illness. Vanier (1999) sees this privileged access to the divine enjoyed by members of the l’Arche community who have a learning disability. Foster (2010) discusses the well-researched phenomenon of near-death experiences, where people describe seemingly spiritual phenomena such as tunnels of light, divine beings or the appearance of dead relatives. Spiritual sensibility may be enhanced in severe illness and disability (McSherry and Ross, 2012, p 213), and as clinicians we perhaps need to be open to this fact and therefore willing to facilitate discussions pertaining to spirituality.

Whether these are true numinous experiences or a result of neurological, physiological or pharmacological events in a way does not matter – it is the individual’s opinion of these, their ability to communicate what they mean to them, and the possible effect of this on their recovery and sense of well-being which is of importance. Of all the participants with aphasia, only Lindy reported experiences associated with her illness which could be deemed supernatural, in the form of visions seen whilst in a coma. Most did not report such events, but whether this meant they did not have them, had them but did not remember, had them but were unable to articulate them or had them but did not want to tell me, is unclear.

Other participants did, however, express what gave their life meaning. Peter had his garden and Joel his religious belief; Francesca had opera and Amy her home-making. Clinicians need to be ready and open to listen to these expressions of spirituality, but how can we do this? Is the phenomenological attitude clinically useful?

## **6.9 The phenomenological attitude as a therapeutic strategy**

The stories came from three different groups of people: those who had just had their stroke, those who had been living with the effects of their stroke (including aphasia) for some months or years, and those who worked professionally with people with aphasia. Throughout my listening to the stories, and my attempts to understand them, I strove to adopt a “phenomenological attitude” (van Manen, 2016, p 32) of wonder, awe, curiosity and attentive listening. All the details in the stories were novel and unexpected. In order to engender trust

and to offer complete respect, I wanted to hear the stories in a fresh way, uncluttered by previous opinions or experiences.

The traditional phenomenological technique of complete bracketing, of epoché, however, proved an unattainable, and possibly, undesired imperative, in that I found I had to bring of myself to the interviews, the analysis and the writing. Sitting better with the design of the project, the type of participants and with the subject matter was Gadamer's (2013) concept of fusion of horizons. So it was, for example, that when Joel counted to twelve in a given context, our horizons which both contained Christianity fused, and I was able to understand that the concept he was conveying was 'disciple'. By contrast, but also attempting to employ a phenomenological attitude, I listened to and acknowledged Liam's life meaning-makers of sport, despite their not necessarily being part of my own spiritual horizon.

Total communication demands an open and attentive listening style. Van Manen's "phenomenological attitude" (2016, p 32), which incorporates a sense of reflective wonder, allows us to view a phenomenon with fresh and accepting eyes. A subject such as spirituality, with all its nuance and idiosyncrasy, perhaps demands above all other topics to be received with this type of attitude. The stories in the thesis are rife with events and opinions open to controversy, such as visions of dead relatives, celestial beings and everlasting life. It was vital that I, as researcher, maintained this phenomenological, non-judgmental yet congruent stance in order to engender trust and an open dialogue. In the same way, it is vital that we, as therapists and other healthcare professionals, listen to our clients with openness, whatever they may be conveying to us. It is a mark of dignity and respect to listen attentively (Sinclair and Chochinov, 2012, p 288). The SLT and OT both cite time as one of their therapeutic tools, particularly when listening to someone communicate about emotive issues; "it's a rule of mine, I do not rush" seems to be one of the SLT's aphorisms.

As clinicians, we also bring of ourselves to the clinical encounter and, rather than being viewed as too subjective or unprofessional, this fusion should be applauded as an important component of rapport-building and trust engendering. Particularly when topics of an intimate or personal nature are being discussed with clients with aphasia, adopting a "phenomenological attitude" (van Manen, 2016, p 32) and seeing our clients with a "phenomenological gaze" (van Manen, 2016, p 38) can only enhance interaction and make for more successful connection. The phenomenological attitude may help facilitate a "therapeutic understanding and effective clinical empathy" (Swinton et al, 2011, p 650) vis à vis spirituality in SLT.

## 6.10 Use of the Mosaic approach

The extraordinary narrative techniques employed in telling the spiritual stories created rich Mosaics (Clark, 2001), comprising myriad non-verbal expressions. As Kim (2016, p 72) states, “it is important to allow each of our storytellers to speak for themselves” which, when extrapolated to the world of aphasia, can be translated as *to communicate for themselves*. Although the language of aphasia can bring with it a certain ambiguity, as target words become elusive or grammatical constructs cannot be achieved, this ambiguity in language can be and is mitigated at times by skilled use of augmentative and alternative communication methods. People with long-standing aphasia in particular accrue enormous skill over time in finding methods other than spoken language to convey meaning. Lindy uses the written word almost as naturally as the spoken, and her notebook and pen become an extension of her communication apparatus. The listener soon becomes accustomed to looking down at the shared piece of paper, as well as maintaining eye contact with her, in a way that is pragmatically acceptable. Her output becomes a lasting sign of her thought processes and acts as a permanent referent throughout the telling of the story.

The use of total communication strategies seems to be an outward sign of achieving or beginning to achieve a quest narrative (Frank, 2013). A participant still deep within the chaos narrative, such as Liam, never utilised ramps to augment his spoken output. Those still living the restitution narrative – such as Joel, whose awaited restitution was divine in nature – also used total communication strategies less readily than those overtly living a quest narrative, such as Lindy. Joel seemed content to accept his spoken communication as it is now, in the hope of restored communication skills in life after death.

Complex and abstract issues within this study could be expressed using total communication. Maybe this is a lesson to SLTs but also other healthcare professionals not to shy away from addressing complex and sensitive issues with people with aphasia. The lay chaplain admits to shutting down conversation when verbal output is limited. There is a duty for all healthcare professionals there to engage fully with people with aphasia, whatever it is they are trying to communicate.

## 6.11 Evaluation of the research

At the conclusion of a project, one inevitably reflects on what was successful and on what one might do differently next time. I used the 4 Rs propounded by Finlay and Evans (Finlay, 2011, p 264), namely rigour, relevance, resonance and reflexivity, in order to evaluate the research.

