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Sacred work? Exploring Spirituality With Therapists Working With Stroke Patients With Aphasia

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Speech and language therapists (SLT), occupational therapists (OT) and physiotherapists (PT) on stroke rehabilitation wards have long worked in an holistic way, with the client at the centre of their interventions. However, if we consider our clients to be tripartite beings, comprising body, mind and spirit, do we, in fact, give credence to the spiritual dimension? Are there particular considerations in this regard when we consider those patients who present with communication difficulties following a stroke? Are we able to facilitate expressions of spiritual distress/need in our clients with aphasia who have difficulty verbalising their thoughts and, if so, is it our role to do so? As part of a larger study exploring stories of spirituality with people with aphasia, I interviewed members of the multidisciplinary team on an acute stroke ward. I wanted to explore their understanding of their professional role *vis-à-vis* spirituality. This article focusses on some of the themes which emerged in the interviews with the therapists on the stroke ward: an OT, SLT and PT. Using a hermeneutic phenomenological approach, I encouraged them to talk about their interventions with people with aphasia, their definition of spirituality, and whether they considered facilitation of expressions of spirituality in their clients with aphasia part of their therapeutic remit. Although, of course, this represents a very small sample of therapists, nevertheless some interesting themes have begun to emerge, which I hope will contribute to further dialogue.

KEYWORDS aphasia, spirituality, stroke, speech and language therapy, occupational therapy, physiotherapy

Introduction

Stroke is a common illness (Lee, Shafe & Cowie 2011) that can result in death (Scarborough et al 2009) or serious, life-changing disability (Hankey et al 2007). It is estimated that approximately one third of stroke patients will subsequently present with aphasia, a difficulty with understanding or expressing language, or both (Papathanasiou, Coppens & Potagas 2013), usually within the context of other cognitive abilities being relatively well-preserved.

People with aphasia post-stroke commonly undergo a period of rehabilitation (NICE 2013), including intervention from a speech and language therapist, and a physiotherapist (if physical disabilities are also present) and an occupational therapist (if activities of daily living are also affected).

I have been a qualified SLT for twenty-five years, and have often battled with the idea that, although my role is to help my patients with aphasia to express their basic needs, am I in a position to help them express more than that: to express issues of a more abstract, possibly numinous nature? Is this my role, and, if so, what skills as a therapist, and specifically an SLT, can I bring? In consequence, I embarked on a doctoral study, seeking to explore how

people with severe communication difficulties as a result of aphasia post-stroke expressed their spiritual needs, distress or well-being. I was also interested in whether the professionals working with people with aphasia felt it was within their remit to facilitate expressions of spirituality and, if so, what strategies they had developed to foster this. Five members of a multidisciplinary team were interviewed (a nurse, a lay chaplain, a speech and language therapist, an occupational therapist and a physiotherapist). This paper focuses on the information given by the allied health professionals (therapists). I thought it would be interesting to see whether, as registered members of the Health and Care Professions Council (HCPC), their shared standards of education and training led to a shared philosophy in terms of their remit.

Spirituality and the therapies

Therapists working in rehabilitation have long regarded themselves as holistic practitioners, having the patient at the centre of all they do (Koubel & Bungay 2008). Patient-centred care encompasses the entire being - body, mind and spirit. However, although there has been much research and practice in body function and impairment (World Health Organisation, 2001), and some addressing the psychological dimension of patients (Cruice et al 2003), the literature reveals very little in the way of spiritual intervention with our clients. Occupational therapists, it would seem, are starting to integrate consideration of the spiritual into their assessments and protocols. Kang (2003), for example, proposes a new practice framework for OT in the area of psychospiritual integration, concluding that spiritual occupation should, indeed, be the concern of the OT within the holistic care of their clients. Bursell & Mayers (2010), both OTs themselves, undertook a study exploring the perceptions of healthcare professionals working with people with dementia, in relation to spirituality. The Chartered Society of Physiotherapy has begun to explore the concept of spirituality and how physiotherapy might fit into that concept (Wright 2010). There is no available literature to support the notion that speech and language therapists are yet incorporating the spiritual into their interventions, or into their mind-sets, bar ~~the~~ my own chapter in a recent SLT publication (MacKenzie, in Stokes & McCormick 2015).

This is in marked contrast to nursing, which has a long history of addressing the spiritual dimension of the people for whom nurses care. There is evidence of spirituality being considered in the nursing care of patients with cancer (Carroll 2001), in intensive care (Johnson 2005), and with dementia (Carr, Hicks-Moore & Montgomery 2011). In the area of stroke, there have been a number of nursing studies internationally exploring spirituality (for example, Lamb et al 2008), some of which include the perspective of people with aphasia following stroke (Chow & Nelson-Becker 2010).

