Spiritual care within palliative care: Perspectives from soul carers in South Africa

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Abstract

Although it is well known that effective palliative care requires a broad multidisciplinary approach, inclusive of spiritual care, the latter is often marginalised or undeveloped within palliative environments. In other non-palliative end-of-life environments, aside from the provision of specific religious or chaplaincy care, which may not be appropriate for all, spiritual care is mostly unrecognised. The absence of spiritual care is a deficit within a holistic model of end-of-life care. The purpose of this small-scale study was to elicit information from a group of people providing spiritual care to people at the end of life (designated Soul Carers)[1] as to how they understood their role and practice in the field, as well as to 'map' the extent of the work being done in different areas. Its intention is to make visible what is often invisible in the end-of-life communities of practice. We chose a grounded theory approach, drawing from the reflections and experiences of people who have worked in the field in different places in South Africa, from more recently through to many years spanning the duration of some carers' working lives. Our sample comprised 35 spiritual carers from a diversity of cultural and spiritual/religious backgrounds and locations and who have wide-ranging skill sets. They were drawn from the cohort of participants in Soul Care training courses between 2019-2022. Data generation occurred via a series of facilitated *Zoom* sessions during which participants were guided through a series of questions captured in the Chat tool and through the recording. The thematic analysis of the data provided some key insights into the influence Soul Carers are having on the field of spiritual care at the end of life and how Soul Carers themselves are being influenced by this work. The findings also point to new questions and areas for further research or action.

Key words: soul carer, spiritual carer, death doula, end-of-life doula, death midwife, palliative care volunteer

Introduction

Although it is well known that effective palliative care requires a broad multidisciplinary approach, inclusive of spiritual care (Vissers, *et al.,* 2003), the latter is often marginalised, undeveloped or infrequent within palliative environments (Astrow *et al.,* 2007; Balboni *et al.,* 2013). In other non-palliative end-of-life environments, aside from the provision of specific religious or chaplaincy care (Nolan 2011), which may not be appropriate for all (Liefbroer & Berghuijs 2019), spiritual care is

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[1] The terms 'soul' and 'spirit' are often used interchangeably, and for the purposes of this paper, we do not differentiate between the terms. However, we acknowledge that there are theological differences in how they are understood within different philosophical and religious traditions.

mostly unrecognised. In short, the absence of spiritual care is a deficit within a holistic model of end-of-life care. As the Report of the Lancet Commission on the Value of Death notes, "Much of the value of death is no longer recognised in the modern world, but rediscovering this value can help care at the end of life and enhance living" (Sallnow *et al*., 2022).

One of the ways to better value death and provide support for children and adults with life-limiting conditions and their families is by the inclusion of a 'soul carer' or 'spiritual carer', known more colloquially as a 'death doula'. These trained non-medical carers can provide practical, emotional and spiritual support to enable a peaceful and meaningful death at home and assist families to navigate the necessary practical tasks, emotional needs and spiritual aspects associated with end-of-life. The work of 'death doulas', 'end-of-life doulas', 'illness doulas', 'death midwives', 'soul midwives' (Warner, 2013), 'soul guides', 'spiritual carers', 'spiritual caregivers', 'end-of-life caregivers', 'compassionate companions', 'palliative care volunteers' and/or 'vigilers' is quite well documented in the scholarly literature internationally (Bloomer & Walshe 2020; Dellinger Page, Husain & Kvanvig 2022; Garces-Foley 2022; Robinson, Spencer & Lewis 2019; Zimmerman 2018) and locally in South Africa (Nachmann 2009, 2019; Wood & Fox 2009; Selman *et al*. 2010; Brand 2016; Mahilall & Swartz 2022). There are also commercial institutes that offer training following similar nomenclature (e.g., 'doulagivers'[2], 'thanadoula'[3], end-of-life coach[4]) that are not yet or not well documented in the scholarly literature.

Much of the literature on spiritual care at the end of life describes the training for, and provision of, spiritual care by practitioners in traditional settings of hospital or hospice and includes social workers, physicians, and nurses and other spiritual professionals from diverse backgrounds – chaplains, religious leaders, pastoral counsellors, and traditional healers (Puchalski *et al*., 2022) – but less so on training for spiritual carers and their work in people's homes. According to the scoping review undertaken by Yoong, Goh and Zhang, "most death doulas provide services in clients' homes, and some provide services at the hospices or hospitals" (2022, p. 805). They point out that "most death doulas agreed that training was necessary because it equips them with better knowledge about the roles, legislation, and expectations of death doula work and provides legitimacy to the profession" (Yoong *et al.*, 2022, p. 805).

This paper showcases a 'home-grown' initiative by a group of non-medical, trained carers (designated as soul carers) to provide spiritual care to people at the end of life in non-traditional settings, i.e., in private homes, elder care facilities, or other community spaces where there might be a 'gap' in spiritual care at the end of life. Thus, the notion of 'minding the gap' in spiritual care at the end of life is appropriate. The purpose of this small-scale study was to elicit information from the cohort of participants in Soul Care training courses led by Mary Ryan (DTh) between 2019-2022 to ascertain how they interpreted their role and practice in the field, as well as to 'map' the extent of the work being done in different areas. Its intention is to make visible what is often invisible in the end-of-life 'communities of practice' in non-traditional settings.

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[2] https://www.doulagivers.com/

[3] https://www.kaizenleadershipinstitute.com/end-life-coaching/

[4] https://coachfoundation.com/blog/end-of-life-coach/

Where is the 'gap' to be minded?

Nurses, doctors, social workers, family, persons, and religious workers, i.e., all those involved in the patient's end-of-life care, may well include spiritual care as part of their holistic care of the patient. However, the evidence points to a role for non-medical spiritual carers to support these often over-busy practitioners. A study of student nurses in the Western Cape who were asked to reflect on the aspect of their curriculum on spiritual care reveals that, on the one hand, they did not feel equipped or well enough trained to provide such care, and secondly, that given their usually heavy caseloads, they did not always have the time to sit with patients as needed (Linda, Klopper & Phetlhu *et al*., 2015). The availability of specialised, non-medical spiritual care practitioners can support other professionals with their time and bring important skills honed in the service of those at the end of life.

End-of-life care

In pre-modern times, it was mainly women who were the midwives and healers serving at births, illness and end of life. Felicity Warner, founder of the UK-based School of Soul Midwifery, suggests that there is a whole history of wise medicine (wo)men and traditional healers within all traditions who have done this work. Drawing on their knowledge of herbs and plant life to support their healing work, they presented a challenge to the patriarchal control of religious authorities and were often demonised and their knowledge suppressed. Their wisdom and skill have not been lost, merely submerged, and are being recovered (Warner 2013, pp. 3-14).