### 6.11.1 Rigour

Finlay and Evans (Finlay, 2011, p 264) first pose the question: “has the research been competently managed and systematically worked through”? I have endeavoured to guide the reader through the literature related to the subject of aphasia and spirituality, my methodological decisions, as well as through the methods employed. I believe phenomenology was a useful and apt methodology. It felt congruent both with the subject matter of spirituality and with my desire to keep the participants with aphasia at the centre of the project, researching *with* them not *on* them. Perceiving phenomenon as they were presented to me with an open attitude tallied with my desire to acknowledge and respect the participants. I rejected ethnography as a methodology, recognising that people with aphasia were not a homogenous social group with whom to integrate; however, the principle of being with a group of people for a prolonged period of time could result in rich, deep, “thick” (Geertz, 1973) data.

Creating stories as my results chimed with allowing the participants with aphasia to have a voice, a principle to which I was keen to adhere. By quoting substantial excerpts of participants’ verbal and non-verbal output, I hope that I have given the reader a flavour of the “essence” (van Manen, 1990, p 10) of their true selves, “unmediated through the fallible voices of others” (Mundle, 2011). Like me, some researchers have included the voice of people with aphasia in their research (Mitchell, Skirton and Monrouxe, 2010; Martinsen, Kirkevold and Sveen, 2012; Barrow, 2008; Bronken et al, 2012) by using some direct quotations from their interviews with people with aphasia, but recognise, as I did, that this is unusual and that some research projects (Simeone et al, 2014; Schulz, 2005) have excluded people with aphasia because of the perceived reduction in data quality and increase in research time. A true participatory approach, including participants contributing to design of the project, would have further positioned the participants at the centre of this research.

Viewing the stories through the prism of Merleau-Ponty’s ideas on ambiguity, wonder, language/thought and lived body, and also through Frank’s typology of illness narratives, allowed me to make sense of the data, and develop suggestions for clinicians interested in talking about spiritual issues with their clients.

Rigour was also achieved through assiduous use of participants’ actual words, a research diary and a reflective journal. I also encouraged participants to look at and comment on the data. This was more successful with some participants than others (as discussed in Chapter 2). An improved way of ensuring rigour in the future would be to endeavour to visit participants at least twice in order to talk through data previously collected. Sending written data for participants with aphasia on which to comment could also be construed as non-inclusive; this

could be mitigated in future studies by factoring in follow-up interviews, where data could be presented in an accessible format and scrutinised by the participant and researcher together. Further rigour could have been achieved by enabling a second researcher to listen to the interviews, dwell with the stories and draw out themes.

In listening to the stories, I made the decision not to use a video camera, because of my concerns relating to infringement of dignity. However, the benefits of filming non-verbal behaviour remain useful to the research process, and would allow for more in-depth analysis of non-verbal communication. Having conversations with fewer participants but more frequently over a longer period of time would enable deeper relationships of trust to be forged, meaning participants may be willing to be filmed and the researcher may feel more comfortable in doing so.

### **6.11.2 Relevance**

In chapter 1, I discussed how spirituality as a topic is relatively new to the speech and language therapy literature (Spillers, 2007; Mathisen et al (2015); MacKenzie, 2015; MacKenzie, 2016), and has not before been explored in relation to adults with acquired communication impairment. In contrast to Paley (2008) in the nursing literature who maintains that spirituality is “an invention of the late 20<sup>th</sup> century” (p 9) and that spiritual distress does not exist, I would like to offer a more inclusive model of care, where individuals’ concerns are listened to and valued, regardless of how they are labelled.

Being a new concept in speech and language therapy, there are as yet no published SLT dissenters of spirituality in the literature. This project has hopefully served to open up the dialogue around spirituality in the speech and language therapy arena. It has also helped to show how total communication strategies may be usefully employed to convey myriad facets of the human condition. In our bid to practise in an holistic manner, SLTs may wish to continue this exploration of the spiritual aspect of their tripartite clients.

### **6.11.3 Resonance**

Finlay (2011, p 265) defines ‘resonance’ as the way in which the reader is touched or affected by the research and its findings, and admits that this can “probably only be judged in the eye of the beholder”. Storytelling and story-listening have been at the forefront of my methodology, and I have therefore crafted the thesis like a work of literature, rather than a scientific text. As such, I have dispensed with traditional chapter headings such as ‘method’ and ‘results’, and instead labelled the chapters in a way that prepares the reader for what lies ahead, including a prologue and an epilogue, as one might find in a novel. Each chapter has its

own quotation – sometimes from the spirituality or health literature, sometimes from novels or poems; the aim of this was to create an atmosphere of creativity and wonder. I have referred to the participants' data as 'stories' to further promulgate this sense of newness and wonder, and narrated them in the present tense in order to ensure the reader and the writer met in the same space at the same time.

To ensure the people with aphasia were at the centre of this research, I have included their expressions of spirituality verbatim (in the case of their spoken output) and accurately described (in the case of their non-verbal output), including phonetically transcribed paraphasias and pauses. I have the sound and sight of the participants in my head, but I hope this also gives the reader a flavour of the essence of the participants' spiritual stories.

#### **6.11.4 Reflexivity**

I have attempted to position myself clearly throughout the thesis. Firstly, I have used the first person throughout and, where applicable, I have used my own clinical and life experience to illustrate a point. As Holliday (2007, p 137) notes, in a "postmodern qualitative research paradigm" such as this, "the presence and influence of the researcher are unavoidable, and indeed a *resource*, which must be capitalized upon." Secondly, I foregrounded my fore-meanings in chapter 2, in order that the reader might have an understanding of the cultural, societal and, indeed, spiritual influences in my life and how these might have impacted my listening to and relating of the participants' stories. I have explained to the reader the phenomenological imperative of the epoché and why this was considered but adapted using the thoughts of Gadamer (2013) and van Manen (2016, p 32), to produce a "phenomenological attitude". Acknowledging my fore-meanings, whilst attempting to be open and attentive during the interviews and when making sense of the stories, sat better with me both as researcher and as clinician.

Connection was identified as an important constituent in the success or otherwise of the encounters. In a further development of this study, therefore, I would want to carry out fewer interviews but in more depth. In this way, I would be able to forge a relationship with participants, perhaps creating an atmosphere more conducive to intimate conversations about spirituality. Visiting and conversing with people on several occasions would also help me to understand better their preferred method of communicating, possibly even exploring new ones with them. Revisiting Joel knowing how important his Christian faith was to him, armed with relevant artefacts, opened up our dialogue and allowed the conversation to reach depths that may not have been possible without the referent clues. Clark's (2001) Mosaic approach to communicating without words, or supplementary to words, in the research arena encourages

us to explore novel ways of communicating, perhaps more encompassing than the traditional concept of total communication. Use of artefacts, photographing and map-making may all serve to enrich the expressive communication of people with aphasia.

