



City Research Online

City, University of London Institutional Repository

Citation: Mackenzie, S. (2020). "Is All in All": Exploring Spirituality with People with Expressive Aphasia Using a Phenomenological Approach. *Journal of Disability & Religion*, doi: 10.1080/23312521.2020.1776189

This is the accepted version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/24370/>

Link to published version: <https://doi.org/10.1080/23312521.2020.1776189>

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

City Research Online:

<http://openaccess.city.ac.uk/>

publications@city.ac.uk

“Is all in all”: exploring spirituality with people with expressive aphasia using a phenomenological approach

Although spirituality has been discussed extensively in the healthcare literature in general in the last twenty years, there is a paucity of speech and language therapy literature related to the subject. Spiritual concerns may be brought to the fore and need to be expressed after serious illness. However, following stroke, some patients may present with difficulties in their communication, such as aphasia. This research asks the following research question: what is it like to express your spirituality when you have aphasia?

Eight people with aphasia were interviewed about their spirituality using a phenomenological approach. The interviews were transcribed and analysed using a flexible analytic approach, and themes common to several participants were identified.

Participants were able to express ideas of spirituality and life-meaning using a variety of communication methods. Speech and language therapists need to be mindful of their patients’ spiritual concerns if therapy is not to become superficial.

Word count: 5762

Introduction

The concept of spirituality and spiritual care has to date been discussed little in the speech and language therapy (SLT) literature, and the spiritual concerns of SLT clients remain largely neglected (MacKenzie, 2015; Mathisen, 2015). Defining a term such as “spirituality” is a difficult, and arguably potentially reductive, task. Some have argued that its power perhaps lies in its inability to be reduced to a definable concept (Swinton and Pattison, 2010). Nevertheless, it is perhaps useful to gather together 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) talk about “purpose and meaning of human existence” and Swinton (2010) of “meaning, purpose, value, hope and love”. Despite the professional imperative of working in an holistic manner, speech and language therapists (SLTs) have not routinely considered the spiritual aspect of their clients, concentrating instead on the body and mind. Although issues relating to spirituality in healthcare have proliferated in the nursing literature (Ross, 2010), and are beginning to appear in some allied health literature (Rumbold, 2018), very little spirituality research has as yet been carried out by SLTs with participants with communication impairment (MacKenzie, 2015).

However, according to Mathisen et al (2015), SLTs may be doing their clients a disservice if they do not consider spiritual concerns during therapy; they cite the “largely neglected clinical relevance” (p. 2309) of spiritual issues within the sphere of speech and language therapy. Given that religion/spirituality has been shown to provide coping strategies for people with illness (Konig, 2012; Homan and Boyatzis 2010), may lead to healthier lifestyles (Konig, 2012) and that being aware of a client’s spiritual concerns may foster empathy, compassion and rapport (Mathisen, 2015), it is puzzling why speech and language therapists have to date not fully embraced the idea of considering spirituality in the assessment of and intervention with their clients (MacKenzie, 2015).

Within a multidisciplinary team, it may be the SLT who is best-placed to facilitate completion of word-based spiritual assessments, such as the FICA (Puchalski, 1996), and to advise chaplains and other pastoral workers on the best way to facilitate conversation with someone with a communication impairment. However, because spirituality is not routinely considered by SLTs, this may not be routinely happening.

Negative impacts of not including spirituality in SLT practice may include the fact that therapy could become superficial by not incorporating aspects important to an individual. If spiritual issues are not incorporated into therapy and therapy goals, this may negatively impact on the success of therapy. Clients may also need the help of an SLT in order to access religious or spiritual resources or practices which may help with the healing or therapy process (Mathisen, 2015).

Literature suggests that those facing crises in their lives – including serious illness and disability – may seek answers to spiritual issues and may need to voice existential questions (Burke and Niemeyer, 2012). How people with communication impairment can do this, and whether this can be facilitated by professionals such as speech and language therapists, forms the crux of this study.

This research is an addition to the current developing narrative around spirituality in healthcare in general and in speech and language therapy in particular (MacKenzie, 2016), and seeks to explore spirituality and spiritual concerns with people with communication impairment. The study took the form of a phenomenological exploration of the lived experience of people with aphasia following stroke expressing their spirituality. The research question was as follows:

- What is it like to express your spirituality when you have aphasia?

