

## **Spirituality and/or religious faith: A means for coping with the effects of Amyotrophic Lateral Sclerosis/Motor Neuron Disease?**

Short title: Spirituality and faith in ALS/MND

Mary R O'Brien, Reader in Health Research, Evidence-based Practice Research Centre (EPRC), Edge Hill University, Ormskirk, Lancashire, UK.

David Clark, School of Interdisciplinary Studies, University of Glasgow, Dumfries Campus, Scotland, UK.

### **Corresponding author**

Mary R O'Brien, Evidence-based Practice Research Centre (EPRC), Edge Hill University, Ormskirk, Lancashire, UK. L39 4QP.

Email [obrienm@edgehill.ac.uk](mailto:obrienm@edgehill.ac.uk) +441695 650918.

## **Spirituality and/or religious faith: A means for coping with the effects of Amyotrophic Lateral Sclerosis/Motor Neuron Disease (ALS/MND)?**

### **Objectives**

The notion of spirituality/religious belief is recognised internationally as a domain within end of life care and is important in patients' and carers' quality-of-life. When faced with incurable illness patients often become more philosophical about their life; many seek comfort in spiritual or religious philosophies. Our intention was to understand how personal spirituality and religious faith might help those living with ALS/MND to cope with their impending death.

### **Methods**

Unsolicited narratives (Internet and print-published) written by individuals diagnosed with the terminal condition ALS/MND were analysed thematically. Narratives from 161 individuals diagnosed with ALS/MND written over a period of 37 years from 1968-2005 were included.

### **Results**

The findings reveal that religious faith sustains and helps people to avoid despair; personal spirituality helps them make sense of what is happening to them.

### **Significance of results**

The use of personal narratives by people with ALS/MND has provided the vehicle for sharing their deepest spiritual and religious thoughts with others. The place of spirituality and religious faith within ALS/MND care should not be underestimated. Assessment of religious or spiritual needs should become a routine part of practice and is the responsibility of all members of the multidisciplinary team.

### **Keywords**

Spirituality, religious faith, motor neuron disease/amyotrophic lateral sclerosis, written narratives, coping

## **INTRODUCTION:**

Motor neuron disease (MND), also known as amyotrophic lateral sclerosis (ALS) is a terminal neurodegenerative condition, often following a rapidly-progressive course leading to death 3-5 years from onset (Wood-Allum & Shaw, 2010). Management focuses on relieving distressing symptoms, but clear limitations exist as psychosocial effects frequently compound physical symptoms. When faced with a terminal illness, like ALS/MND, there is an inclination to question the meaning of life and death (Young & McNicoll, 1998; Oliver 2002; Grant et al., 2004); thoughts turn towards spirituality and faith for comfort and consolation (Oliver 2002); the importance of religion and spirituality in improving quality of life and decision making as death approaches is acknowledged (Delgado-Guay 2014).

Spirituality is a domain of supportive and palliative care in national policies such as the UK End-of-Life Care Programme (DH 2008), quality-of-life (QOL) measures (WHO 1998), and ALS/MND-specific care recommendations (Mitsumoto et al., 2005). As a concept, spirituality does raise some issues for researchers and commentators. Some identify a 'spiritual turn' in palliative care where perceptions of patients' needs have come to focus on privatised and self-defined meaning structures. Within clinical care this has involved a re-orientation away from explicitly religious engagement with patients and families towards acknowledgement of the wider spiritual concerns of users of palliative care services. In practice it can be difficult to categorise as 'religious' or 'spiritual' patients' concerns relating to the quest for meaning in the face of illness and death or attempts to make sense of suffering and a desire to make interpersonal connections at the end-of-life. But this acknowledgement of a wider, 'post-modern' and syncretistic 'spirituality' should not be at the expense of overlooking the enduring power of religious culture and experience (Clark & Centero, 2014). Recognising this more widely,

some academic commentators have expressed dissatisfaction with arbitrary distinctions between 'religion' and 'spirituality' arguing for a deeper analysis of how they relate to one another (Bender & McRoberts, 2012). Whilst these discussions continue, there remains value in exploring how both 'religious' and 'spiritual' components relate to and shape the experiences, beliefs and interpretations of those affected by serious illness.