The modern era introduced a differentiation of knowledge, where religion, science, politics and governance, and culture emerged as separate spheres (Wilber 2017). Autonomous knowledge silos operated where disciplines functioned independently of the other. For a long time a division in the provision of care has prevailed, with religion traditionally working in the domain of 'cure of the soul'[5], and medicine being preoccupied with healing the body. This division has had an effect on important human experiences of birthing and dying which, under the domains of medicine and science, have mainly been seen as 'medical events' (Marilyn Schiltz, 2008).

Dr Kathryn Mannix, a palliative care pioneer in the UK discusses the medicalising of the human experience of dying, instead of greater humanising. She describes how her grandmother, born in 1900, was not a stranger to the care of the dying at home. Yet, throughout her life, as doctors got better at saving lives, she witnessed the way death moved from the home to something that happened in hospitals, hidden from public view. "In a single generation, people forgot what dying looked like" (Wright, 2020).

Dame Cicely Saunders (1918-2005), founder of the modern-day hospice, and those who have followed in developing the palliative model, introduced a new moment in end-of-life care. It brings

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[5] 'Cure of souls' is a mediaeval term referring to the comprehensive ministry of pastoral care within the Christian tradition, including healing, guiding, sustaining and reconciling. Other world religions such as Islam and Judaism have a similar concept.
Oxford Reference. Retrieved 13 Mar. 2023, from
https://www.oxfordreference.com/view/10.1093/oi/authority.20110803095653805

together different disciplines and knowledges, finding common cause around a patient’s needs for holistic care, including spiritual care and especially for patients experiencing spiritual distress.

Simply described, this model of end-of-life care is based on the following principles:

- begins when illness is diagnosed and continues regardless of whether or not a patient receives treatment directed at the disease;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications;
- requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited;
- enhances quality of life, and may also positively influence the course of illness;
- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- sees palliative care for patients as the active total care of the patient’s body, mind and spirit and also involves giving support to the family; and
- requires health providers to evaluate and alleviate a child's physical, psychological, and social distress (adapted from Hospice Palliative Care Association of South Africa [HPCA, 2014]).

In the palliative model of end-of-life care, spiritual care is seen as carrying equal weight in the total care of patients and their families. The eminently African/South African ‘three-legged potjie’ (three-legged stool) illustrates the three components of balanced care.

Spirituality and spiritual care within the palliative discourse

Spirituality, within the palliative discourse, has been defined as “the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred” (Puchalski et al., 2009).

This definition situates the search for meaning, connection and self-transcendence as a universal dimension within humans. The spiritual search takes on specificities within particular religious or philosophical traditions as they have evolved over centuries. And so religious traditions name the ultimate source of meaning in different ways and develop rituals and practices, material, social and organisational forms which illustrate such diversity (Smart, 1998). While for some, the ‘search’ resolves in an ultimate deity or object of worship and finds organisational or social expression within specific faith communities, this is not universally assumed, making way for those who would self-designate as Spiritual but not Religious – SBNR (Bramadat, 2013, p. 2). Other worldviews, not predicated on a transcendent reality but rooted within a humanist or existentialist frame of reference, with strong ethical commitments, find themselves included in the notion of 'search for meaning and connection'.

By contrast, in our South African multi-religious context, it is important to note the high degrees of religious adherence in the population, where, according to the 2010 Pew Research Centre Report, only 15% of the population of 57 million was reported as not being affiliated to any form of religion or declined to respond (Office of International Religious Freedom, 2022). Even where people may give up on religious affiliation in their adult lives, it is likely that some return to earlier religious connections during times of suffering or at the end of life. Thus, for many people, spiritual care at the end of life will assume some kind of religious character.

As previously mentioned, spiritual carers can provide practical, emotional and spiritual support to someone at the end of life and also assist families to navigate the necessary practical tasks, emotional needs and spiritual aspects of this stage. They have a particular role in helping to alleviate spiritual pain or distress.

> 'Spiritual distress can be defined as the suffering that occurs when a person becomes estranged from the essence of who he or she is, loses any sense of the meaning of life, becomes demoralised and feels a growing sense of fragmentation or disconnection. Through somatization spiritual distress may result in physical symptoms, such as intractable pain, as well as having psycho-spiritual, religious and social manifestations. Investigating the aetiology of pain, including the potential spiritual components of apparently physical pain, is crucial in order to relieve patient suffering, particularly if such pain is proving unresponsive to pharmacological treatment' (Selman *et al.*, 2010, p. 27).

The Report on Spiritual Care in sub-Saharan Africa (2010) develops the categories of spiritual pain or distress that may present at the end of life (see Selman *et al*., pp. 38-40). This research illustrates some of the ways that Spiritual Carers can accompany someone and ease some of the discomfort and distress in the processes of ageing and dying.

Theoretical framework

Integral theory as a theoretical framework for our work

Spiritual Carers form a 'knowledge community' within the discourse community of palliative care. This community is both theoretical and eminently practical. In addition to drawing on knowledge and concepts from multiple disciplines – spirituality and comparative religion, medicine, complementary and traditional healing, psychology and sociology, cultural studies, philosophy and ethics – the specialist knowledge and 'literacy' of spiritual care is also constituted through practices outside the academy through participation in the work of practical caring. In Northedge's (2003) words, this knowledge "is not pinned down on the pages of a book….It arises out of a *process* of discoursing, situated within communities of practice"[6].

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[6] A community of practice (Lave and Wenger, 1991 pages 100ff) is a community intentionally formed around a common focus and by what people do together. Learning happens through *legitimate peripheral participation,* where a newcomer enters the community of practice and learns from the older members through participating in the work of that community, even if there is no specific intentional instruction or a set curriculum to be

This regard for the different 'knowledges' that spiritual carers draw on in their work finds itself in easy conversation within an integral theoretical framework (Wilber), specifically an aspect of this theory, the 4 Quadrant approach[7].

In her article on Integral Medicine, author Schlitz (2008: 62) analyses the positive impact of an integral perspective in medical care, as it pays attention to multiple ways of knowing and includes attention to both the rational and the intuitive, the thinking as well as the feeling, and the biological, sociological, and spiritual dimensions of the human experience (cf. Duffy [2020] has also applied integral theory to mental health). Schlitz encourages medical practitioners to cultivate:

> "a deep appreciation and humility for the divergent systems of health care that coexist in the modern medical context. Chinese medicine, curanderismo (Latin American folk medicine), spiritism, Christian Science, and evidence-based medicine—each offers insights into healing (Schlitz, 2008 page 61).

In making the case for spiritual care as 'minding the gap' in non-traditional spaces in end-of-life care, we will use an aspect of the integral framework – the 4 Quadrants – to explore the way spiritual pain or distress manifests in different ways at the end of life and how spiritual carers draw on different kinds of knowing and a versatile skillset to contribute to the palliative care of those at the end of life.

The 4 Quadrants illustrate four dimensions that are present in every human experience: the personal or subjective experience, the intersubjective interpersonal experience, the scientific or objective aspect of the experience, and the external, social and environmental aspect. These dimensions have been graphically represented in Wilber's original Integral Theory model, as shown in the following diagram (Figure 1).