Method

Following the convention in much qualitative research (Holliday, 2007), I have chosen to use the first person throughout. In the interview extracts, S refers to me, and the participants are denoted by the initial letter of their pseudonym.

Eight participants with aphasia post-stroke were recruited using convenience sampling

(Robson, 2011), three (group 1) from an acute stroke unit, and five (group 2) from various stroke communication groups (table 1). The group 1 participants had had a stroke less than 4 weeks prior to the interview. The group 2 participants had been living with their aphasia for more than 9 months. All participants were given a pseudonym in order to protect their anonymity and consent was acquired through the use of accessible information sheets and consent forms. Full ethical approval was gained from the UK National Health Service (group 1) and from the University Research Ethics Committee (group 2).

All group 1 participants were interviewed by the bedside in an acute stroke ward. Group 2 participants were interviewed either at their own home or in a quiet room next to their stroke group meeting area. Participants all had aphasia but their expressive language skills were markedly more affected than their receptive abilities. Language level or exact type of aphasia was not relevant to the research, therefore formal assessments of language were not carried out. The participants used any communicative method open to them, including speech, writing key words, gesture, intonation, use of artefacts and facial expression.

Discussions took the form of conversational interviews (Kim, 2016; van Manen, 1990) loosely based on a pre-devised topic guide (see appendix 1). However, the conversations were led by the person with aphasia, and so the topic guide acted more as an aide memoire for me rather than a rigid framework. Some participants (Leanne, Joel, Amy and Liam) were interviewed on more than one occasion. David and Peter could only be interviewed once for organisational reasons, and Rosemary was transferred to another health facility after the first meeting, and was therefore also only interviewed once.

Both descriptive and hermeneutic phenomenology approaches were adopted during the study. During the interview stage, when I was listening to the participants' stories, a descriptive approach was used; I attempted to appropriate van Manen's imperative of "thoughtfulness" (1990, p 12), rapport and relationship by listening attentively and transcribing faithfully. However, Finlay (2011, p 120) recognises, "the space between description and interpretation is ambiguous", and as I wrote a summary of each participant's story, my approach became more hermeneutic, as they intertwined with my own cultural, clinical, societal, and spiritual experiences.

I employed van Manen's (2016) "phenomenological attitude" of curiosity, openness and wonder as I listened to the participants talk about their spirituality. Although traditionally phenomenologists are exhorted to bracket off (Moustakas, 1994) their preconceptions and experiences, this was deemed impossible and, indeed, undesirable. I am a qualified speech and language therapist, with my own opinions and experiences of spirituality; Gadamer's (2013) useful concept of "fusion of horizons" therefore seemed more apposite. Gadamer exhorts the researcher to acknowledge their own prejudices (or what he calls "fore-meanings"), but at the same time to listen attentively and respectfully to the other's experiences. I brought my own fore-meanings to prominence by a process Gadamer refers to as "foregrounding". 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)

All interviews were audio recorded using a Sony ICD-PX312 digital voice recorder. Any written or drawn communicative material was captured either by keeping the paper on which words, numbers or pictures were written, or by photographing these. I also endeavoured to write detailed notes after the interview in a research log, to record gestures or other non-verbal communication which might not be immediately apparent in an audio recording.

After interviewing, I took time to dwell with (Heidegger, 1962) or immerse myself in (Robson, 2011) the data, by listening and re-listening to the audio recordings. Each interview was then transcribed verbatim, including transcribing neologisms (non-English words) and phonemic paraphasias (where more than 50% of phonemes are correct) using phonetic script (International Phonetic Alphabet). Pauses and fillers were noted, as was the inferred communicative intent of intonation. Some of the utterances were impossible to transcribe, due to concomitant motor speech disorders (apraxia of speech and dysarthria) in some instances, and due to noise on the ward in others. 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); key themes were identified, and each participant's interview(s) was then written up in the form of their own story; this was in order to maintain and value the individual identities of the participants, recognising that sense of identity is often compromised after stroke (Ellis-Hill and Horn, 2000; Shadden, 2005). Themes common to all eight stories were also identified, and these are presented in this paper. Analysis of the themes through the lens of some concepts propounded by Merleau-Ponty (2002), such as ambiguity, was also carried out, and is reported in a separate paper (MacKenzie and Marsh, 2018).