## **6.12 Developing the project**

This project was exploratory in nature. At the beginning, I was unsure as to how the idea of exploring spirituality in SLT clients would be viewed by my SLT and other colleagues. I wondered if I would be derided for considering it; as a concept, spirituality was rarely, if ever, discussed within SLT and I feared I may have been wide of the mark. Although other healthcare professionals such as nurses had pioneered the concept of being open to the spiritual side of their patients, this had barely been discussed in the field of SLT.

Before I embarked on the interviews with the participants, I had no idea how they would respond; they might well have had nothing to communicate to me, or I might well not have had the skills or sensitivity to ask the right questions. I am again indebted to Lindy for allowing me to interview her first, and also to my student 'guinea pigs', so that my courage was "screwed to the sticking place" (*Macbeth, Act 1 Scene 7*) and my skills of interviewing about such a sensitive topic were, if not honed, at least chiselled. Now that the concept of spirituality and how clients with aphasia may express spiritual issues has been further explored, my hope is that this will open up dialogue within the profession, and lead to further exploration of the topic both with people with aphasia and also clients with other aetiologies affecting their speech and language, such as learning disability and dementia.

Further total communication or Mosaic (Clark, 2001) methods of communicating spiritual issues could be explored. Clark (2001) often uses cameras with the children in her studies, to enable them to take photographs of objects that are meaningful to them. The children are then encouraged to talk about the image. This facilitative technique could also be beneficial to people with aphasia; if possible concomitant physical disability allows, they may be able to take photographs of objects whose lexical label they are not able to find, or for whom the image may aid in the word-finding process. Photographs, like Lindy's written words, also provide a permanent referent and can be useful to refer to as the discussion progresses. This use of photographs is akin to the Photovoice technique (Wang and Burris, 1997) used in some qualitative health investigations, such as in Levin et al (2007), Catalani and Minkler (2010), Burke and Evans (2011), Thomas et al (2013), and Ulmer et al (2016). Photographs taken by participants with aphasia could act as a useful referent for discussion, similar to the use of artefacts in the interviews with Joel.

Mosaics might also include established alternative/augmentative communication strategies, such as Talking Mats™, adapted to include pictures related to spirituality. Non-verbal individuals would be able to express their spiritual needs and opinions by using relevant pictures placed on the mat, with facilitation from a carer.

If, as a profession, we intend to embrace the spiritual domain with our clients, more research could be carried out with different SLT clients, such as those with learning disabilities, or with dementia, again making use of Mosaic (Clark, 2001) techniques in order to empower clients to 'talk' about their spirituality.

## **6.13 Conclusion**

What I had hoped for when embarking on this study was to stimulate debate in the area of spirituality and the allied health professions. Spirituality has not traditionally been a part of SLT input, despite SLTs considering themselves to be holistic practitioners. The literature states – and the stories in this thesis bear testament to the fact – that spirituality is difficult to define and is revealed differently in each individual. A person's spirituality may manifest itself in religion and belief, but, as we have seen, it may also reside in being in nature, in art or in gardening.

Literature suggests (Koenig, 2012) that encouraging spiritual expression can contribute to the healing process, and can offer some bolstering of coping mechanisms in people who are at the end of life (McClain, Rosenfeld and Breitbart, 2003). Berg et al (2012) suggest that people suffering severe, life-limiting illness tend to engage in more spiritual or religious conversations. What of those patients who have suffered a severe, life-changing illness, who are not able to voice their spiritual issues?

Speech and language therapists are the members of the multidisciplinary team whose remit and expertise is in communicating with people for whom communication is problematic. Not only does our training incorporate attentive listening and therapeutic rapport-building, but we also have in-depth knowledge of how language may be affected by a neurological condition such as stroke, and how communication in these instances may be facilitated. It is incumbent on us as a profession to empower other members of the multidisciplinary team to communicate as effectively as possible with people with communication disorders about a variety of issues, including spirituality. Koenig (2012) posits that all healthcare professionals should share the responsibility for assessing patients' spiritual needs by taking a spiritual case history, and it may fall to the SLT in multidisciplinary teams to facilitate this with clients with communication impairment. In chapter 1, I cited Mathisen et al (2015, p 2318) who suggest that there are potential negative outcomes of not considering the spiritual aspects of the

clients with whom we work. They question whether therapy is superficial if important facets of the client are ignored, or whether not addressing spiritual concerns may negatively impact on achieving SLT communication goals. Added to this, they claim, is the role SLTs may play in enabling clients to access again life resources which sustain or make a person whole, such as church liturgy.

Speech and language therapy student practitioners are not, however, encouraged on their pre-registration training programmes to consider the spiritual needs of their clients. No UK SLT training institution, to my knowledge, includes modules or sessions on spirituality in healthcare. SLT practitioners would perhaps feel more confident in facilitating expressions of spirituality with their clients with communication impairment if they had some understanding of spirituality and how spiritual wellbeing may correlate with physical wellbeing. SLTs may also feel more confident in helping their multidisciplinary colleagues in their spiritual conversations with people with communication impairment, if they had received further training in that area. The more that spirituality is discussed within healthcare in general, and in speech and language therapy in particular, the more SLTs and SLT students are likely to consider it as just one of the several aspects of the human condition that can enter into the therapy room. Implicit in the WHO's (2001) fourth classification of functioning, namely wellbeing and the mitigation of distress, is the concept of an individual's spirituality:

“What contributes to a person's health and brings about healing does not simply involve pharmacological agents or clinical interventions but convictions made manifest in the humanity of care and our faith in that which gives our lives meaning and purpose.” (Cobb, 2012,p 117).

As such, all healthcare professionals, including speech and language therapists, need to be mindful of the spiritual aspect of their clients, and be ready to address spiritual needs, distress and well-being, by listening attentively to and facilitating the telling of spiritual stories.

## Epilogue

**“Voices may reach us...but what they say to us is imbued with the obscurity of the matrix out of which they come, and, try as we may, we cannot always decipher them precisely in the clearer light of our own day.”**

***(The Handmaid's Tale, Margaret Atwood)***

If part of the purpose of telling stories is to help us make sense of life-changing events (Frank, 2010, 2013; Barrow, 2008; Ross, 2010; Hurwitz, Greenhalgh, and Skultans (2004)), these narratives are as important for people with aphasia following stroke as for those individuals who have suffered other catastrophic events. Part of that sense-making narrative may well include issues of a spiritual nature.