Few studies, mainly using quantitative methods, have considered the influence of religiosity and/or spirituality on those affected by ALS/MND. These should be treated with caution not least as they rarely engage with the ways in which spirituality and religiosity are shaped by culture. But they do suggest that religious well-being and QOL are positively correlated in ALS/MND (Dal Bello-Hass et al., 2000); that people with ALS/MND who attend religious services and pray regularly use these experiences in coming to terms with the illness (Murphy et al., 2000) and that religious faith features strongly in coping with ALS/MND (Hecht et al., 2002), particularly amongst practising Catholics and Protestants (Murphy et al., 2000), and is protective against distress and depression (Rabkin et al., 2000). One study shows that as the illness progresses, reliance on religious beliefs increases (Nelson et al., 2003); this in turn appears to influence important decisions (Murphy et al., 2000). A Dutch study reported 20% of patients died from euthanasia/physician-assisted suicide, but those for whom religion was important were less likely to seek to end their lives prematurely (Veldink et al., 2002).

Knowing that life has meaning and is productive is important to patients (Bolmsjö, 2001). Spirituality and religiousness provide frameworks to interpret and understand experiences within wider existential contexts (Murphy et al., 2000). Evidence exists that prayer/belief in God are significant factors in coping with increasing dependence, stress and anxiety (Nelson et al., 2003). For some a shift from 'self-enhancement' (power, achievement, hedonism) towards 'self-transcendence' (benevolence, universalism) occurs during the disease trajectory (Fanos et al., 2008), reflecting developing philosophical perspectives about life through living with ALS/MND (Young & McNicoll, 1998). A rare qualitative study identified the importance of faith in accepting ALS/MND and finding value in the time remaining (Foley et al., 2007). ALS/MND caregivers' sense of burden, general well-being and QOL are positively associated with religiousness (Calvo et al., 2011) and related directly to patients' spirituality and existential well-being (Pagnini et al., 2011).

Past studies have generally sought to quantify experiences. A clear gap exists in understanding the role of spirituality and religious faith in coping with ALS/MND from the patient's perspective. We set out to address this omission through a detailed exploration of spirituality and faith within written accounts of living with ALS/MND.

## **METHODS:**

We adopted a qualitative methodology as it is only possible to understand aspects of human beliefs, attitudes or behaviour by accessing personal views or 'inner states' (Sullivan, 2010). We followed a novel approach utilising unsolicited illness narratives written by those diagnosed with ALS/MND. Such accounts focus on events that narrators regard as important which are self-selected and therefore not influenced by the researcher.

A systematic four-stage process uncovered Internet and print-published narratives written by people with ALS/MND (O'Brien & Clark, 2012). This began with a general scoping exercise, conducted using Internet search and Meta-search engines and database searches (Web of Science, CINAHL, Medline, Care data, Lexis Nexis) with a range of search terms including personal narratives, experiences and writing together with nomenclature used e.g. ALS, MND and Lou Gehrig's disease. Electronic searches of online bookstores and ALS/MND association websites worldwide were also carried out. Removal of duplicate/inappropriate material and assessment against specific inclusion criteria (see Table 1) completed the four-stage process. Little methodological guidance existed, however our approach had similarities to comparable studies (Hardey, 2002; Pitts, 2004). Narrative and personal account are used interchangeably and apply to personal stories of living with ALS/MND, regardless of genre or length of story. Those who wrote the accounts are referred to as authors, or narrators, recognising their intellectual ownership of creative works (Pitts, 2004).

Insert Table 1 about here

## **Ethics**

As this research formed the basis of the first author's Doctoral studies, guidance was sought from the University Ethics committee, which agreed that formal ethical approval was not required. The contention was that the study involved only the use of publicly-available material; no interaction occurred between narrators and researcher, therefore consent for its use was not required (Eysenbach & Wyatt, 2002). Furthermore, recognising the data as creative works (Pitts, 2004) demanded that extracts are acknowledged and correctly attributed to the narrators with the use of real names. This is required for any print-published narratives under copyright regulations, as well as Internet narratives covered by creative commons deeds. We cannot know

authors' reactions to their narratives being included in this study; consideration of their reasons for writing may provide clarity. Many aimed to share experiences and raise awareness of ALS/MND, being included here allows their narratives to be shared with different audiences, often long after their death.

## **Analysis**

Key demographic details of the authors and bibliometric features of the narratives were identified to understand the characteristics of the authors and their stories. Thematic analysis, a means to identify, analyse, report and interpret themes within data was adopted (Braun & Clarke 2006). Analysis progressed from description to interpretation and theorising broader meanings referring to the wider literature. Analysis was inductive, with identified themes strongly linked to the data through coding (Table 2), without attempting to apply pre-existing coding frames or theoretical perspectives or subject to our own analytic preconceptions (Braun & Clarke 2006). Familiarisation was achieved through repeated reading of each unit of text (Braun & Clarke 2006); NVivo computer software helped manage the data. The process was fluid, moving from one text to another 'checking the main features; confirming previous accounts; identifying common elements; and developing a common story' (Holloway & Freshwater 2007; p85), simultaneously interpreting findings to determine which parts of narratives were thematically connected.