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learnt. Through participation, 'newcomers' are gradually transformed into 'old-timers' who will initiate more newcomers into the practice. Participation shapes the identity of members of the community, and newcomers begin to gain the knowledge and acquire the skills necessary for them to become 'master' learners, the experts and specialists in the life of the community, and thus to shape the community (p. 55).

[7] Philosopher Ken Wilber is the primary proponent of integral theory, which is essentially a philosophical 'map' that brings together ancient and contemporary theories in philosophy, psychology, contemplative traditions, science and sociology. It is premised on the view that human beings, and indeed the whole physical world, are constantly evolving to greater levels of complexity and that each theory and philosophical tradition has something of value to contribute to an understanding of these developments. Thus all perspectives, from pre-rational, traditional, and modernist through to postmodernist worldviews, have validity in the context of the evolutionary stage and local conditions within which they are manifesting, alongside their limitations. Each changing stage of development brings with it the potential for an enlarged human experience and enlarged perspectives on the human experience, as we draw on more and diverse knowledge to help us live and do better. Integral theory can help us look at end-of-life care and to see some of the limitations of the past and present models and to imagine the kind of care we would like for others and for ourselves when we reach that stage. Wilber uses a number of heuristics to develop his integral explanation of human development, including terms like 'lines, levels, stages and quadrants'. Whilst acknowledging these other aspects that could also be shown to have a bearing on the subject of end-of-life life care, this paper focuses only on his notion of Quadrants. (See A Quick Intro to Integral Theory available at https://www.dailyevolver.com/theory/)

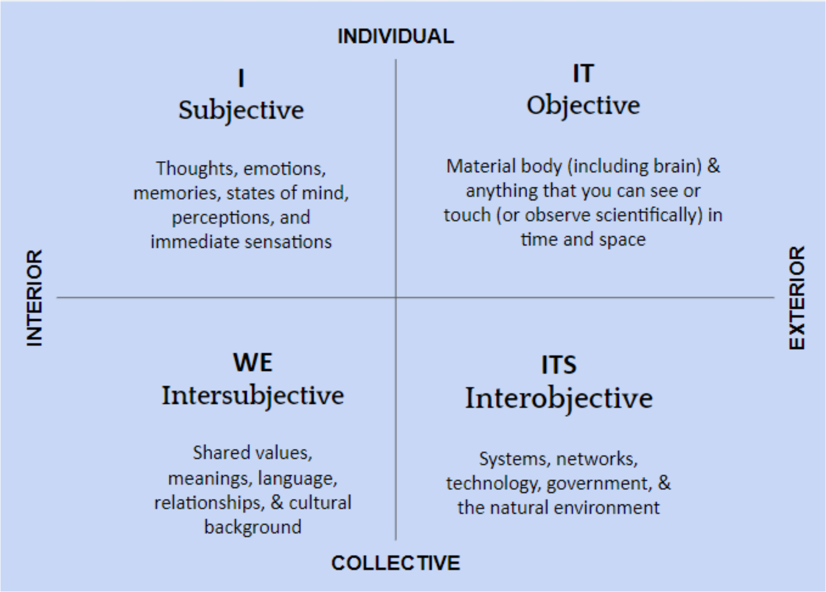

Figure 1: Wilber's (2014) 4 quadrants

Spiritual pain and how it manifests using the 4 quadrants

Different manifestations of spiritual pain or distress that may present at the end of life have been identified (Brayne & Fenwick, 2008; Wood & Fox, 2009; Selman *et al.,* 2010, pp. 38-40). These are shown to correlate with the 4 quadrants in the integral approach and are represented in each of the quadrants in Figure 2.

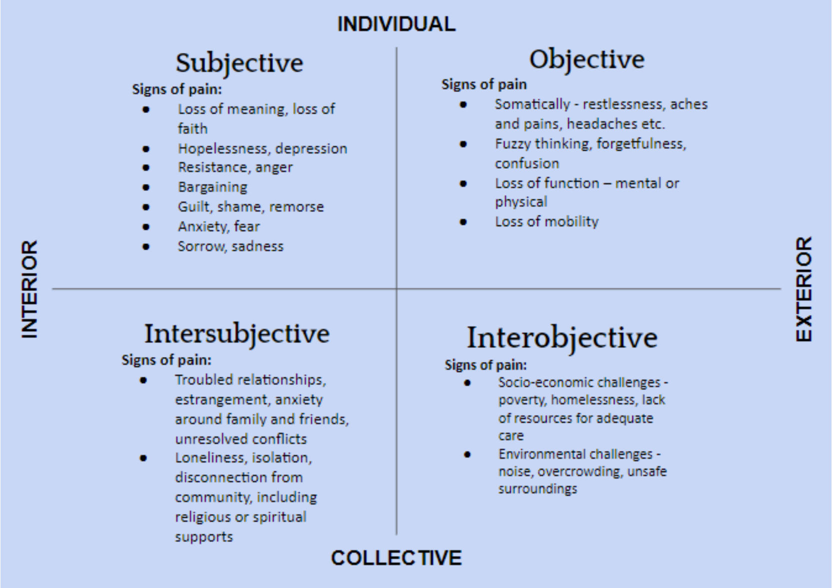

Figure 2: Signs of pain at the end-of-life following Wilber's 4 quadrants

Spiritual care using the 4 quadrants

Providing spiritual care in non-traditional settings requires of carers a versatility and fluency to 'mind the gap' which may not be managed within the current medical dispensation.

Subjective (Interior)

Here the focus is on the inner world of the person being cared for at the end of life and the spiritual pain they are displaying. Individuals at the end of life may experience a range of emotions, including fear, anxiety, sadness, and grief. This quadrant also points to the person's feelings about their illness, life and death, and the support or lack thereof that they are seeking. For some, being connected to nature and beauty is soothing; for others, remembering and telling stories, and others are still nurtured through religious rituals, comforting readings from sacred texts, praying, singing, meditating, and listening to poetry and music. Others yet may need to set their affairs in order or to speak about painful and difficult experiences. None are mutually exclusive.

Through deep listening, observation, compassion and attention to what is unspoken, the soul carer can support individuals at the end of life in processing their emotional, psychological and spiritual experiences, finding some meaning and coherence in their life experiences. This is predicated upon the soul carer being offered some access to the person's inner world – whatever it is the person is willing and able to share. "In this kind of listening, we simply absorb. I have to banish the temptation to offer advice and solve problems. I have to banish the temptation to bring in my own experience in a kind of one-upmanship; any kind of self-disclosure must be judiciously chosen (Guenther 2011, p. 253).

Intersubjective (relational)

The interpersonal domain focuses on the relational world of the person: their family and friends, the medical or care staff, and other social, religious or cultural connections.

Tuning into the relationships that surround the 'person', we learn which ones are helpful and supportive, which ones need to be healed, and which are unhelpful or even toxic. The person may request help to connect with family, friends, and religious or spiritual groups.