With this in mind, and with the current healthcare driver of attending fully to patients' dignity (The Mid Staffordshire NHS Foundation Trust Inquiry, 2013; NHS England), it is incumbent on all healthcare professionals to enable all patients to express their illness narratives, including the spiritual aspects. Speech and language therapists have a particular role to play in terms of facilitating these narratives with people with aphasia.

Healthcare professionals need to be mindful of the aetiology focus that has become prevalent in the twentieth century and at the beginning of the twenty-first, with professionals perhaps not paying enough heed to the psycho-social-spiritual side of their patients. As Swinton (2014, p 26) points out, “the tasks of the day can easily overpower the experiences of the client” in a busy healthcare environment. In this post-modern era, carrying out care duties seems to have taken over from care itself, with patients/clients being seen increasingly as bodies to be cured whilst tasks are ticked off and targets met. Sometimes lost is the essence of the patient as a fully integrated tripartite being, encompassing body, mind and spirit. One of my hopes for this project is that it will encourage all healthcare professionals – and speech and language therapists in particular – to shift their focus and fully embrace holistic care; care of the body, mind and spirit.

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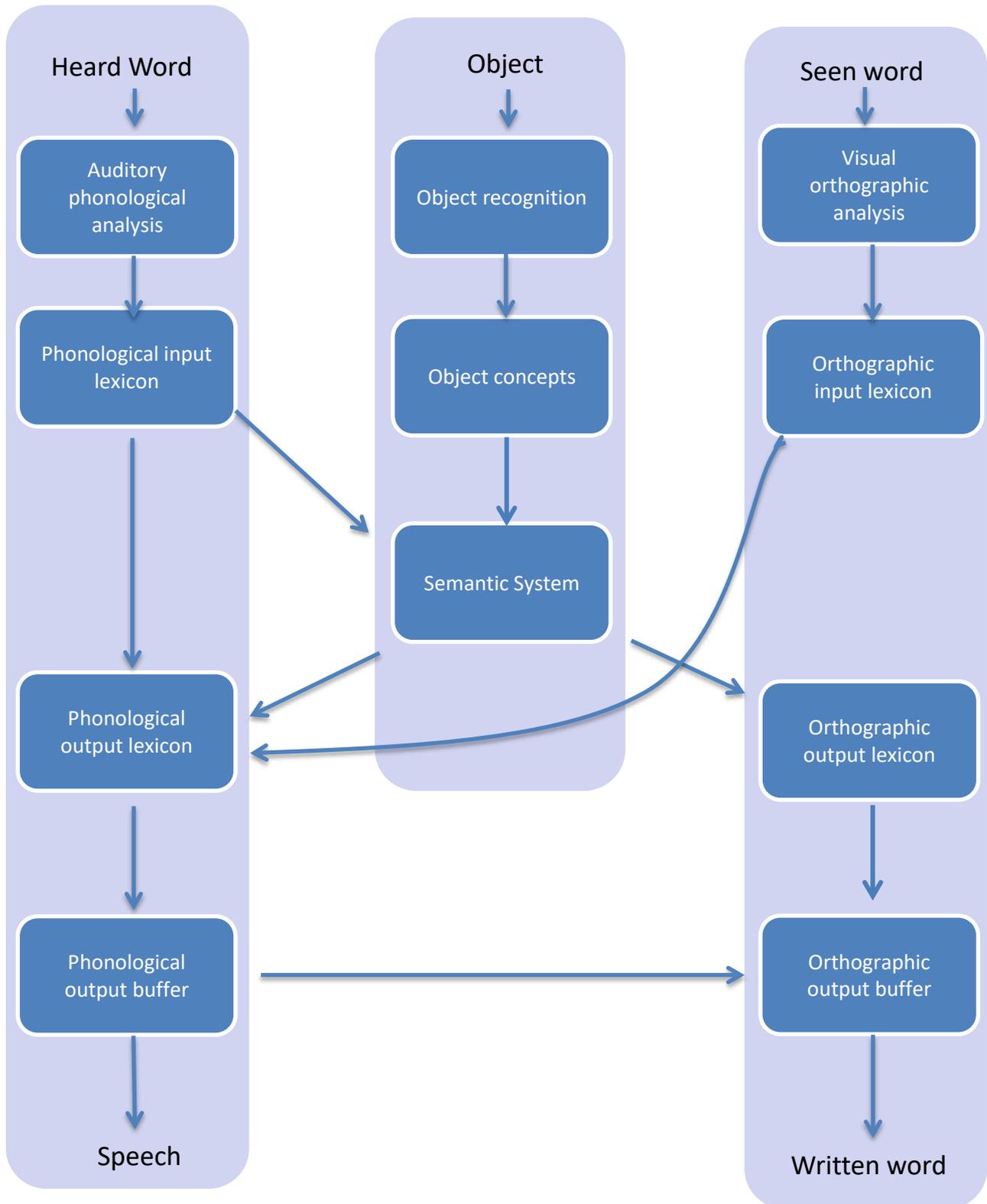
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## **Appendices**

# Appendix I: The Cognitive Neuropsychological Model of Language Processing

(based on Patterson and Shewell's 1987 logogen model)



## Appendix II: Consent forms and information sheets



### CONSENT FORM (groups 1 and 2)

Centre Number:

Study Number:

Participant Identification Number for this trial:

Title of Project: **Exploring stories of spirituality with people with aphasia**

Name of Researcher: Sophie MacKenzie

1. I confirm that I have read the information sheet dated May 2014 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
  
3. I agree to being recorded but understand that I can ask for recording to stop at any time
  
4. I understand that any personal information that I provide will be kept strictly confidential
  
5. I agree to my General Practitioner being informed of my participation in the study.
  
6. I agree to take part in the above study.

\_\_\_\_\_

Name of Participant

Date

Signature

---

Name of Person  
taking consent

---

Date

---

Signature

## Information Sheet (groups 1 and 2)

### Exploring stories of spirituality with people with aphasia

A Research Project by Sophie MacKenzie

A research project is being conducted by Sophie MacKenzie of Canterbury Christ Church University (CCCU). Sophie is a speech and language therapist and PhD student. This is part of her PhD research.



Sophie wants to shed light on how people with aphasia express spirituality.

Sophie intends to interview people with **aphasia** about **spirituality** and what gives their life **meaning**.

#### **What would you be required to do?:**

Have a conversation with Sophie for about 1 hour



Talk about what spirituality means to you.