If we are to accompany our patients along the therapeutic road (Kvale and Brinkmann 2009), to steer them from the chaos of new-found disability to the quest of acceptance (Frank 1995), surely we need to be viewing them as whole beings, which includes their spiritual dimension? The difficulty for professionals working with people with aphasia post-stroke is: how do we facilitate these expressions of spirituality, and is it in fact our role as therapists to do so?

Methodology

I employed a hermeneutic phenomenological approach: Van Manen (1997) posits that when carrying out a phenomenological study, it cannot be wholly descriptive but must contain an

element of interpretation. I was concerned with finding meaning in the lived experiences of my participants, attempting to get to the essence of their role, remit and responsibilities when they are working with people with aphasia, or as Husserl (in Van Manen 1997) puts it, to go right 'zu den Sachen', or to the things themselves.

Husserl (in Van Manen 1997) propounded the concept of bracketing or epoché during phenomenological research, a means of parking one's biases, prejudices and experiences in order to listen with an 'unfettered stance' (Moustakas 1994) to what participants might have to say. Although I wanted to be completely open and 'unfettered' by my own prejudices, it was impossible for me to bracket off my experience of myself as an SLT, my knowledge of working as a therapist with people with aphasia and in a similar team to which my participants belonged, and indeed my own ideas of spirituality. As such, the interviews became, I think, a peer to peer chat, an accepting and open environment in which to share and discuss.

Method

A stroke rehabilitation team in a local hospital was approached and an SLT (female), OT (female) and PT (male) recruited purposively by asking for expressions of interest in taking part in the study. **It would help to mention their gender here.** NHS ethical clearance and a Trust research passport were obtained.

Each professional was interviewed once for approximately 45 minutes in a quiet room off the ward (OT and PT) or at the university (SLT). A topic guide was given to the participants a few days before the interview took place to enable them to start thinking about some of the concepts and ideas. However, the discussions did not always adhere to the guide if interesting concepts arose, thus creating a 'conversational interview' (Kim 2015) rather than a semi-structured interview (Robson 2011). At the end of each interview, I asked "Do you have anything else you would like to add?" Without exception, every participant did. The SLT continued the conversation via text for a few days.

Conversations were digitally audio-recorded, then transcribed verbatim. Themes were discovered (Braun & Clarke 2006) for each interview and superordinate themes spanning all interviews were considered. Although this represents a small sample of participants, some interesting ideas and themes have begun to be uncovered. What follows here is a summary of some of the main themes.

The Speech and Language Therapist's Story

One of the key themes running through the SLT interview is that of identity: of 'masks' falling away during times of crisis, but also, conversely, of clients' identity in terms of their life role or career being maintained within the narrative. So, on the one hand, the SLT talks about a former President of the United States who had a stroke and subsequent aphasia. She expresses how she is sure he would have wanted to be treated as a man in distress, rather than as a man of power and influence, almost as if his standing did not count for anything in the depths of tragedy and illness: "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."

On the other hand, she often gives examples of clients with whom she has worked, and always tells me something about them, their occupation or their age. It is as if she is attempting to solidify their identity, which is so often threatened by stroke (Ellis-Hill & Horn

2000). As the SLT herself says: "*When identity is threatened, a person's 'intactness' is threatened, and that can result in suffering.*"

The SLT views certain elements of her job as conducive to facilitating conversations of a meaningful nature. Even in the busy-ness of the acute stroke rehabilitation unit, she allows herself to give time and attention to patients: '*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.*'

It is perhaps one of the privileges of the SLT profession that we have the luxury of being able to allocate time for communication, indeed it is our *raison d'être*. However, the SLT also admits to holding meaningful conversations "between the technical bits", in perhaps a more opportunistic way. For instance, she may be carrying out an oromotor examination or be asking biographical questions as part of a language assessment, and some meaningful conversation takes place almost accidentally around these activities. The SLT is often in close physical proximity to the patient: "*the work that we do, it's personal.*" This may mean that trust and closeness are engendered early in the interaction, making more sensitive topics more likely to be broached. Swinton (in Cobb, Puchalski & Rumbold 2012) talks about how the other needs 'to come close to understand me', which may perhaps be viewed literally or figuratively.

The SLT is also, of course, well-versed in total communication strategies (such as using gesture, drawing, pictures) which can help facilitate expression for people with aphasia, as well as (from her training and experience) being aware of active listening techniques. Both of these may render the whole interaction scenario conducive to talking about many and varied topics, including those of a sensitive nature such as spirituality.

Like all the healthcare professionals, however, the SLT is aware of the limits of her remit, and of the need sometimes to refer to chaplaincy. Her role in this case seems to be one of suggesting communication facilitation strategies, or being a mediator in a three-way conversation, to facilitate expression and understanding of what is being discussed between the patient and the chaplain.