Results

Definitions of spirituality

For some, notably Joel, Leanne 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 Leanne, 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 Galatians 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 aloud, and in this way he was cued into the word “spirit”; so, although the fruits of the spirit were verbalised by me, he in fact instigated the idea non-verbally through finding the Bible verse, and indeed he completed it verbally:

J: *(long pause – reaches for Bible again)* OK *(finds Galatians)* 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

For others, there was an emphatic lack of overlap between spirituality and organised religion, although they still professed to a faith. Both David and Francesca were adamant that their spirituality was completely divorced from the Church of England or any other religion. For example, this extract is from Francesca's interview:

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 did both claim a belief in a higher being. David stated that he believed in Jesus Christ, and Francesca said "Jesus maybe, maybe not" although it was unclear whether she was 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 the conversation with Rosemary did not progress to it), the concept of spirituality seemed to evoke overwhelmingly positive feelings. For example, Leanne equated 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, employed 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 appeared to be all-encompassing and perhaps inextricable from other facets of life:

“Life (*with definite intonation*) yep”

Peter, like Francesca, considered himself to be a spiritual being, but was unsure how to put that into words, or of what he believed 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 struggled to express his spirituality:

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

so Peter was also at a loss and "can't think of anything" when asked for his definition of spirituality.

Spirituality as meaning-making

Despite the evident difficulties of explaining what the term spirituality may mean to them, participants did express the spiritual aspects of their lives in a number of ways. The question "what gives your life meaning" was often posed as a prelude to asking the more numinous "what does the term spirituality mean to you?".

A number of participants were animated when talking about their meaning-makers. Peter explained 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 was considerably longer, and included accurate and intricate gesture to convey meaning. In contrast, vocabulary deserted him when trying to define spirituality, and the gesture he used served 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 was 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 gives meaning to Leanne'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

Although David is a fine artist, he eschewed art as his meaning-maker and instead mentioned his children. However, he did not elaborate, and I was 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

His response was brief and may be a reflection of the fact that I was a relative stranger and that rapport had never really become established. Perhaps it is just a truism that children give our lives meaning, and the statement therefore needs no further explanation or exegesis.

Both Leanne and Francesca mentioned their parents in their conversations. For both, parents represented protection and comfort. Francesca's father held her hand (she used speech and gesture to express this) as she went into the computed tomography scanner, just after her stroke. She also compared her mother's love of ballet to her own love of opera; it is not without a hint of pride that she talked about her mother not being of the social class one might associate with ballet-lovers, but that she was "working

class but yep yep yep.” She also self-corrected 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 felt recent. Leanne’s parents featured 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 loved his motor sport and his cat, Amy derived purpose and meaning from household chores and her pets, and the thing Rosemary missed most about home was her television.

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 Leanne both appeared steadfast in their faith and in their beliefs. Joel used facial expression, intonation and definite head shaking to emphasise the fact that God was the most important aspect of his life, and that his faith had 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 believed that “God will be glorified”, so perhaps he saw his disability as a testimony of faith. Leanne, too, used intonation and head nodding very effectively to convey that, despite her illness and subsequent disability, she still believed 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 Leanne’s unwavering faith may be linked to their belief in the fact that, as Christians, they believe they will receive the gift of eternal life and inhabit a new body in heaven:

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*)

Religion and liturgy

Leanne, Joel and Amy all professed a faith and indicated that they took part in organised religious activities. Amy used gesture and speech to talk about prayer and blessing. Joel used artefacts to cue himself into half-remembered liturgy; for example, looking at and touching a communion wafer enabled him to express the words “body”, “blood” and “testament”, and the pertinent snippet of liturgy “in remembrance of me”.

Both Leanne and Joel still took part in services at their respective local churches. They both admitted that speaking prayers aloud was no longer possible, but that they were able to pray without words. Joel has an element of surprise in his voice, as he affirmed that he still participated fully in liturgy and worship, as if to say ‘of course – why ever not?’. Leanne said at one point that she was able to recite well-known prayers such as the Hail Mary, but was unable to engage fully in, for example, confession. When I asked her if she was able to recite liturgy, she graphically gestured her lips being zipped shut.

Visions

Both Leanne and David reported seeing visions as integral parts of their spiritual stories. David reported seeing a vision of someone whom he intimated was 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

David says that this was a "positive" experience for him, which conveyed comfort and protection.