Insert Table 2 about here

Analysis was conducted by the first author; the second author undertook independent review. A number of themes were identified; our focus here is on the role of spirituality and faith in coping with ALS/MND. Elements of Braun and Clarke's (2006) checklist for good thematic analysis (Table 3) were applied to assure the trustworthiness of the data.

Insert Table 3 about here

## **RESULTS:**

We ultimately obtained 161 narratives written between 1968-2005, emanating mainly from the USA, Europe, Canada, and Australia, consisting of 64 Internet and 97 print publications. The youngest author, at diagnosis, was 20 while the oldest was 71. Only narratives which specifically addressed aspects of spirituality/faith are included here, this amounts to 54 of the 161 included in the main study; see Table 4 for demographic details of this sub-set. The findings are supported with quotations, from this sub-set, which are exemplars indicative of the viewpoints expressed.

Numerous narrators refer to the strength acquired from seeking a spiritual understanding of their circumstances. This may consist of pursuing traditional religious beliefs, placing hopes for the future in their *God*; or it may involve a spiritual route, seeking answers to important questions about the self and life in general via a more philosophical and non-theistic route.

Insert Table 4 about here

### **Religious beliefs**

Drawing strength from their faith, there is a sense that individuals' beliefs help them cope with their illness. Despite being aware that their condition will progress, narrators have confidence that their faith will help them tolerate the on-going deterioration.

*'I know life will get tougher as my condition deteriorates but I am assured that my Lord will sustain me'.* Ann Robinson

Strong religious views were expressed by many. They recall the inescapable nature of their illness but draw on faith, as well as friendships, to help in their ordeals.

*'I did not choose this journey, but my faith, my family and my special friends enable me to cope with the challenges that I face'.* Mary Nowotny



Often, there is an impression of giving thanks for making these personal resources available.

*'I have more than my share of wonderful caregivers. It's the Lord's blessing'.*

Mike Watson

For some, there is no question that religious beliefs are vital in avoiding despair. When she writes, 'to have hope you have to have Jesus in your life', Michelle Cornell effectively means that without her religious beliefs she would be hope-less. Holding similar views, others claim faith as the cornerstone of the ability to cope with ALS/MND.

*'Just like almost every person with ALS I know, my faith in God is the basis of my coping.*

*When nothing else or no one else can bring back a positiveness, faith and prayer can'.*

Pete Oliver

It is conceivable that those with strong religious views might question their faith following diagnosis. Having pursued a religious life, to be faced with a life-limiting condition could seriously test an individual's beliefs. Narrators recall initial anger at God for their affliction.

*'I took a deep breath and told God exactly what I thought of him and just how much I resented being in His church; He had let me down. How could He deprive James of his mother? Going to worship was definitely off my agenda. Josephine Bulford*

However, others resist the temptation to blame God for their illness.

*'The way I cope with this is I don't believe that this disease and death is attributed to God's will-that somehow He planned this event. I think they're just something that happened in the course of nature'. Chuck Hollenbach*

It appears, for most authors with strong religious convictions, that their beliefs are maintained

and often strengthened following diagnosis.

*'Many good things have come as a direct result of having ALS/MND.....my Christian faith has become deeper and stronger'. Josephine Bulford*

Such authors place their trust in God, believing they will not be burdened beyond their ability to cope.

*'I know we all ask ourselves everyday "Why me Lord?" I have found faith in GOD. We are never given more than God thinks we can handle'. Sherry Ketzbeau*

It is perhaps to be expected that those with strong religious convictions will draw on these to cope with approaching death.

*'Whatever tomorrow holds, God will give me the resources I need to deal with it. I realise the end will eventually come. But God has taken away my old fear of death*

Charlie Wedemeyer

However, there is also evidence that some narrators' decision-making is influenced by their beliefs. When viewing life as God's gift to them, there is justification for taking any actions required to sustain life, such as the use of artificial ventilation.

*'God offers victory over death....I believe victory over death is offered to us now, in the midst of life. It is a victory over fear, a victory over despair, a victory over grief, a victory over those forces that can ruin our lives'. Joe Martin*

## **Spirituality**

In describing his spiritual journey through illness Phillip Simmons considers that traditional religions may regard God as 'a God of goodness and love' preferring not to associate him with the more inclusive view 'God of good and evil, light and darkness, sweet and bitter, harmony and discord'. It is this more comprehensive approach that Simmons adopts in coping with his condition.