The Occupational Therapist's Story

Like the SLT, the occupational therapist talks about the importance of time: time to get to know the patient and their method of communication. So, during a washing and dressing session, for example, the OT has time to really 'be' with that patient: "we get lots of time with the patients and lots of in-depth stuff, quite personal stuff sometimes as well." She recognises that, for someone with a communication impairment such as aphasia, even more time might be needed, and she identifies this as a useful strategy in managing this client group: "*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.*"

OTs are holistic practitioners, who deal with all aspects of a person's life. This includes dealing with personal care and questions of a personal nature, so the OT sees discussion of spiritual issues between the OT and their patient as a natural extension of that:

"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...anything that sort of fulfils them and makes them happy.*"

Conversations with people with severe stroke, when death is pending, are common on the stroke unit, and the OT identifies how expressions of existential angst in these distressing situations are even more problematic for patients who are unable to verbalise, or for whom communication is compromised:

"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."

The Physiotherapist's Story

The physiotherapist, too, works in close physical proximity to his patients, and is keen to engender trust and to create therapeutic rapport: *"So as they confident that yeah, I think...I have got someone who understands me, I think they communicate better their fears."*

He is happy to talk to patients about spiritual issues "if they initiate it". Interestingly, he begins by explaining how he would respond to an existential question such as 'Why did this happen to me?' in a purely organic, medical way. However, he then concedes that perhaps some questions sometimes require a non-organic, possibly numinous response: "Are they just 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." He begins to see the question from a person-centred perspective, understanding that perhaps the patient is hunting for understanding that goes beyond the purely pathological, beyond nomothetic knowledge: "Yeah, there could be other explanations the patient is trying to find."

Of all the healthcare professionals interviewed, the PT seems the most aware of the limits of his role as regards spirituality and of the possible dangers of extending beyond that remit. He mentions the possibility of healthcare professionals being seen as proselytising if they talk about spirituality with their patients: "Maybe they could be seen as trying to influence people into their own religion." This is a stance that rings true when one considers recent media stories, such as that of the nurse in North Somerset suspended without pay for praying with a patient (BBC 2009).

The PT talks about the changing face of healthcare, inasmuch as it has moved from being concerned purely with the body, to looking at psychological and psychosocial impacts of illness and disease. He ponders on whether it is now time for the health service to give better recognition to the spiritual dimension of patients: "When the NHS realises this was something maybe we are actually leaving out and then I think it will become a topic again that is openly discussed."

The Multidisciplinary Story

All three therapists interviewed gave different definitions of what spirituality means to them. This reflects the general consensus within the literature that defining spirituality is well nigh an impossible feat (Bash 2004), although some have tried:

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 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.' (Murray & Zentner 1989).

For the speech and language therapist interviewed, all human beings are spiritual and that is what "makes you come alive." The occupational therapist viewed spirituality as "what guides *people's lives*" and she cites religion, sewing, gardening, exercising, watching the sunrise, all as spiritual endeavours which enable individuals to cope with life. For the physiotherapist, the term spirituality first speaks to him of religion, but then comes the realisation that it could perhaps encompass more than 'just' religion: he says "I mean if someone has got no religion, they still have thoughts about what they think about themselves and their future and their past."

Spirituality is perhaps a concept that defies definition because of its uniqueness to each individual.

The therapists all attested to working in an holistic way, incorporating all facets of their clients in their interventions. The concept of spirituality, therefore, was one that they could reasonably comfortably consider under this banner of holistic, person-centred care. As the OT says: "*I think it's part and parcel of someone's life.*" The PT adds: "*You can't just treat one aspect of it with this condition.*"

They are all willing, therefore, to discuss spiritual issues with their clients if the clients themselves so wish. The PT shows some reluctance, however, in that he is anxious not to overstep the mark or contravene NHS Trust policy. He also recognises the expertise of the chaplain as the professional perhaps better suited to addressing spiritual issues, someone "designated as qualified to handle spiritual issues." He also shows great tact and humility, when he does not want to "*sort of trivialise someone's beliefs and spiritual wellbeing.*" The OT, too, shows some reluctance to engage in conversations of a spiritual nature (although she will do so): "*Not necessarily wanting to, it's just that we get drawn into that.*"

In the post-Francis era (the Mid Staffordshire NHS Foundation Trust Public Inquiry 2013), it is interesting and perhaps not surprising that all three therapists interviewed spoke about dignity, respect and valuing as key components in the care of their clients. The SLT, for example, strives always to "create an atmosphere that says you matter" and she describes her intervention with clients as "sacred work". The PT talks about treating the whole person, including taking account of the client's own values: "They look at themselves and their value systems as well, and if you are not recognising them you could do your best physically to treat someone and still miss the point." The OT talks about dignity and respect for non-verbal clients, even when full, two-way conversation is not possible, when the client is not able to voice their concerns or engage the therapist in conversation: "So I think the respect and dignity is there and you would treat the people in the same way that you would that could verbalise..."