Spiritual carers also pay attention to the cultural, religious and family beliefs and practices that shape the way the person thinks about illness and death. This calls for skilfulness in responding to those whose class, racial, cultural and religious stories may be different from that of the carer.

Where there are fractures in interpersonal relationships, there might be a role for the spiritual carer to facilitate reconciliation or healing processes or rituals. The complex histories and injustices that have shaped lives and relationships in South Africa's racially and economically skewed society may well surface old wounds and justifiable pain and anger. Here the spiritual carer is simply called to bear witness to the person's story "without advising or fixing or saving" (Palmer, 2016).

Objective (exterior)

This quadrant refers to what is going on in the person's physical body as their illness or ageing progresses and also the losses or deterioration in the person's sensory and brain activity. It includes the treatment or palliative procedures being applied and how the person is responding to them.

Spiritual carers work alongside the medical staff and do not interfere with the treatment regime agreed on by the person with their medical practitioner. However, they are attentive to where more support might be needed. Caring for another at the physical level offers many opportunities for physical interventions, including touch and visual, auditory, kinaesthetic and general sensory support, as well as relaxation and breathing exercises.

A regulated tone of voice, gentle touch and other sensory interventions like soft colours, warm ambience and soothing music are known to have a calming effect on a person who may be fearful or agitated. In addition, there is evidence to suggest that meditation in terminal stages can increase pain tolerance, improve mood, sleep quality, and overall well-being, and reduce anxiety, stress, and mental confusion (Candy et al., 2012; Zeidan, 2016); and mindful breathing can have an impact on reducing or soothing pain (Guan et al., 2021). Spiritual meditation is also found to increase a person's sense of 'connectedness' to a greater whole, which is especially relevant towards the end of life (Agora Spiritual Care Guideline Working Group, 2013).

Interobjective (external)

This quadrant refers to the more intimate environment surrounding the caring situation, including the physical environment, i.e., the things around the 'person', the stimuli, and the colours, sights and smells that may be soothing and healing, or disruptive or uncomfortable. It includes the setting of the person's home or institution. Is the environment conducive or detrimental to caring and gentle dying[8]?

Time in nature and simple gardening activities (Stuart-Smith, 2021), softening the ambience, respecting privacy, and decluttering the space are all tasks spiritual carers may undertake. Sometimes small adjustments within the context of the person's personal environment can make a great difference, e.g., facing a bed towards a window, rearranging the room, or taking the person outdoors into the fresh air.

Spiritual carers are often drawn into situations where there is real physical deprivation and need for food, shelter, security, medical care and pain relief. 'Minding the gap' may well require facilitating interventions on the person's behalf. At the same time, this quadrant refers to the broader economic, racial, social, political and environmental systems and structures that shape individual experiences. In the context of end-of-life care, this might involve the healthcare system, legal systems, and social support networks and, most specifically, the policies and resources available to support end-of-life care. Spiritual carers as participants in political and social processes also engage in activism and advocacy on behalf of justice and transformation.

The model described above suggests that spiritual pain and care for the whole person at the end of life requires awareness of all these 4 quadrants. They are never static, and all are constantly arising, although sometimes one quadrant may be more dominant than another.

Spiritual carers within the 4 quadrants

No one sits outside of the care relationship, and "the work of healing demands that we let ourselves be touched. We, too, are vulnerable to being healed by the encounter" (Guenther 2011, p. 254). Puchalski, in arguing for spiritual or reflective formation as part of professional development of

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[8] 'Gentle Dying' is the title and subject matter of Felicity Warner's book (2008), Hay Books.

clinicians, makes the point that both the patient and clinician are “transformed through illness, suffering and loss” (Puchalski & Guenther 2012, p. 254).

In responding with empathy[9] to the spiritual pain manifesting in the person being cared for, the spiritual carer may also be affected by the interaction. We now see how each of the quadrants shows up in the spiritual carer’s experience.

Spiritual carers have their own **Subjective (Inner)** experiences, some of which might be triggered by the encounter with the other. In such a case there is the potential for transference or projection onto the person being cared for. Thus, spiritual carers need to develop self-awareness[10] and practices to help them stay centred and in touch with their own inner world.

As much as carers are tuning into the relational world of the person-family relationships, community and cultural bonds, the spiritual carer has to be conscious of their own **Intersubjective (relational)** world and what shapes it – their culture, race, gender, class or worldview. These may be different from the person they are caring for. Managing these two worlds requires sensitivity to the potential for an uneven power relationship to develop, often in unconscious ways.

The **Objective (Exterior)** world of the spiritual carers is also ‘in the room’ with the patient’s world. Spiritual carers also experience physical challenges and illness or times when they feel anxious and distracted. This too has to be acknowledged, as well as the impact of serving a patient with a debilitating condition which may make caring difficult. Attention to self-care, breathing, relaxation and meditation practices helps the spiritual carer to self-regulate.

Managing the **Interobjective (external)** dimension of end-of-life care may not be easy where the social welfare systems are in disarray and spiritual carers themselves are not in a position to ‘mind all of the gaps’. Spiritual carers are equally impacted by their environments: racism, humiliation, poor or no remuneration, silencing, load shedding, community violence and lack of resources. These are all aspects of carers’ situatedness in the South African socio-political-economic environment. All these factors impact on the spiritual carer and their ability to provide care.

While attentiveness to the spiritual carer’s own inner work is not common in the literature (see, for example, Linda *et al.*, 2015), we argue that ongoing personal and spiritual development and self-care are essential to avoid burnout and the potential for harm being done through lack of awareness of the ‘shadow side of caring’[11]. Joan Halifax frames the positive benefits of doing shadow work:

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[9] Empathy (then) is the ability to understand another's distress without either ignoring its significance or being overwhelmed by one's own emotional response (Gibson et al., 2011 page 9).

[10] McLaren (2011) emphasises the development of self-awareness as an important component of empathy.

[11] Repeated exposure to human suffering and working with dying and bereaved people can lead to deep emotional anguish on the part of the soul carer, and can negatively influence the well-being of the carer and the quality of patient care. This is referred to as the dark or “shadow” side of care (Renzenbrink, 2007). Joan Halifax (2008, chapter 12) identifies 5 aspects of the shadow that may play out with carers: the hero or the rescuer – believing they are the only one who can help; the saviour; the priest – spiritually inflated, on an emotional high from being around suffering, offering lofty advice or preaching; the martyr – who takes on everything but is resentful and possibly suffering from burnout or compassion fatigue; the parent – controlling and patronising, giving instructions or commands; and the expert – who acts in a clinical or professional manner but is emotionally distanced from the situation and avoids connection.

> “When the shadow of caretaking shows its ugliest face and we feel the most lost and confused, it’s then that we stand on the very ground for opening our hearts and letting go of our concepts … Buried in the coals of this fire (of our failures) lie the deepest opportunities to practise not-knowing and bearing witness – and, finally, to trust in presence. Perhaps afterward, we’ll find ourselves more available, somewhat more humble, and wiser for it all” (Halifax, 2008 p. 121).