*'A wholeness and connectedness in which all things, good and evil, are divine, all part of the sacred dance of creation.....in facing every day the failure of my own flesh, in facing every day the reality of suffering around me, I have found my life's greatest spiritual challenge'. Phillip Simmons*

While trying to make sense of life, some look for a positive aspect to emerge. There is a feeling of being used for some 'higher purpose', as a spiritual example of how to live under difficult circumstances. For some, there is a sense of being blessed with a tranquil composure and a hope that if others recognise this tranquillity, they will acknowledge its origins.

*'I think perhaps the miracle has been the serenity of spirit that I have been given. I consider it a precious gift from God. If I am being used for a higher purpose and if people see a light in me, I hope they recognise the source'. Nancy Lohrke-Meeker*

There is a clear sense of turning misfortune into advantage; authors comment on acquiring strength of character when faced with a deteriorating body.

*'When confronted with weakness, strengths are created and events shaped in ways which are never possible by sheer power'. Brian Smith*

Phillip Simmons writes of spiritual life involving one's interior journey, thinking, meditating and arranging one's own feelings and views of the world. He highlights 'for most of us spirituality gets expressed-even transformed-only in our relationships with others'. This reflects comments on the comfort drawn from the community of people involved with them- family, friends and caregivers.

*'I consciously receive the love, caring and prayers of others into myself as healthy energy'.*

Pete Oliver

In his search for a personal spiritual sign Morrie Schwartz is unsuccessful, but he recognises others' claims of spiritual connections with God or some 'higher power'. He encourages others to search for spiritual comfort, but warns it may be elusive.

*'Seek the answers to eternal and ultimate questions about life and death, but be prepared not to find them. Enjoy the search'.* Morrie Schwartz

While Schwartz does not undergo the 'spiritual oneness experience' he seeks, he knows that friends view him as a spiritual person. They see his example of living with a terminal illness, and producing creative works held in high esteem, as an illustration of true spirituality. For others, this notion of spirituality is evident in a greater good emerging from their illness-the ability to share experiences with others and ease their suffering.

*'My misfortune in life has actually turned out to be a gift; a gift I can give to many'.*

Jay Rouelle

Furthermore, shifting the emphasis away from their own demands to the needs of others reflects spirituality in action.

*'Caring about others certainly adds meaning to my life. For a change I'm not asking for and receiving help, but giving it, a situation that is much more satisfying'.*

Myra Rosenfeld

Here we have people with ALS/MND revealing the strength derived from religious or spiritual beliefs. Seeking answers to life's questions at an existential level enables many to cope with their illness and experience a sense of peace with their situation as they approach death.

#### **DISCUSSION:**

This qualitative study aimed to understand the effect that religious faith and personal spirituality can have for people with a diagnosis of ALS/MND as they prepare for their death. Religious faith helps them to avoid despair, while personal spirituality can help them to make sense of what is happening to them. The importance of an internal connection to a higher being amongst the dying was noted by Dobratz (2013). A key finding in our study supports this assertion and suggests a connectedness with God, or a higher power, demonstrated by the comfort drawn from feeling secure and reassured despite an uncertain future. However, in this study, connectedness also appears to extend to relationships with family and friends and is apparent in the consolation gained from the presence of this wider community.

In ALS/MND, religious or spiritual beliefs are significantly related to quality-of-life, particularly as the illness progresses (Dal Bello-Hass et al., 2000; Pagnini et al., 2011). In this study, authors described how their beliefs helped remove the fear associated with death and provided the personal resources needed to face their approaching death. This lends support to Murphy et al., (2000) who reported that people with ALS/MND who are more religious or spiritual are more hopeful with fewer concerns about death.

A shift from self-enhancement towards self-transcendence is recognised (Fanos et al., 2008) which reflects the development of a more philosophical perspective about life from living with ALS/MND (Young & McNicoll, 1998). This was particularly evident within the current study as narrators demonstrated their ability to use their misfortune to the benefit of others. Simply writing the story of their illness to share their experiences with others, and potentially ease their suffering, indicates the emergence of a greater good from their personal tragedy. Although life with ALS/MND is not easy, people typically maintain an holistic approach seeking meaning and purpose amongst physical weakness and emotional discomfort. Narrators demonstrated such characteristics searching for positive outcomes indicating their lives had meaning. This supports the notion that spirituality and religiousness provide a source of comfort and serenity directly impacting on quality-of-life (Nelson et al., 2003). For many, meaning in life was associated with spirituality and transcendence (Fegg et al., 2010), which lends support to the work of Vachon et al., (2009) who identified meaning and purpose as key elements within spirituality at the end of life.