Use writing/ photos/ drawings/ gesture if it helps.

Be videorecorded.

**To participate in the project you must be someone who has aphasia following a stroke.**

#### **Procedure:**

Sophie will come to your house or somewhere else of your choice. You and Sophie will have a conversation for about 1 hour. Sophie may take notes and you will be filmed. A video will help the researcher look at things like drawing and gesture. You can ask for the filming or the interview to stop at any time.

**Benefits to you:** you will be able to talk about your thoughts and feelings around spirituality to an interested listener.

**Possible disadvantages to you:** discussing spirituality may bring up some deep emotions for you.

**Feedback:**

Sophie will send you a summary of the conversation. You can give your comments.

**Confidentiality**

All data (including the video) and personal information will be stored securely within CCCU premises in accordance with the Data Protection Act 1998 and the University's own data protection requirements. Data will be stored on a password protected memory stick. Data can only be accessed by Sophie MacKenzie. After completion of the study, all data will be made anonymous (i.e. all personal information associated with the data will be removed). Data will be kept for no longer than 6 months after the end of the study.

**Results of the project**

The study will be written up as a thesis. A summary of the thesis may be submitted as a journal article. Some information from the study may be presented in lectures.

**Deciding whether to participate**

- you do not have to take part in this study
- Please contact Sophie if you have any questions or concerns
- You are free to stop being part of this study at any time – you don't have to give a reason.

**Any questions?**

Please contact Sophie at:

Email	Telephone	Address
S.R.Mackenzie@gre.ac.uk	0208 331 8924	Nelson Building Central Avenue Chatham Maritime ME4 4TB
Sophie.mackenzie@canterbury.ac.uk		



## CONSENT FORM

**Title of Project:** Exploring stories of spirituality with people with aphasia

**Name of Researcher:** Sophie MacKenzie

**Contact details:**

**Address:** School of Health and Social Care (Nelson 003)  
Central Avenue  
Chatham Maritime  
ME4 4TB

**Tel:** 0208 331 8924

**Email:** S.R.Mackenzie@gre.ac.uk

**Please initial  
box**

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that any personal information that I provide to the researchers will be kept strictly confidential
4. I agree to take part in the above study and to be audio recorded.


-----  
Name of Participant

-----  
Date

-----  
Signature

-----

-----

-----

Name of Person taking consent  
(if different from researcher)

Date

Signature

-----  
Researcher

-----  
Date

-----  
Signature

Copies: 1 for participant  
1 for researcher



## Exploring stories of spirituality with people with aphasia

### PARTICIPANT INFORMATION SHEET

A research study is being conducted at Canterbury Christ Church University (CCCU) by Sophie MacKenzie.

#### Background

During this study, Sophie intends to explore how people with severe expressive aphasia following stroke express their spiritual distress/ needs/ well-being. She will be interviewing people with acute and chronic aphasia, and also members of the multidisciplinary team (MDT).

#### What will you be required to do?

Participants in this study will be required to:

- Take part in an interview with the researcher, during which you will have the opportunity to discuss the issues relating to spirituality when working with people with expressive aphasia
- Be recorded

#### To participate in this research you must:

- Be a member of a multidisciplinary team, working with people who have aphasia following a stroke
- Have experience of talking to and listening to people who have had a stroke

#### Procedures

A mutually convenient time and place for the interview will be negotiated with you. The interview should take about one hour. The interview will be recorded to enable analysis of the discussion.

#### Feedback

Interviews with members of the multidisciplinary team will form part of the qualitative data for this study. Eventually the thesis will be available to be read by participants.

### **Confidentiality**

All data and personal information will be stored securely within CCCU premises in accordance with the Data Protection Act 1998 and the University's own data protection requirements. Data can only be accessed by Sophie MacKenzie. After completion of the study, all data will be made anonymous (i.e. all personal information associated with the data will be removed). The job title of the MDT participants will be included in the study, as this may have direct relevance.

### **Dissemination of results**

The study will be written up as a thesis. A summary of the thesis may be submitted as a journal article.

### **Deciding whether to participate**

If you have any questions or concerns about the nature, procedures or requirements for participation do not hesitate to contact me. Should you decide to participate, you will be free to withdraw at any time without having to give a reason.

### **Any questions?**

Please contact Sophie MacKenzie at:

[Sophie.mackenzie@canterbury.ac.uk](mailto:Sophie.mackenzie@canterbury.ac.uk)

[S.R.Mackenzie@gre.ac.uk](mailto:S.R.Mackenzie@gre.ac.uk)

School of Health and Social Care  
University of Greenwich  
Nelson 003  
Central Avenue  
Chatham Maritime  
ME4 4TB

Tel: 0208 331 8924

## Appendix III: Referral information request sheet (group 1)



Exploring stories of spirituality with people with aphasia

Checklist for Group 1: people with severe, acute aphasia

To be completed by qualified Speech and Language Therapist

Patient name:

Please tick either yes or no to each question:

Is the person:	yes	no
medically stable?		
presenting with severe expressive aphasia? *		
presenting with good auditory comprehension? **		
able to give consent?		

May I approach the person and explain the study to them?		
--	--	--

\*expressive language is telegraphic/ relies heavily on total communication strategies to convey ideas/ severe word-finding difficulties

\*\*able to understand utterances containing 3 information-carrying words or more

If you have ticked yes to every question, this person may be eligible for the study.

Please send form to Sophie MacKenzie ([sophie.mackenzie@canterbury.ac.uk](mailto:sophie.mackenzie@canterbury.ac.uk)) on completion.

## Appendix IV: Topic guides



Exploring stories of spirituality with people with aphasia

Interview topic guide (groups 1 and 2)

The plan is that the interviews will be unstructured, but topics that may be covered include:

- Can you tell me a bit about what happened to you? (tell me about your stroke)
- Can you tell me something about what is really important to you?
- What gives your life meaning?
- What does the word “spirituality” mean to you?
- Do you talk over spiritual issues with anyone? If so, who?

## Topic guide: MDT members (Group 3)

I am interested in the experience of different healthcare professionals in working with people with severe aphasia. Specifically, I am interested in how people with severe aphasia convey issues relating to spirituality.

First of all, I'd like to ask you what you know about aphasia.

What is your experience of working with people with severe aphasia.

Can you tell me about ways you help people with aphasia to express themselves?

Do you think there are some issues that are easier and some that are more difficult for people with aphasia to express? Which issues/ concepts are easier? Which are more difficult?