While attending to personal shadows is important, spiritual carers also have to face the shadows within South African society and how they manifest, sometimes unconsciously, as racism, religious or cultural chauvinism, sexism, homophobia, and classism. This is as much personal as it is collective work to be done. If left unattended, it stands to reproduce the very opposite values of what spiritual carers intend and undermine the caring work they do (see Mahilall & Swartz, 2022).

Methodology

Background to the Soul Carers training programme

The Soul Carers training programme, offered by Mary Ryan (DTh), is aimed at training and supporting a cadre of non-medical carers to provide spiritual care to patients and their families within their homes, neighbourhoods or local communities.

The underpinning values and dispositions emphasised in the programme include compassionate[12] service, a willingness to be present with the one at the end of life and their family, deep respect for the other and their story, and a nonjudgmental and listening stance.

Initiated in 2019 in Cape Town, the affordances of online connectivity have made it possible to extend the training to include participants from the Helderberg, the Garden Route, Durban and Johannesburg as well.

The programme comprises a short course conducted over a period of 10 weeks which includes input, discussion, readings, and reflection exercises. Participants attend the course for different reasons:

- to process their own losses, or to learn how to accompany a family member or person at the end;
- to enrich their professional repertoire, or to complement other end-of-life training received in the workplace or religious organisation;
- to practise as a soul carer in the community.

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[12] The principle of compassion lies at the heart of all religious, ethical and spiritual traditions, summed up in the Golden Rule, which calls on all to treat others as we wish to be treated ourselves. Having compassion impels us to honour the sanctity of every person, to treat everybody, including ‘the enemy’, with justice, equality and respect, to refrain from inflicting pain on others, and to work to alleviate the suffering of others (Charter of Compassion, 2008 summarised).

Participants who wish to join the 'community of practice'[13] – the Soul Carers Network (SCN) – are required to complete an end-of-course assessment task and participate in a discernment process around their availability and suitability for this work in the public space. The SCN is an association of soul carers who assemble regularly for ongoing formation, mutual support and debriefing, and advocacy work.[14]

Since 2019, 109 people have attended the training programme. Of these, 102 of the participants were female and 7 male. Ages ranged between mid-30s to late-70s, with most participants falling within the 50–70 age range.

Unsurprisingly, during Covid, attendance at the courses increased as everyone struggled to deal with the multiple losses in our midst, and the *Zoom* platform made online participation in courses possible under conditions of strict lockdown. Course participants are adherents of different religious or spiritual traditions (Unitarian, Christian from different denominations, Anthroposophy, Buddhist, Divine Light International Ministries, Muslim, and Jewish), practitioners and teachers of different schools of meditation, and secular humanists. They are engaged in a variety of professions and occupations including medical practitioners (nurses, medical doctors); elder care facility matrons or managers; allied medical professionals (social workers, psychologists, counsellors, speech therapist, physiotherapist, drama therapists, home based carers); complementary healers (Chinese medicine, Reiki, reflexology, aromatherapy, massage, colour and sound therapy, Yoga teachers); hospice volunteers; religious/spiritual practitioners (clergy, spiritual teachers, spiritual companions, presiders and facilitators of religious/spiritual rituals); professionals in education, business & law, administration, life coaching; creatives (artists, writers); and advocacy workers in the end of life and palliative sector.

Selection of research participants

A purposive sampling method was used to select participants for the study.

In November 2022, an invitation to participate in the study was extended to the 109 people who had participated in the Soul Care training between 2019-2022. Of those, 46 people responded positively to the invitation, and 35 of those attended one of the *Zoom* focus group sessions for the purposes of data collection. The request for participation in the study was framed within the context of the forthcoming Palliative Care Conference (April 2023). Participants were invited to attend an hour-long *Zoom* session to contribute to the generation of a paper for the Conference by sharing their experiences in end-of-life care. It was noted that contributions would be recorded, but confidentiality was assured and that any direct quotations would be anonymised in the final paper. This assurance was repeated at the beginning of each *Zoom* workshop.

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[13] Lave and Wenger (100ff) describe how a *community of practice* is a community intentionally formed around a common focus and by what people do together. Learning happens through *legitimate peripheral participation,* where a newcomer enters the community of practice and learns from the older members through participating in the work of that community, even if there is no specific intentional instruction or a set curriculum to be learnt. Through participation, 'newcomers' are gradually transformed into 'old-timers' who will initiate more newcomers into the practice. Participation shapes the identity of members of the community, and newcomers begin to gain the knowledge and acquire the skills necessary for them to become 'master' learners, the experts and specialists in the life of the community, and thus to shape the community (55).

[14] https://www.soulcarersnetwork.co.za/

Dates and *Zoom* links were circulated, and participants could choose to attend one of the 8 possible *Zoom* focus groups. Apart from the 2 group facilitators, who were also participants in the study, no one had any knowledge of who else might be present in the *Zoom* group with them, nor about all the participants in the study.

At the beginning of the session, participants were welcomed, and the process for the focus group was explained as a reflective/writing process and not a debriefing or discussion session. Opportunity to read aloud and discuss their contrIbutions was provided at the end of each session. Participants were then asked to respond to 11 pre-set questions and to type their responses in the chat box (see Appendix A).

Limitations of the data collection method

Although the online data collection methods adopted enabled Soul Carers from various provinces in South Africa and from the UK to participate, some participants felt the chat facility limited their communication on the more reflective questions; others felt that they needed more time to think before writing; and some lost connectivity or were interrupted during the session.

Attempts were made to remediate the shortcomings by inviting those who wanted to send in email responses after the session. This may account for the unevenness in length and reflective depth of the responses.

Profile of participants in study

Location of soul carers

Of the 35 participants who contributed to the facilitated online data-gathering events, 34 were from South Africa, and one was from the United Kingdom. Of those in South Africa, 28 hailed from the Western Cape, with most (23) living in Cape Town, Somerset West (2), and one each in Franschhoek, George and Knysna; five from Gauteng, all living in the Johannesburg area; and one living in the Eastern Cape in Kenton-on-Sea. The uneven provincial distribution is completely understandable, as the Soul Caring courses initially commenced as face-to-face offerings in Cape Town and only later, especially during the COVID-19 period, pivoted to online *Zoom* sessions, which allowed people from anywhere to join. The original question posed about where the soul carer lived and worked was based on the assumption that these were coterminous, but this proved not to be always true, as at least one soul carer lives in the Western Cape but works across the Eastern Cape, Gauteng, and KwaZulu-Natal, and a number of others live in one suburb but work in other suburbs.

Capacity in which spiritual care is offered by soul carers

In response to the question, “In *what capacity do you offer spiritual care?”*, 24 soul carers responded that they were a friend, a family member, or a neighbour; 19 were volunteers; 18 offered spiritual care as part of their professional work (e.g., medical – nursing, social work, physiotherapy; non-medical – religious and spiritual practitioners, complementary therapists); and 11 were employed carers. As soul carers offer spiritual care in more than one capacity, the total number exceeds the number of soul carers (Figure 3).