Leanne related two stories involving visions. One, when she saw her deceased parents forming a barrier between herself and the angel of death, and another when she experienced angels surrounding her whilst in a coma after her stroke. She reported that her parents shielded her from the frightening vision of Azrael, and that the angels brought a sense of peace and beauty.

Meaning-makers being taken away post stroke

Although all the participants reported diverse meaning-makers in their lives, from pets to opera, God to gardening, many of them also reported a common loss of or change to that meaning-maker post-stroke. They reported no longer being able to engage in the activity as they might have done prior to the onset of their disability. For example, Leanne was formerly a published novelist but, now that she is no longer able to construct art of that length and complexity, the new post-stroke Leanne is a poet, often drawing on her stroke and aphasia experience as subject matter. For Leanne, although she had been deprived of one meaning-maker through aphasia, another had taken its place.

Neither Leanne nor Joel were able fully to engage in church services. As a Roman Catholic, Leanne was not able to participate in confession, for example, and Joel was no longer able to pray aloud. However, both claimed still to be able to communicate with God via silent, unspoken prayer, or through nature. In one of the conversations with Joel, there was a glimpse of some frustration, as he tried to talk about a particular verse in the Bible which he was unable to find; he instructed his wife to find it, too, and when she flicked further back in the Bible, he physically stopped her and said “no, no”, with an air of exasperation. I wrote in my notes that Joel’s wife “drifts away as he continues to search”; this felt like a common occurrence, with Joel knowing the verse from scripture he wanted but not being able to find it.

As well as finding life meaning in opera, Francesca talked about her love of photography, but her physical disability now precluded 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 admitted to the fact that his not being able to work in the garden in the winter negatively impacted his mental health; being deprived of his meaning-maker had an obvious effect on his wellbeing and health:

“Oh, yes, yeah...erm...this...this...the best time of year when it’s it [bòm] 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”.

Physical needs take precedence over spiritual

There was a common theme in the group 1 stories of physical needs taking precedence over discussions of the numinous. This was illustrated by Amy not always being

available for a conversation, because she was seeing a therapist as part of her rehabilitation programme. She was also often preoccupied with mealtimes and drinking, satisfying her physical needs before the numinous could be tackled. Liam, too, had many physical issues with which to contend, including a nasogastric tube, swallowing issues and a productive cough. Rosemary was only available for one interview in the acute stroke unit, limiting the opportunity for deepening the discussion to include spirituality, as she was transferred to another unit to continue her (physical) rehabilitation.

Discussion

A perennial discussion in studies of spirituality is the relationship between religion and spirituality (Tacey, 2012). This relationship – or lack thereof - was mirrored in the responses of the participants when they were asked the question “what does spirituality mean to you?”. Some conflated spirituality and religion, the one being synonymous with the other for Leanne and Joel. Most participants (except Liam and Rosemary) were able to attempt a definition of spirituality, despite the fact that this is deemed to be a difficult task even with intact speech and language skills (Van der Veer, 2012). Other participants equated spirituality with those aspects which gave their life meaning, in line with Swinton’s (2010, p 19) definition of spirituality which incorporates “meaning, purpose, value, hope and love”. In this way, Peter talked animatedly about his garden and Francesca about her love of opera. Of note is the fact that Peter employed more complex communication skills when discussing his garden than, for example, trying to provide a definition of spirituality. When defining spirituality, his language was lacking in content words (nouns, verbs, adjectives) and he produced many fillers (such as “er”). By contrast, he used both more verbal language as well as intricate gestures to explain how he grafted one plant onto another in his garden. Francesca was able to name several

composers, despite proper nouns often being particularly problematic for people with aphasia (Beeson, Holland and Murray, 1997); perhaps this bears testament to the importance opera and composers held in her life. Francesca described the wonder of the words and music, and is also cued into the word “emotional”; it seems that opera tapped into a facet of her being which is not necessarily body or mind, but may be construed as spirit.

Being able to engage in meaning-makers in their lives changed for many of the participants. Perhaps part of the rehabilitation process is to accept the loss of meaning-makers and to discover new ones, as clients move into Frank’s (2013) quest illness narrative, adapting to a new way of being. Leanne is perhaps the participant who demonstrates best being in the quest stage of recovery, as she adapts her writing from novels to poetry.