What does the term "spirituality" mean to you?

Do you think it is part of your role to help people with aphasia express spiritual issues?

(if not, whose role is it?)

(if yes, can you tell me a bit about how you might do this?)

Can you tell me how you help people with aphasia express spiritual issues?

## Appendix V: Example of transcribed interviews

### Amy, group 1

S: So, Amy, when you're at home, do you go to church or anything like that?

A: Yeah

S: Do you? Ah – which church?

A: Go [lɪəʊ] go same place

S: Do you? Ah, is that important to you?

A: Yeah (*gestures praying with both hands*)

S: Yeah – saying prayers

A: Want to know...want to know come in [tʌtʃ] (church) (*gestured prayer*)

S: to pray, yeah

A: yeah

### Joel, group 2

S: So, last time we talked a bit about how important your faith was to you

J: Yes

S: Yes

J: Yes [ɑɪ ] yes [ɑɪ ] (*emphatic intonation*) (*laughs*)

S: Absolutely...important to you. And we talked about going to church...er

J: Yeah, yeah

S: Are you still going to church?

J: Yes, all the time, yeah

S: Brilliant. And I notice here (*at the side of the room, there is a flipchart, with the words "John 10<sup>27</sup> hearing God" written on it*)

J: Yeah

S: Did you have Bible study here?

J: Yes (*laughs*)

S: John 10: 27 hearing God

J: Yes (*laughs*)

S: Excellent – that's great. So does that happen regularly?

J: Yes (*emphatically*) yes [ɑɪ ] yes [ɑɪ ] yes

S: So do you and your wife run that group?

J: Yes, well for now er...er...Oh God...for now

S: for now

J: Yes

S: OK, so it's not a regular thing?

J: No...yeah, yeah, yeah

S: OK, so people come to your house...?

J: No no no...er...me and you

S: Ah, OK, you and your wife

J: Yes

S: Ah, I see, so it's not a group?

J: No no no

S: It's private study

J: Mmm

### **SLT, group 3**

S: So thinking about your concept of spirituality and that's kind of, it's yours, do you ever discuss things of a spiritual nature with your patients?

SLT: Yes.

S: Or they with you?

SLT: Yes. I was going to say yes, sometimes... OK, when you approach a person at the bedside there are maybe clues, so for example there may be a crucifix lying on their bedside table or a bible or a daily devotional, or sometimes there are clues in the greeting cards, so people will say something like 'we miss you in church, God bless, we are all praying for you on Sunday' you know, so those where people are... they are spiritual and I would call that religious.

And then there are people who, listening to their stories and their concerns, you know, like I mean just... just some examples are there's a 98 year old woman who, she had some minor language problems that resolved with the thrombolysis but she was 98, compos mentis, able-bodied, but I was assessing her language to make sure that she didn't require a follow-up in the community or perhaps she did.

But she started talking with me about how her mother died when she was a little girl, when she was 4 years old and how she went to live with an aunty and how she hadn't thought of her mother until now and so we had a meaningful conversation about life, ...you know, so just being... needing people where they're at, yeah.

S: And do you think, just thinking of the 98-year-old woman, do you think ... There was something about you as a speech and language therapist which helped her open up and explore that area around her mum and her mum dying and stuff...

SLT: I know so, I know so and it's simply sitting down, taking the time and you do do. It's ... you are doing the technical bits, you know, looking in a person's mouth, asking them the

biographical questions and so on but then in between that, having the meaningful conversation, yes, yes.

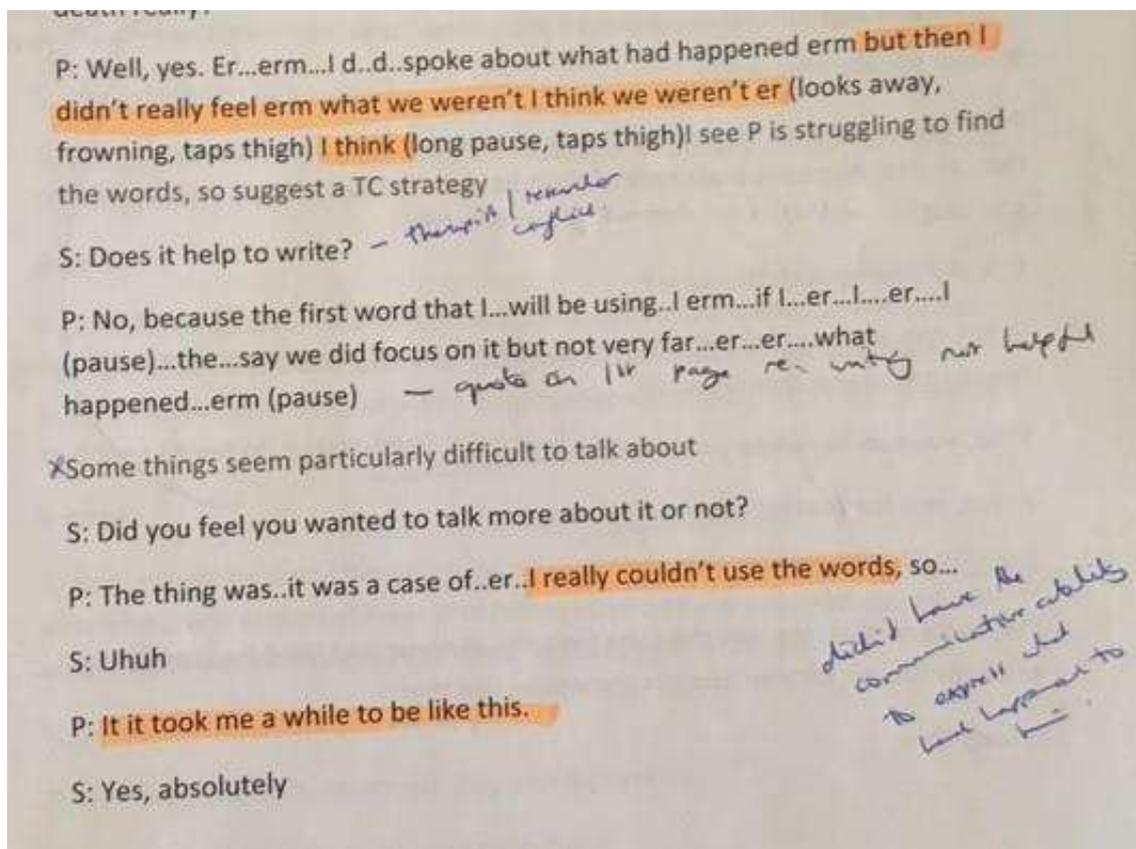
Yeah, yeah. Do you know it's funny... I was just looking at... as I was thinking about this interview, certain things that... rules that I live by – I don't know if you would like to hear them.