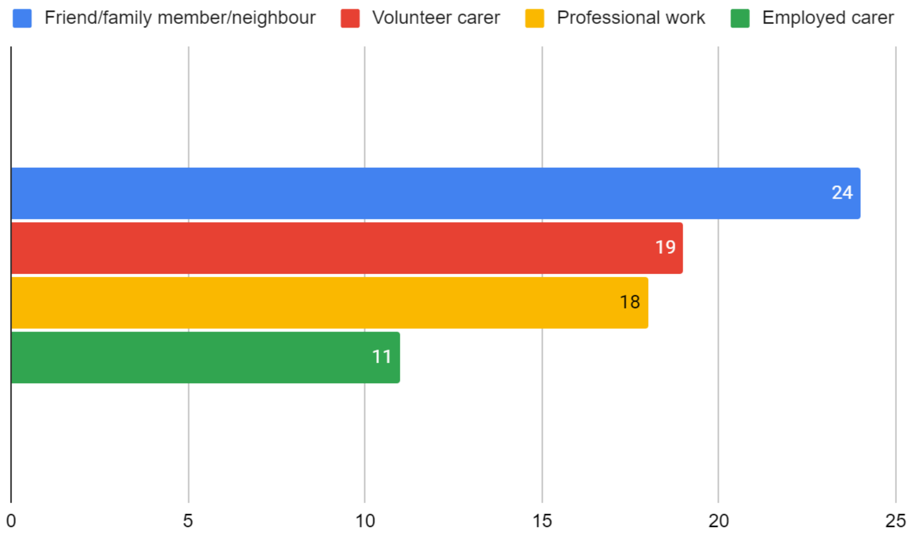


Figure 3: "In what capacity do you offer spiritual care?"

Conditions and age of those to whom spiritual care is provided

When asked with whom they work, 24 replied that they supported the ageing, and 22 replied that they journey alongside those with terminal conditions. Most soul carers accompany adults 22 and only a few (7) companion children (Figure 4).

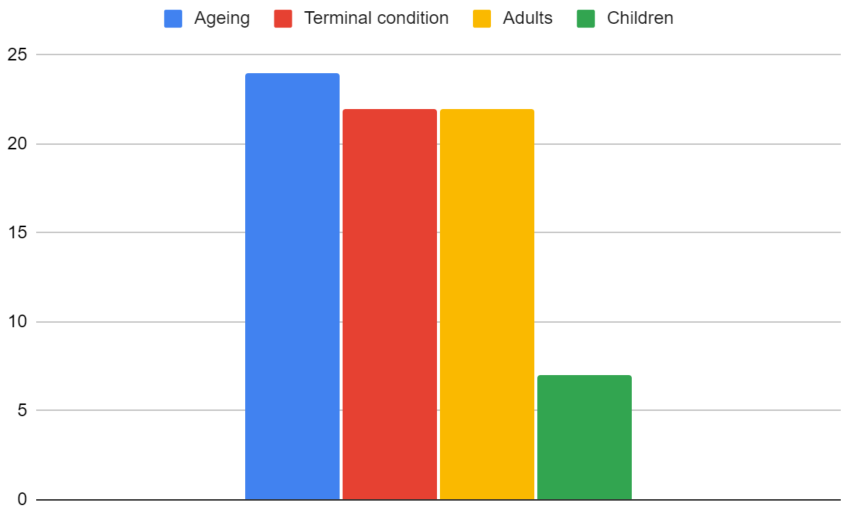


Figure 4: With whom do you work?

Sites of spiritual care

As can be seen from Figure 5, 32 of the 35 soul carers offer spiritual care in people's homes. Sixteen offer care in a facility (e.g., hospice, clinic, hospital, elder care facility); six in churches or religious communities; and six in other sites of practice (e.g., community centres, in the workplace, private practice at home, online).

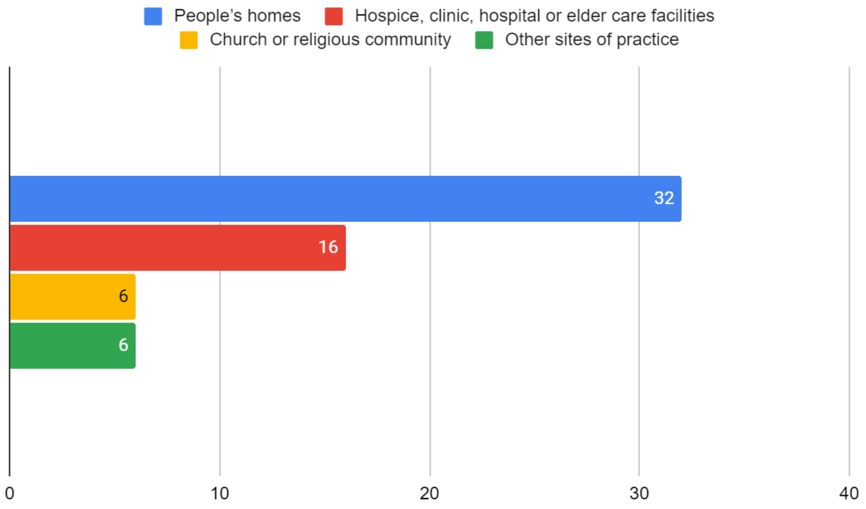


Figure 6: In what contexts do you offer your services?

Form of spiritual care

As can be seen from Figure 7, the most predominant form of care is visiting and companioning (28). Twenty-three soul carers facilitate difficult conversations and involve the friend with some activity (e.g., reading, playing games, music, art activities); 20 undertake traditional caring tasks; 19 offer administrative support with end-of-life affairs and documentation; 19 pray, anoint and bless; 17 create and facilitate rituals; 15 engage in other activities such as grief counselling, supporting the family caregivers, supporting staff at day centres and hospices, and advocating for those at end-of-life through workshops, talks, etc. 12 provide training and/or counselling for soul carers, nine offer support with legacy work (e.g., life story writing), and six raise awareness about spiritual care. It is difficult to ascertain the scope and intensity of "soul care" as the activities extend from informal visiting to formal training. We would need a much more sensitively calibrated set of data-gathering methods and instruments to better understand the variation in scope of soul-caring activities and fluctuation in intensity, and even then, soul carers may not be able to recall the type and intensity of soul-caring activities.