Participants who profess a faith (Joel, Leanne and Amy) all intimated that their faith had not wavered following their stroke. Some differences in being able to access liturgy and church services were alluded to, and could form the basis of further study.

Leanne and David both shared intimate stories of visions in relation to their spirituality. According to McGilchrist (2010), the right cerebral 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” (p. 177). 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. There exists the possibility that people with an impaired left cerebral hemisphere where, according to McGilchrist (2010), certainty

abounds, use their unimpaired hemisphere to embrace ambiguity and all that is uncertain and unproven (MacKenzie and Marsh, 2018), such as equivocal visions.

Participants in group 1 whose strokes had occurred only a few weeks prior to the interviews, and who were all still in an acute hospital setting, were less able to engage in conversations about spirituality than those in group 2 who had been living with their disability for longer, and who were no longer in hospital. 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. Participants in group 1 could also be viewed as living in Frank's (2013) chaos stage of illness recovery, when "the suffering is too great for the self to be told" (p. 115). Because of their aphasia, they 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.

Although the 4 Rs propounded by Finlay and Evans (Finlay, 2011) were used in order to evaluate this research (namely rigour, relevance, resonance and reflexivity), there were inevitably some limitations. It was a small scale project with only eight participants and those who professed a faith were all of a Christian background. Further studies would benefit from sampling larger numbers of participants, and perhaps from purposively sampling participants with diverse professed faiths.

In addition, 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) this was apparent in only some of the current stories (Leanne 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. 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.

Conclusion

This study sought to explore how people with a significant communication impairment post-stroke – namely, aphasia – were able to express issues relating to their spirituality. It concurs with Mathisen et al's (2015) proposition 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) because SLTs may be the best-placed professionals to facilitate completion of such a word-based assessment with clients with communication impairment. In this study, participants used a number of non-verbal adjuncts to their speech (for example, gesture, drawing and facial expression), and were facilitated to do so by a speech and language therapist. 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; Joel in group 2 made use of artefacts in order to aid expression. Thirdly, use of WHO coding in pastoral and spiritual care may make for more holistic and client-centred goals (WHO, 2002). Participants with aphasia in this study demonstrated an ability to engage in discussions around spirituality, particularly those who had been living with their aphasia for some time. It was clear

from both their verbal and non-verbal expression that for Peter, Joel, Francesca and Leanne in particular, their spirituality was an intrinsic facet of their life and should therefore be taken into account when planning therapeutic intervention. Finally, if SLTs become truly holistic practitioners who are open to discussing spiritual issues with their clients, they may be better placed to facilitate discussions of spirituality between clients with communication impairment and pastoral care experts, such as chaplains.

Declaration of interest

There are no declarations of interest.

References

- Beeson, P.M., Holland, A.L. and Murray, L.L. (1997) 'Naming famous people: an examination of tip-of-the-tongue phenomena in aphasia and Alzheimer's disease', *Aphasiology*, 11(4/5), pp. 323-336
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3(2) 77-101
- Burke, L.A. and Neimeyer, R.A. (2012) 'Meaning making', in Cobb, M., Puchalski, C.M. and Rumbold, B. (eds) *The Oxford Textbook of Spirituality in Healthcare*. Oxford: Oxford University Press, pp. 127-133
- Cobb, M., Puchalski, C. and Rumbold, B. (2012) *The Oxford Textbook of Spirituality in Healthcare*. Oxford: Oxford University Press
- Ellis-Hill, C. and Horn, S. (2000) 'Change to identity and self-concept: a new theoretical approach to recovery following stroke', *Clinical Rehabilitation*, 14(3)
- Finlay, L. (2011) *Phenomenology for Therapists: researching the lived world*. Chichester: Wiley-Blackwell
- Frank, A.W. (2013) *The Wounded Storyteller: body, illness and ethics* (second edition). Chicago: The University of Chicago Press
- Gadamer, H-G. (2013) *Truth and Method*. London: Bloomsbury
- Heidegger, M. (1962) *Being and Time*. Oxford: Blackwell Publishing
- Holliday, A. (2007) *Doing and Writing Qualitative Research* (second edition). London: Sage
- Homan, K. J., and Boyatzis, C. J. (2010) 'Religiosity, sense of meaning, and health behaviour in older adults', *The International Journal for the Psychology of Religion*, 20(3), pp. 173-186
- Kim, J-H. (2016) *Understanding Narrative Inquiry*. United States: Sage Publications