S: I would love to hear them.

SLT: I feel like the work that I do (and I don't mean to sound like a flake) but I think it is sacred work because I think if you need to see me, you are obviously having a bad day, you know, you have had a stroke, you are OK.... So I do believe it's sacred work. The thought of... I try to make my work an act of kindness and the third thing is... well 'do no harm', yeah.

## Appendix VI: Examples of annotated script and themes table

### Example of annotated script (Peter, group 2)



### Example of themes table (Peter, group 2)

Theme	Subthemes	Examples in transcript	Interview	Page
Relationship	Family	So but erm that's what it is with me. I go out and visit people er my daughter, she live in C er and and my wife she [lid] (lives) in S	1	7
	With researcher	Oh, yes. I couldn't, no, I couldn't talk at all and er then C (name of speech and language therapist) at the...er..(cat descends from back of chair behind P's head and we both smile and laugh)	1	3
	People at the stroke group	P: erm (pause)...people that I can talk to is the stroke group (many attempts) S: A and the other people at the stroke group?	1	4/5

		P: Yes S: So you get support from them? P: ( <i>long pause</i> ) we tend to just talk about anything		
Trauma of stroke	Difficulty articulating trauma	S: could you ask him for help? P: erm (sharp exhalation) I don't know erm I really don't know erm...	1	1
		Er...erm...I d..d...spoke about what had happened erm but then I didn't really feel erm what we weren't I think we weren't er ( <i>looks away, frowning, taps thigh</i> ) I think ( <i>long pause, taps thigh</i> )	1	4
		The thing was...it was a case of...er...I really couldn't use the words, so...	1	4
	Difficulty verbalising trauma to medical staff	P: er the people in charge...way above them ( <i>gestured "above"</i> ) they wouldn't talk me like a...er...they wouldn't talk to me about ( <i>hand gestures</i> ) what happened because they were...er... ( <i>pause</i> ) erm no because then as I say I really couldn't talk to them anyway, so. S: Are these like doctors and consultants and that sort of person? P: yes, that's what I think, yes	1	5
	Difficulty verbalising trauma to chaplain	P: No...I would talk to 'em...er...but not knowing what I had erm I couldn't talk to them anyway ( <i>nods</i> )	1	6
Garden	Importance of garden	S: What's important to you? P: ( <i>with energy</i> ) what's [ɪmpɔ:tət](important) to me is getting on with the garden ( <i>smiles</i> )	1	6
			1	7
	Passion/enthusiasm for garden	what I did then, I [dʌk] (dug) out some of the plants anyway, others I erm cut them in two. I bought one half so I had six hundred plants erm erm erm but then I bought them with me so  S: So, what do you get, working in	1	8

		the garden? What does it do for you? P: Ah ( <i>shakes head, shrugs shoulders – as if to say “so much! – smiles</i> ) er...pause...I do [lʌb] (love) ...I love my garden...I like the flowers but I also like the birds and the bees and everything else erm...erm...( <i>gesture – animated</i> )	1	8
	Effect on mental health when unable to garden	Oh, yes, yeah...erm...this...this...the best time of year when it's it [bɔm] (warm) and when it's warm...I don't...I erm...live...I live a bit...I get...(pause) ( <i>shakes head, sighs</i> ) (pause) when it's not nice out there, I get a bit low	1	9
	Eloquence and clarity of gestures when talking about garden	I did erm this was three different plants and I ( <i>gesture with both hands, finger of left hand crossing fingers of right</i> ) then er er created plants er er and then erm oh they would just small bits of erm they were just small bits of garden and I joined all of the things together and made it what I did was er if I can hoe ( <i>gestures hoeing</i> )		
	Wanting to get back to gardening after cancer diagnosis	So now I really think that I don't..I can't I can't do do it anymore...I think I'll get on with me garden and er that's ...and that's ( <i>gesture</i> ) that's because I don't want to I don't want to er...I don't want anything I don't want anything er...(pause – <i>shakes head</i> ) S: you've had your fill of being ill P: yes, I don't want anymore S: You, you just want to get on with the garden? P: yes	1	11