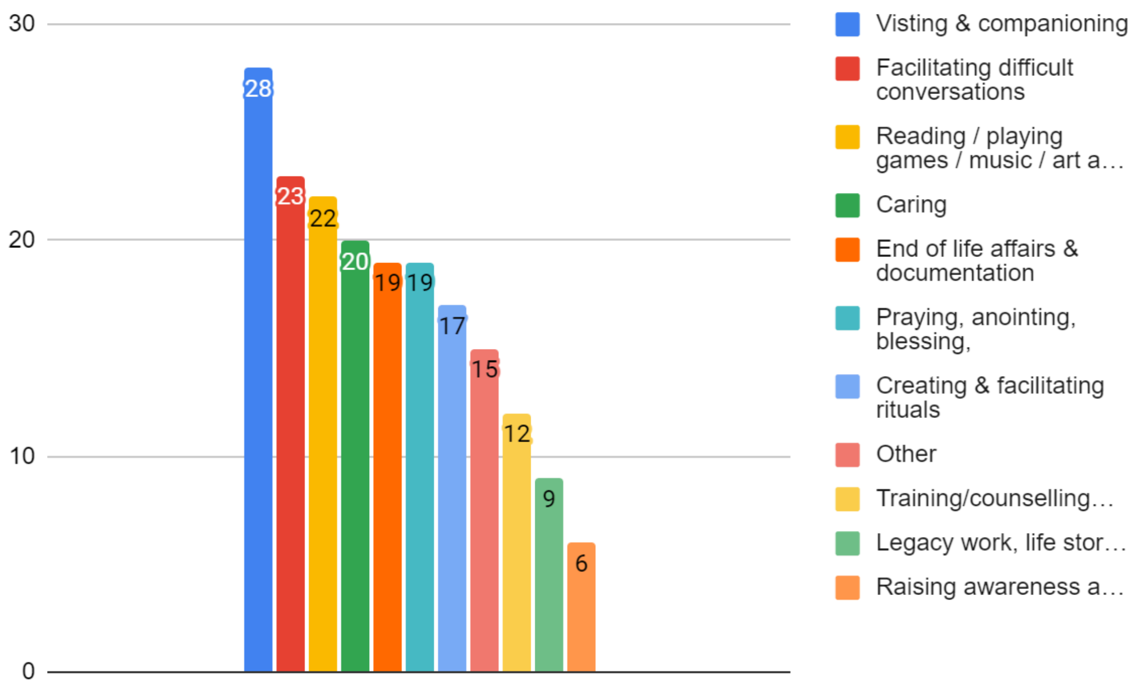


Figure 7: Forms of spiritual care

Years of spiritual caring work

We asked participants, “When *did spiritual care at the end of life become a clear focus in your life?”* but the data provided was not easy to categorise, as soul carers found it difficult to answer accurately, and some didn't answer at all. A few had recently completed soul care training, and some have worked in this field for almost the whole of their working lives.

Numbers of people who have received spiritual care

Even our tentative question: *“Could you estimate how many people might have received spiritual care from you?”* did not yield comprehensive responses. However, there seemed to be a nascent pattern that the uncertainty about the number of people supported increases with the actual number supported. In other words, those who have supported 10 or fewer ‘friends’ seem to be able to recall this, but after that, respondents use words such as "about", "around", "possibly", and "guess" to describe how many people to whom they have offered spiritual care.

Data analysis

The responses from the *Zoom* focus groups were collated verbatim into an MS Excel spreadsheet, thematically coded by all four participant researchers and then organised analytically according to Wilber's Four Quadrant framework. Each code was grouped into one of the four quadrants or domains, representing the:

- subjective experience (the interior of the individual / the individual interior) (I),
- objective behaviour (the exterior of the individual / the individual exterior) (It),

- intersubjective culture (the interior of the collective / the collective interior) (We), or the
- interobjective systems (the exterior of the collective / the collective exterior) (Its).

Note: In the data analysis the term 'soul carer' is used to refer to this specific group of spiritual carers.

Subjective (interior)

Given that spiritual care is primarily located in Wilber's Upper-Left quadrant (UL), which represents the **subjective**, **individual** perspective, it is unsurprising that the majority of the responses clustered around the individual interior (I) domain.

Key themes that appeared within the interior space that reflect the ways in which soul carers support the subjective experience of the person ageing or dying are presented below in the order of frequency.

Soul carers support for subjective experience of person ageing or dying

As indicated in Figure 7 above, soul carers may offer a number of activities to support the person who is ageing or dying, always where appropriate and where the person indicates willingness to participate. These may include having difficult conversations; reading; playing games; music and art activities; assisting with documentation or legacy work; praying; anointing; and blessing. These activities form part of the soul carer's deeper intention to accompany and support the person at the end of life in non-prescriptive ways. Soul carers describe how they understand the deeper emotional and spiritual support they are offering.

"Being with"

In this study, several soul carers described their engagement with a person at the end of life as "*being with*" or "*holding a space for*" them. Previous studies mention both "being with" (Sallnow *et al*., 2022) and "hold space" (Rawlings *et al*., 2019) as frequent tasks of those providing spiritual care. In this study we endeavoured to tease out what this "being with" and "holding space" might mean for soul carers and analysed the data to identify what they might be experiencing emotionally, psychologically and spiritually. We need to make clear that as these are constructs that we are overlaying on actual experience, these categories serve merely to help us understand the complexity of the subjective experience, not to prescribe or define these fluid experiences.

From the soul carers' perspectives, "being with" is associated emotionally with being "fully present" with the patient by *"hold[ing a] space for their emotions to run their course"* and *"holding a [...] compassionate and non-judgemental space"* by providing the *"gift of stillness and not-knowing", "closeness", "equanimity"* and *"empathy"*. 'Being with' is also associated with acceptance, as one carer said, "I *also needed to just 'be' with [the patient], not try to fix things."* So when soul carers refer to 'being with' a person emotionally/psychologically, they are offering presence, compassion, a non-judgemental attitude, stillness, closeness, equanimity, empathy, companionship, containment and acceptance.

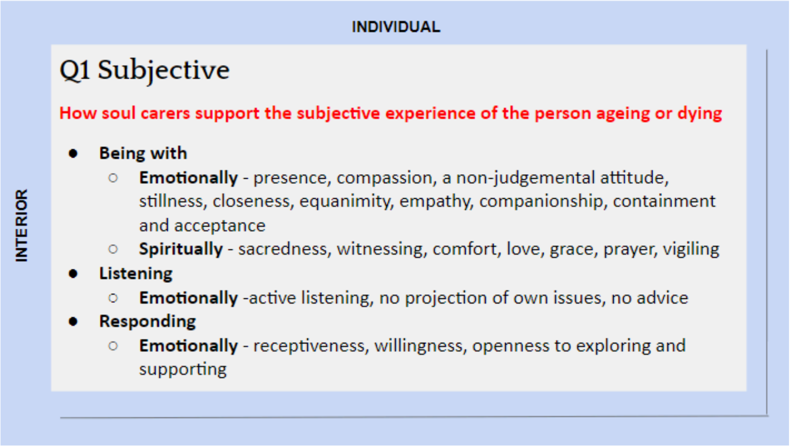
'Being with' is also associated with spiritual care where soul carers offer a "*sacred space*" to the patient on their "*sacred journey … [in] exploring the difficult journey of coming to terms with their* *illnesses"* or, equivalently, *"creating a sacred space where I am witnessing, listening and allowing someone to experience their journey into the unknown (death)".* Soul carers also mention being able to offer *"hallowed comfort"* as *"there is so much love to comfort us" and* offer "*prayers"* because *"grace abounds in the universe".* Soul carers are also willing *"to vigil with [the patient] to the end".* When soul carers refer to 'being with' someone in a spiritual sense, they are referring to sacredness, witnessing, comfort, love, grace, prayer, and vigiling.