Discussing issues of a spiritual nature with people with expressive aphasia

People with expressive aphasia have good functional auditory comprehension skills. Thus, they are able to understand what is said to them, but are unable to respond verbally, or verbal utterances are limited. Different people present with different degrees of expressive aphasia post-stroke, from mild word-finding difficulties to 'no talk' (McVicker 2007), a complete inability to produce words. Because other cognitive abilities are largely intact, expressive aphasia presents as a frustrating condition, whereby the individual has concepts in mind but expression of those concepts is problematic.

The OT identifies how difficult it can be to have meaningful conversations with someone with significant expressive language problems: *"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."* The PT recognises how more nebulous concepts, such as spirituality, may be particularly challenging to express for people with aphasia: "Someone with communication sort of difficulties will find it a bit difficult to convey that abstract nature of spiritualism [sic]"

SLTs have long been used to facilitating expressive abilities through total communication strategies (Sharp, Tompkins & Iverson 2007; Sachett, 2002; Farias, Davis & Harrington, 2006), such as gesture, drawing, writing key words and use of pictures and photographs. These strategies also provide a permanent referent, which both communication parties can continue to use throughout the conversation. These techniques enable the person with aphasia to express concepts non-verbally. By their very nature, however, it is the more concrete, less abstract concepts and ideas which may be expressed this way; the more abstract a concept, the more difficult it is to express this using one of these total communication techniques.

Being used to the concept of total communication, it is unsurprising, then, that the SLT I interviewed talked about being in tune with patients' non-verbal communication in order to understand them, as well as using pictures and objects to aid their expression. She cites the example of having a conversation with a patient about the necessity for enteral feeding, because of a severe, life-threatening swallowing difficulty: "If you give me the go-ahead, I may present pictures of say a headstone and Rest in Peace, or I bring an actual feeding tube, a PEG tube that would go in your tummy so that a person can see what it actually looks like, so that they know what I am talking about."

The OT, too, is cognisant of total communication strategies and discusses using photographs, picture cards and communication charts with her patients with aphasia. The PT talks a lot about the "barrier" of aphasia and the "frustration" that can come about but he does not mention use of total communication strategies. It may be that by the very nature of his job, he is giving and receiving many physical prompts which may replace to some extent the need for verbalisation.

Discussion

All three therapists working with people with aphasia interviewed for this study felt that, to a greater or lesser extent, it was within their remit as therapist to discuss issues of a spiritual nature with their patients, should the patient so desire. They all recognised the tripartite nature of their patients, and that one cannot separate off the spiritual from the other dimensions of body and mind which go to make up the whole person. However, they were also all cognisant of the invaluable role of the chaplaincy team and local ministers; they did not seek to usurp the chaplain's role but rather were open to spiritual discussions coming up in day-to-day activities. Both the OT and the SLT mentioned good, positive working relationships with the chaplaincy team, and the PT also makes reference to the "special sort of help" available to patients from the chaplains. Perhaps there is scope for even closer working between chaplains and therapy staff, each profession learning from the others for the benefit of the patient.

Given that people with aphasia seemingly do bring up issues of a spiritual nature with the professionals working with them, it seems incumbent on these professionals – and perhaps most especially the speech and language therapist – to explore more the use of

alternative and augmentative communication strategies available, and adapt these for use when discussing spiritual issues. Although both the OT and the SLT used total communication strategies (such as drawing) and so-called 'light tech' alternative and augmentative communication aids (such as picture charts) with their clients with aphasia, perhaps other alternative and augmentative communication (AAC) choices could usefully be explored. For example, Talking Mats (www.talkingmats.com) is a well-known and well-used technique for enabling people with learning disabilities, dementia or stroke to express preferences. Talking Mats is 'an interactive resource that uses three sets of picture communication symbols – topics, options and a visual scale – and a space on which to display them' (Talking Mats, 2015). Currently, topics include 'activities' or people', but one could envisage perhaps an extension of some of these topics to include pictures related to spirituality, such as places of worship, or feelings/ opinions/ questions related to serious illness and disability.

There has been a steep rise in the availability of iPad AAC applications recently, which may well be an area for exploration in terms of enabling people with aphasia to express their spirituality. Of course, one of the limitations of using AAC with people with aphasia is that their spoken expressive difficulties are often mirrored in their written expression, so that text-based AACs may not be viable as a method of functional communication.

Expressive aphasia robs the patient of an intrinsic human ability, and need; to communicate. Since communicating even basic needs and wants can be problematic and challenging for people with aphasia, how much more difficult is it to express more abstract concepts of belief and faith, meaning and life purpose? Each professional needs to share best practice, using their expertise to enhance the ability of the person with aphasia to express all their needs, wants and opinions, including those that fall into the nebulous category of 'spiritual'.

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