Those with ALS/MND rate self-transcendent values higher than self-enhancement values (Fegg et al., 2005), reflecting coping strategies which appear to be inherent in terminal illnesses. More-educated individuals tend to move towards self-transcendence in palliative care situations (Fegg et al., 2005). Our findings support this assertion; those who made their living from writing, e.g. academics and authors, clearly demonstrated this shift. Nowhere perhaps was this more evident than in the writings of Philip Simmons and Morrie Schwartz, both university professors. However, what is clearly apparent from our findings is that people from a variety of backgrounds, e.g. Jay Rouelle, a dental laboratory technician, also display this trait.

In a similar fashion, but with reference to chronic illness, Garrett (2002) regards healing not as *cure* and more than *coping*; it involves *transformation* of the sick person into a better individual, with an altered attitude to life focusing on others. People with Multiple Sclerosis can be altered by the discovery of a divine element, transforming them and the illness; losses become gains, contentment is achieved and peace of mind obtained (Robinson, 1990). This personal renovation may not occur without the illness experience (Robinson, 1990). We have shown that there is evidence here of such a change in attitudes, indicating that *transformation* is also possible with terminal conditions. Authors demonstrated this through their sense of growing as an individual, acquiring inner strength and serenity; a change in focus with concern for others was indicative of spirituality in action.

#### **CLINICAL IMPLICATIONS:**

Spiritual care concerns recognition 'that people can find healing within themselves, even in the midst of dying' (Puchalski, 2012, p. 64) sometimes connecting to external resources- beliefs, objects, relationships- that people turn to in times of need. The importance of spiritual care in healthcare in assisting patients to understand the turmoil resulting from serious illness, by helping them consider the meaning and purpose of their lives, is well supported (Ming-Shium, 2006; Dobratz 2013). To neglect the spiritual needs of patients, and their families, is both ethically and legally wrong (Fiifi-Amoah, 2011). However, the importance of spirituality within ALS/MND care is underestimated (Lambert, 2006) despite recommendations for its inclusion within an interdisciplinary/multidisciplinary approach (Mitsumoto et al, 2005), encompassing the family to reduce the likelihood of prolonged grief (Pagnini et al., 2011). This study confirms the importance of faith and spirituality in coping with ALS/MND, but there is a clear need to raise awareness of this amongst health care professionals involved in providing care. The requirement to assess spiritual and religious needs of patients should become a routine part of care provision

and is ultimately the responsibility of all members of the multidisciplinary team (Delgado-Guay 2014). Helping people find an element of meaning and purpose to their lives may contribute to improving the experience of living with ALS/MND (Plahuta et al., 2002).

#### **LIMITATIONS:**

There is no claim that the views expressed are representative; inclusion was limited to those able to compose and make their narrative available for others to read. Only those narratives which specifically addressed spirituality or religious faith were included in this analysis. While such beliefs help some people cope with illness, for others they may not be effective and can be problematic (Cobb, 2008). What is missing here are views from those who did not gain consolation from religious or spiritual beliefs, or did not document them; consequently the findings are inevitably biased towards a positive viewpoint. However, they do confirm the place of spirituality and faith in coping with ALS/MND. Other voices missing from this study include those of family carers of people with ALS/MND and healthcare professionals involved in providing care. To gain a thorough understanding of the topic further research involving these groups is required.

Undertaking *passive analysis* (Eysenbach & Wyatt, 2002) meant it was impossible to verify findings with the narrators, however, discussion of the themes with healthcare professionals involved in the care of people with ALS/MND, worldwide, has confirmed the credibility of the findings.

#### **CONCLUSION:**

Societal attitudes frequently deny mortality hindering the expression of existential questions about life and death (Grant et al., 2004); personal illness narratives provide the vehicle for sharing deep thoughts, some of which may be of a spiritual or religious nature. The availability of such illness narratives provides access to pertinent stories from an infinitely more diverse sample



than could be obtained using more conventional techniques and avoids intrusions into people's lives as they cope with illness; as such this approach can be regarded as distinctly non-intrusive. Furthermore it allows voices to be heard, often many years, after individuals have died. The approach could ideally be utilised with other conditions and hard-to-reach groups.

## **FUNDING**

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors

## **COMPETING INTERESTS**

Competing Interest: None declared.