## Appendix VII: Summary of themes

### Summary of the themes in groups 1 and 2

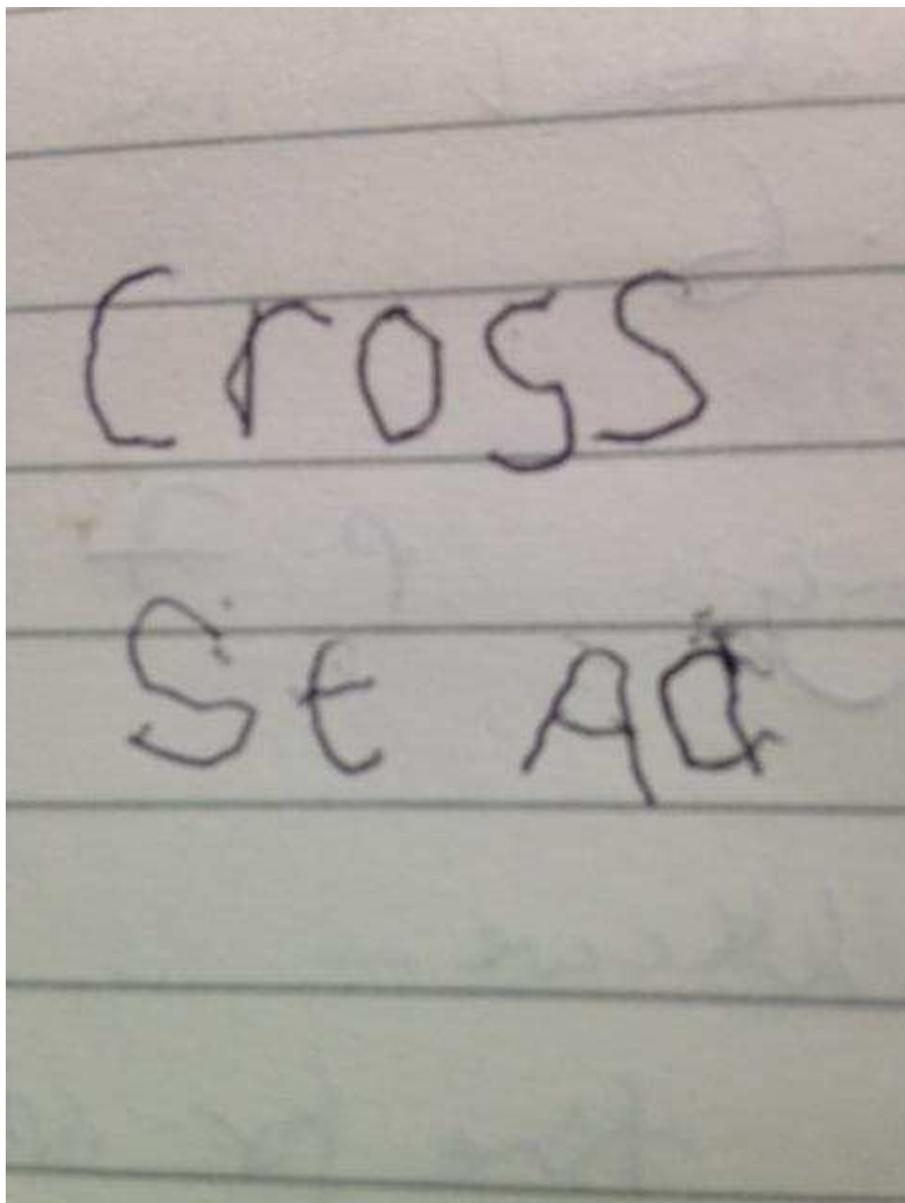
Theme	Participant
Family and relationships	Amy Liam Francesca David Peter
Pets	Amy Liam
Art	Lindy Francesca
Sport	Liam
Faith, church and religious belief	Amy Lindy Joel David
Visions	Lindy Joel
Resurrection	Lindy Joel
Chaplains and priests	Amy Lindy Joel David
Liturgy	Lindy Joel
Pilgrimage	Lindy
Loss	Liam Joel Francesca
Nature	Lindy Peter
Busyness and work	Francesca

### Summary of the themes in group 3

Theme	Participant
Spirituality/ having spiritual conversations	SLT OT PT Lay chaplain
Sacredness	SLT
Spirituality as part of MDT remit	SLT OT Nurse PT
Overstepping remit	PT
Skills of therapist/ MDT	SLT OT
Danger of proselytising	PT
Dignity	SLT
Identity	SLT OT
Rapport/ relationship	SLT OT Lay chaplain
Time	SLT OT Lay chaplain
Love	Lay chaplain
Loss	SLT OT
Referral on to others	SLT OT PT Nurse
Avoiding people with aphasia	Lay chaplain

## Appendix VIII: Example of total communication

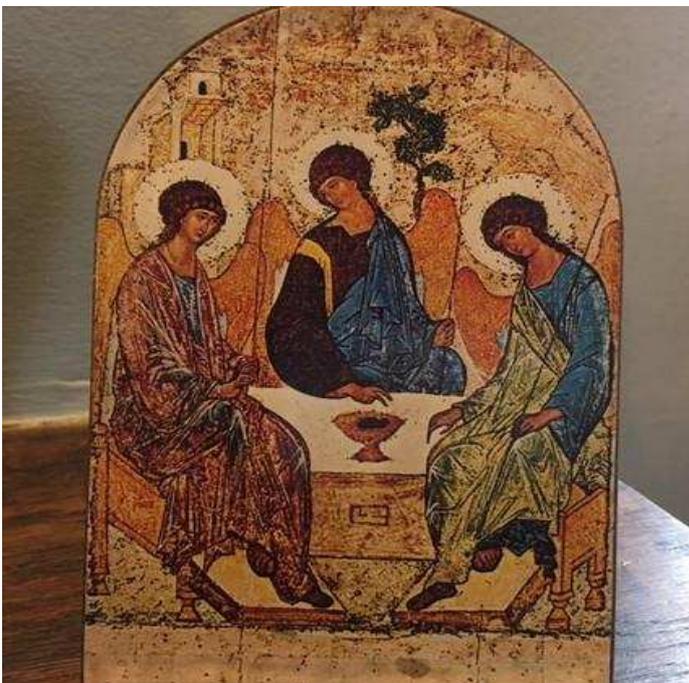
Joel's (group 2) writing



**Appendix IX: Examples of artefacts used in interview with Joel (group 2)**



**Trinity symbol sculpture**



**Hospitality of Abraham icon**



**Holman Hunt's Light of the World picture**

## Appendix X: Accessible summary of the thesis

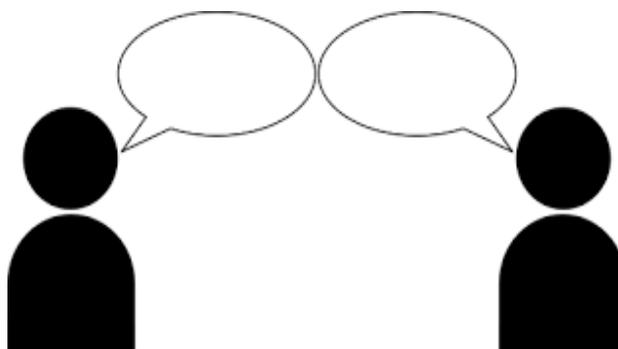
After an illness, people often have difficult questions and thoughts that they want to express. These may be about life,  
meaning  
or God.

It is important for people with **aphasia** to be able to talk about their **spirituality** – especially after a stroke. It can help in coming to terms with what has happened to them.

### I wanted to find out:

- How do **people with aphasia** talk about **spirituality**?
- Are professionals happy to talk about **spirituality** with **people with aphasia**?

### What did I do?



I had conversations with 8 people with **aphasia**.

I also had conversations with:

- a speech and language therapist
- an occupational therapist
- a physiotherapist
- a nurse
- a lay chaplain

### **What did I discover?**

People with **aphasia** can and do talk about spirituality. They use speech but also gestures, tone of voice and writing. They talk about complex and sensitive things.

It helps if the listener gives **time**.

It helps if the listener is **open** and **accepting**.

### **What does this mean for people with aphasia?**

Therapists can help people with **aphasia** to express their **spirituality**.

### **What does this mean for speech and language therapists?**

Speech and language therapists should be happy to talk to people with **aphasia** about everything.

If they **listen openly**, with a sense of **wonder**, people with **aphasia** will feel heard.