- Koenig, H.G. (2012) 'Religion, spirituality, and health: the research and clinical implications' *ISRN Psychiatry*, pp.1-33
- MacKenzie, S. (2015) 'Spirituality and speech and language therapy', in Stokes, J. and McCormick, M. (eds.) *Speech and Language Therapy and Professional Identity: challenging received wisdom*. Guildford: J and R Press, pp. 127-141
- MacKenzie, S. (2016) 'Sacred work? Exploring spirituality with therapists working with stroke patients with aphasia', *Journal for the Study of Spirituality*, 6(1), pp. 78-88
- MacKenzie, S. and Marsh, I. (2018) The philosopher of ambiguity: exploring stories of spirituality of people with aphasia through the lens of Merleau-Ponty *Journal of Disability and Religion*
- Maslow, A.H. (1954) *Motivation and Personality*. New York: Longman
- Mathisen, B., Carey, L.B., Carey-Sargeant, C.L., Webb, G., Millar, C. and Krikheli, L. (2015) 'Religion, spirituality and speech-language pathology: a viewpoint for ensuring patient-centred holistic care', *Journal of Religion and Health*, 54, pp. 2309-2323
- McGilchrist, I. (2010) *The Master and his Emissary*. London: Yale University Press
- Merleau-Ponty, M. (2002) *Phenomenology of Perception*. Abingdon: Routledge Classics
- Moustakas, C. (1994) *Phenomenological Research Methods*. United States: Sage Publications
- Puchalski, C. M. (1996) Spiritual assessment in clinical practice, *Psychiatric Annals*, 36(3), pp. 150-155
- Robson, C. (2011) *Real World Research* (3rd edition). Chichester: Wiley
- Ross, L. (2010) 'Why the increasing interest in spirituality within healthcare?' in McSherry, W. and Ross, L. (eds.) *Spiritual Assessment in Healthcare Practice*. Keswick: M and K Ltd, pp. 5-16

- Rumbold, B. (2018) 'Introduction: Spiritual Care and Allied Health Practice' in Carey, L.B. and Mathisen, B.A. (eds) *Spiritual Care for Allied health Practice: a person-centred approach*. London: Jessica Kingsley, pp.11-21
- Shadden, B. (2005) 'Aphasia as identity theft: theory and practice', *Aphasiology*, 19(3-5), pp. 211-223
- Swinton, J. (2010) 'The meanings of spirituality: a multi-perspective approach to the 'spiritual'', in McSherry, R. and Ross, L. (eds) *Spiritual Assessment in Healthcare Practice*. Keswick: M and K Publishing, pp. 17-35
- Swinton, J. and Pattison, S. (2010) 'Moving beyond clarity: towards a thin, vague, and useful understanding of spirituality in nursing care', *Nursing Philosophy*, 11(4), pp. 226-237
- Tacey, D. (2012) 'Contemporary spirituality', in Cobb, M., Puchalski, C. and Rumbold, B. (eds) *The Oxford Textbook of Spirituality in Healthcare*. Oxford: Oxford University Press, pp. 473-479
- Van der Veer, P. (2012) 'Culture and Religion', in Cobb, M., Puchalski, C. and Rumbold, B. (eds) *The Oxford Textbook of Spirituality in Healthcare*. Oxford: Oxford University Press, pp. 169-174
- Van Manen, M. (1990) *Researching Lived Experience: human science for an action sensitive pedagogy*. Albany: The State University of New York Press
- Van Manen, M. (2016) *Phenomenology of Practice*. Oxford: Routledge
- World Health Organization (2002) *WHOQOL Spirituality, religiousness and personal beliefs (SRPB) field-test instrument* Geneva: World Health Organization

Appendix 1
Topic Guide

Interview topic guide (groups 1 and 2)

- 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?

Table 1. Table to show participants in groups 1 and 2

Group 1: people living with their aphasia for < 4 weeks	Approximate time since onset	Group 2: People living with their aphasia for > 9 months	Approximate time since onset
Liam	2 weeks	Leanne	5 years
Amy	2 weeks	Joel	3 years
Rosemary	4 weeks	David	9 months
		Peter	2 years
		Francesca	15 years