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<b>Include</b>	<b>Exclude</b>
Literature [diaries, memoirs, Web site entries, newspaper/journal articles], personal narrative, documenting the experience of living with a diagnosis of ALS/MND whether in print or on the Internet, written by people with ALS/People with MND (PALS/PwMND)	Narratives in verbal or visual format i.e. as a plays, films, and radio performances.  Literature containing personal opinion rather than personal experience; with a focus on fund raising, general ALS/MND information and carers' experiences. Literature not written by PALS/PwMND
Narratives written in English or with an English translation available	Narratives that are not available in English
Narratives containing personal demographic details about the author	Narratives without personal demographic details about the author
Narratives based on personal experiences of living with ALS/MND	Narratives based on imaginary experiences
Narratives originally written by PALS/PwMND but subsequently edited by others prior to publication	Narratives written by others about PALS/PwMND
Narratives which are verifiable as being the work of PALS/PwMND (i.e. publisher's copyright; link to/from recognized organization or appropriate Web site)	Narratives which cannot be verified as being the work of PALS/PwMND

Table 1: Inclusion/exclusion criteria applied to all narratives (published with permission from Sage Publications & Mark Allen Publishers)

Code	Categories
Sense making	<ul style="list-style-type: none"> <li>- Seeking answers to difficult questions</li> <li>- Finding meaning in life</li> </ul>
Inner strength	<ul style="list-style-type: none"> <li>- Expressions of Faith/Hope</li> <li>- Resources to cope</li> </ul>
Example to others	<ul style="list-style-type: none"> <li>- Higher purpose</li> <li>- Salvaging good from bad</li> <li>- Benevolence</li> </ul>
Blame	<ul style="list-style-type: none"> <li>- Illness tests beliefs</li> <li>- Illness strengthens beliefs</li> </ul>
Higher Presence	<ul style="list-style-type: none"> <li>- Humour</li> <li>- Hope</li> <li>- Faith</li> <li>- Spirituality</li> <li>- People</li> </ul>
Preparation for death	<ul style="list-style-type: none"> <li>- Tranquillity</li> <li>- Fear reduced</li> </ul>
Power of prayer	<ul style="list-style-type: none"> <li>- Mental strength</li> <li>- Positive attitude</li> <li>- Others' prayers</li> </ul>

Table 2 Examples of coding and categories identified during analysis

1. Each data item has equal weight
2. Themes are generated from a thorough coding process rather than anecdotally
3. All relevant extracts for each theme have been collated
4. Themes have been checked against each other and back to the data
5. Themes are internally coherent, consistent and distinctive
6. Data have been analysed and interpreted, not just paraphrased or described
7. Data extracts illustrate the analytic claims
8. Analysis tells a convincing tale and well-organised tale about the data and the topic
9. There is a good balance between the analytic narrative and the illustrative extracts
10. Sufficient time has been taken to advance through each stage of analysis
11. The rationale and specific approach to thematic analysis is clearly explicated
12. There is good fit between what you claim to do and what you show you have done

Table 3. Elements of Braun and Clarke's (2006, p96) checklist for good thematic analysis applied to this study

Name	Age at diagnosis	Location	Occupation	Religious/spiritual identity	Source
Aloysius Schwartz	57	Philippines	Priest	Roman Catholic	Aloysius Schwartz. Killing me softly: the inspiring story of a champion of the poor. St Pauls/Alba house. 1993
Angela Riggs	64	USA		Spiritual comments	Angela Riggs. When the music stopped; I kept on dancing- a story of courage, hope and the magnificence of the human spirit. Bookpartners. 1995
Anne Robinson	49	Australia	Welfare worker	Christian	Anne Robinson. One day at a time. In: Rahman Z (ed) Cornflower blues. Living with MND. New South Wales: Fast books, 1999; pp27-35
Aurore Desrosier	64	Canada	Teacher	Reference to God	<a href="http://www.alsindependence.com/Aurora_Desrosier's_Story.htm">http://www.alsindependence.com/Aurora_Desrosier's_Story.htm</a>
Bert Woodard	25	USA	Construction worker	Spiritual comments	<a href="http://www.bertwoodard.com/">http://www.bertwoodard.com/</a>
Betty Ferguson	-	USA	Teacher	Reference to God	Betty Ferguson. I have risen like a phoenix. In: Oliver J, Findlay T and Schudy P (eds) In Sunshine and in shadow. Personal portraits of ALS. Kansas: Keith Worthington ALS Society, 1986; pp122-124
Brian Smith	56	Canada	Accountant	Christian	Brian & Lyn Smith. Closing comments: ALS- a spiritual journey into the heart of a fatal attraction. Clements publishing 2001
Charlie Wedemeyer	30	USA	Football coach	Reference to God/prayer	Charlie & Lucy Wedemeyer. Charlie Wedemeyer: an autobiography. Michigan Zondervan 1993
Cheryl Mathews-Prock	51	USA		Reference to God	<sup>o</sup> <a href="http://alsnetwork.com/cheryl.htm">http://alsnetwork.com/cheryl.htm</a>



Chuck Hollenbach	38	USA	Businessman	Reference to God/spiritual comments	Chuck Hollenbach. Chuck's story. In: Feigenbaum D (ed) Journeys with ALS. Virginia: DLRC Press, 1998; pp 109-112
Clara Joseph	42	USA		Anglican	<a href="http://www.users.bigpond.com/paulfran/clara_joseph.htm">http://www.users.bigpond.com/paulfran/clara_joseph.htm</a>
Dan Maloney	57	Canada	Dairy sales	Reference to Good Lord	<a href="http://www.alsindependence.com/Dan's_Story.htm">http://www.alsindependence.com/Dan's_Story.htm</a>
Darrell Cospser	-	USA	Insurance	Reference to God	Darrell Cospser. Darrell's story. In: Feigenbaum D (ed) Journeys with ALS. Virginia: DLRC Press, 1998; pp250-54
Debbie Tope	44	USA	Sales assistant	Christian/reference to prayer	° <a href="http://www.focusonals.com/">http://www.focusonals.com/</a>
Dennis Kaye	30	Canada	Logger	Spiritual comments	Dennis Kaye. Laugh, I thought I'd die- My life with ALS. Penguin Canada 1993
Don Moore	67	USA	Military	Spiritual comments /reference to Lord	° <a href="http://members.aol.com/pjungles/PjunglesBegin.html">http://members.aol.com/pjungles/PjunglesBegin.html</a>
Doug Jacobson	35	USA	IT	Christian	<a href="http://www.jakesan.com/">http://www.jakesan.com/</a>
Evelyn Bell	50	Canada	Sales	Christian/spiritual comments	Evelyn Bell. Cries of the silent: my journey with ALS. ALS Society of Alberta
George Breedlove	45	USA		Reference to God/prayer	° <a href="http://home.rochester.rr.com/breedlove/george/index.htm">http://home.rochester.rr.com/breedlove/george/index.htm</a>
Jack Carlin	-	Canada		Reference to God/prayer	<a href="http://www.alsindependence.com/Jack_Carlin's_Story.htm">http://www.alsindependence.com/Jack_Carlin's_Story.htm</a>
Jackie Williams	-	Australia		Reference to God	° <a href="http://55jer.com/jackies%20page.htm">http://55jer.com/jackies%20page.htm</a>
Jason Becker	-	USA	Musician	Reference to God/spiritual comments	<a href="http://jasonbeckerguitar.com/">http://jasonbeckerguitar.com/</a>
Jay Rouelle	33	USA	Dental laboratory technician	Spiritual comments	Jay Rouelle. Terminally sane: One man's journey beyond Lou Gerhig's disease. Vermont, Jarou Publishers. 2001

Jenny Richards	33	UK	Teacher	Christian	Jenny Richards. Love never ends. Lion Oxford.1990
Joan Schuster	21	USA	Secretary	Roman Catholic	Joan Schuster with James A Costa. In the garden of Gethsemane. A memoir. Elma Printing Alma NY. 2001
Joe Martin	-	USA	Banker	Reference to God/Faith	Joe Martin and Ross Yockney. On any given day. John F Blair Publishers. 2000
Joel Sitkiewitz	-	USA	General manager	Reference to Faith	Joel Sitkiewitz. Joel: his life, adventures and ALS. Katish Communications. 1992
Josephine Bulford	-	UK	Nurse	Christian	Josephine Bulford. Jo's Story. In: Feigenbaum D (ed) Journeys with ALS. Virginia: DLRC Press, 1998; pp 1-13
Kim Connor	37	Canada		Reference to God	<a href="http://www.alsindependence.com/Kim's_Story.htm">http://www.alsindependence.com/Kim's_Story.htm</a>
Leroy Kramer	-	USA	Military	Reference to God	<a href="http://home.pacbell.net/ranger-1/">http://home.pacbell.net/ranger-1/</a>
Luther Conant	50	USA	Film Producer	Quaker/spiritual comments	<a href="http://www.lutheroutloud.com/">http://www.lutheroutloud.com/</a>
Marc Reynolds	49	Canada	Engineer	Methodist	<a href="http://members.rogers.com/r.reynold/">http://members.rogers.com/r.reynold/</a>
Mary Nowotny	56	USA	Nurse	Reference to God/Faith	Mary Nowotny. Mary's story. In: Feigenbaum D (ed) Journeys with ALS. Virginia: DLRC Press, 1998; pp 72-78
Maureen Helman	43	Australia	Cookery demonstrator	Reference to Lord/prayer/spiritual comments	Maureen Helman. Reach for the stars. In: Rahman Z (ed) Cornflower blues. Living with MND. New South Wales: Fast books, 1999; pp79-87
Michael Jack	30	USA	Public Relations	Reference to being Religious	Michael Jack. Lemonade, silk purses and other thoughts on optimism. In: Rahman Z (ed) Cornflower blues. Living with MND. New South Wales: Fast books, 1999; pp21-25
Michelle Cornell	32	USA	Housewife	Christian	<a href="http://www.meetmyfriend.com/">http://www.meetmyfriend.com/</a>

Mike Watson	48	USA	Computer programmer	Reference to Lord/Faith/prayer	Mike Watson. Mike's story. In: Feigenbaum D (ed) Journeys with ALS. Virginia: DLRC Press, 1998; pp 91-95
Morrie Schwartz	77	USA	Academic	Spiritual comments	Morrie Schwartz. Morrie in his own words: life wisdom from a remarkable man. Dell publishing New York 1997
Myra Rosenfeld		Canada			Myra Rosenfeld. No other choice: fight In: Oliver J, Findlay T and Schudy P (eds) In Sunshine and in shadow. Personal portraits of ALS. Kansas: Keith Worthington ALS Society, 1986;p39
Nancy Lohrke Meeker	70	USA		Reference to God/spiritual comments	Nancy Lohrke Meeker. Nancy's story. In: Feigenbaum D (ed) Journeys with ALS. Virginia: DLRC Press, 1998; pp 217-223
Nick Billen	-	USA	Firefighter	Reference to God	<a href="http://www.nick-billen-alslougehrigsdisease-foundation.org/">http://www.nick-billen-alslougehrigsdisease-foundation.org/</a>
Patricia Sequin-Tremblay	35	Canada	Nurse	Reference to prayer	<a href="http://www.alsindependence.com/Patsy's_Story.htm">http://www.alsindependence.com/Patsy's_Story.htm</a>
Paul Brock	53	Australia	Educator	Spiritual comments	Paul Brock. A Passion for Life. An Inspiring story of Resilience and Hope. ABC Books. 2004
Pete Oliver	-	USA		Reference to God/prayer/Faith	Peter Oliver. If I stick it out. In: Oliver J, Findlay T and Schudy P (eds) In Sunshine and in shadow. Personal portraits of ALS. Kansas: Keith Worthington ALS Society, 1986; p11
Peter Fillipoff	67	Canada	Federal employee	Reference to being a believer/prayer	<a href="http://www.users.bigpond.com/paulfran/Fillipoff.htm">http://www.users.bigpond.com/paulfran/Fillipoff.htm</a>
Phil Simmons	35	USA	Academic	Reference to world religions/spiritual comments	Philip Simmons. Learning to fall: the blessings of an imperfect life. Hodder and Stoughton, London. 2002

Rob Marshall	37	UK	Factory worker	Reference to prayer	<a href="http://homepage.ntlworld.com/rob.shaz/">http://homepage.ntlworld.com/rob.shaz/</a>
Robb Thompson	-	USA			<sup>o</sup> <a href="http://voiceforjoanie.org/homepages/thompson/thompson.html">http://voiceforjoanie.org/homepages/thompson/thompson.html</a>
Robert Horn	-	USA	Academic	Reference to spirituality/serenity	Robert Horn. How will they know if I'm dead-transcending disability and terminal illness. St Lucie Press 1997
Ron Crane	34	USA		Reference to God/Faith	<sup>o</sup> <a href="http://members.aol.com/rlove607/index1.html">http://members.aol.com/rlove607/index1.html</a>
Sherry Ketzbeau	-	USA	Nurse	Reference to God/Faith/spiritual comments	<a href="http://lindenwoods.tripod.com/index.html">http://lindenwoods.tripod.com/index.html</a>
Vanessa Moses	25	USA		Christian	Vanessa Moses. Van's story. In: Feigenbaum D (ed) Journeys with ALS. Virginia: DLRC Press, 1998; pp 125-136
Willie Maddren	44	UK	Professional soccer player	Christian	Willie Maddren with Dave Allen & Hilary Maddren. Extra time. The official biography The Final Chapter 2 <sup>nd</sup> Ed Maddren MND Fund. 2005
Zana Walker	46	Australia	Teacher	Reference to Zen Buddhism	Zana Walker. Zana's story. In: Feigenbaum D (ed) Journeys with ALS. Virginia: DLRC Press, 1998; pp194-205

Table 4. Demographic details of authors including references to religion/spirituality. Names used are the author's real name since all narratives were publicly available from internet or print-published sources. [N.B. Most authors did not specify a particular religious identity, although from the vocabulary used it could be assumed that the majority were Christians. Many authors simply refer to 'God' 'Lord' or 'Faith' or mention 'prayer' and/or 'beliefs', while others include spiritual comments suggesting an 'exploration of meaning in life', 'connection' 'interaction' 'mediation' or 'transcending the self'] All web links accessed 23.06.14. <sup>o</sup> indicates web link is no longer functioning