Listening

Active listening emotionally to the ageing or dying person is aptly described by a soul carer as *"listen[ing] to the patient with all of my heart"* and by another as *"listen[ing] to more than words"* or similarly as *"listen[ing] acutely (verbalised and non-verbalised)".* Other phrases used to describe the quality of listening include the advice to "*listen and not project one's own issues" and not "to fill space with should do's,* [but] *rather with what is".* When soul carers listen, they are listening actively to what is verbal and non-verbal without projecting their own issues or filling the space with advice.

Responding

Soul carers reflected their responsiveness to persons ageing or dying by explaining how they approached an end-of-life setting. For example, one soul carer explained that she had learnt "*to take it slow [sic] and calmly and to feel my way and to follow where the person who is dying or even ageing wants to go*". Another carer responded by *"explor[ing] the risks and difficult situations in the safety of home",* while another named a difficulty as the experience *of "existential dread"*. One strategy employed was "*reading end-of-life books together very slowly and talk[ing] about almost every paragraph … it opened the space for the difficult conversations*". In sum, when soul carers refer to being responsive to the person, they reveal an unhurriedness and calmness in their approach and a receptiveness, willingness, and openness to exploring and supporting the difficulties identified by the person ageing or dying using whichever strategies identified as helpful by the person.



INDIVIDUAL

INTERIOR

Q1 Subjective

How soul carers support the subjective experience of the person ageing or dying

- **Being with**
  - **Emotionally** - presence, compassion, a non-judgemental attitude, stillness, closeness, equanimity, empathy, companionship, containment and acceptance
  - **Spiritually** - sacredness, witnessing, comfort, love, grace, prayer, vigiling
- **Listening**
  - **Emotionally** -active listening, no projection of own issues, no advice
- **Responding**
  - **Emotionally** - receptiveness, willingness, openness to exploring and supporting

Figure 8: How soul carers support the subjective experience on the person ageing or dying

Intersubjective (relational)

In addition to support for the person, soul carers also mentioned their contribution to supporting the relational world of the person who is ageing or dying. They describe this support in different ways.

Comfort for family

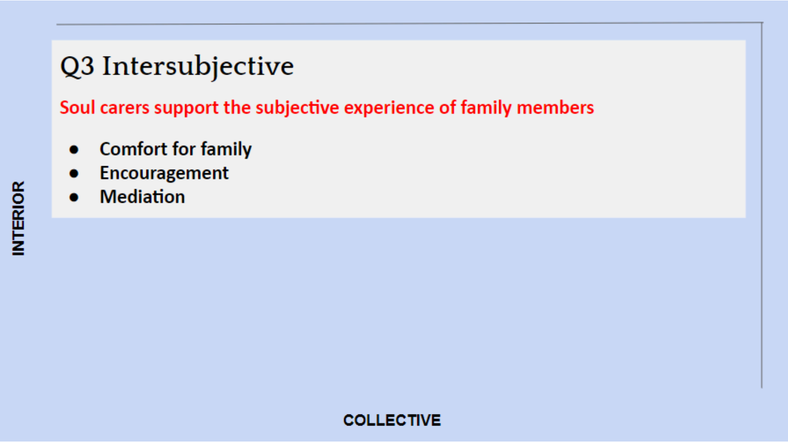
This “being with” also extends to those around the ageing or dying person: “*holding the space for the immediate family and close friends of the bereaved”* to assist them in *“finding containment in the very rocky first week after”* their bereavement and “*being with a five-year-old [and] helping her to comprehend the passing of her grandmother [and] comfort her loss*”.

Encouragement

“Being with” the family includes encouragement: *“much of my role is to show and remind the patients and their family, especially, that they have the resources and the wisdom to know what to do and how to be*.”

Mediation

Soul carers are also involved in a proactive role of mediating: “*to mediate for the patient and family at the end of life”.* In an unusual collaboration involving the soul carer and the patient, together they “*designed workshops for a [hospice] day care group*”.



Q3 Intersubjective

Soul carers support the subjective experience of family members

- Comfort for family
- Encouragement
- Mediation

Figure 9: Soul carers support for the subjective experience of others

Objective (exterior)

Through their calm disposition and various body therapies and sensory stimulation, soul carers support the person physically.

Steady, peaceful presence

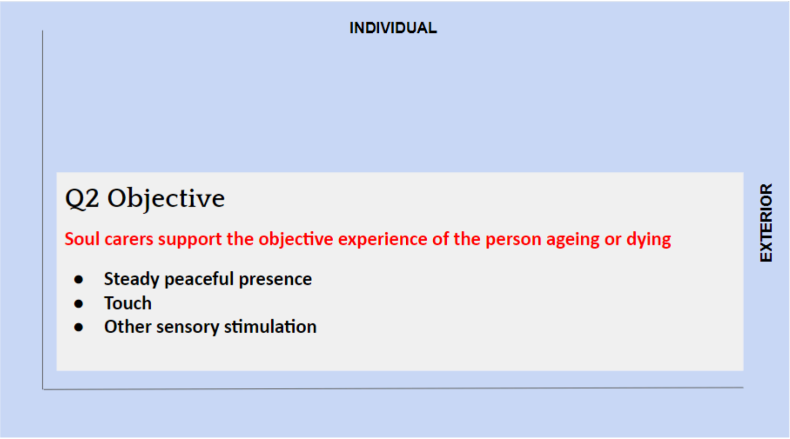
Soul carers used words like "*peaceful presence*" and "*people who are distressed are in need of closeness",* suggestive of the calm and soothing presence the soul carer brings to the patient who may be feeling anxious or fearful. Introducing calmness, peace and warmth into the space can help reduce anxiety and fear through the mechanism of co-regulation.[15]

Touch

Soul carers described the way they responded to some of the physical needs of the person through touch, either in the form of massage with essential oils or just gentle touch: "*offering a light touch", responding with a gentle touch when it is called for,* and "*stroking gently*". Soul carers shared about the intimacy of the touch: "*I put my hand on his heart*" and "*the [friend] died in my arms; it felt like I was holding a new life of mystery*".

Other sensory stimulation

Soul carers also use music, art and nature in their care.



Q2 Objective

Soul carers support the objective experience of the person ageing or dying

- Steady peaceful presence
- Touch
- Other sensory stimulation

Figure 10 Soul carers support for the objective experience of others

Interobjective (relational)

Soul carers described doing things to elevate or enhance the atmosphere in the room of the dying person by lighting candles, playing music or singing: "*I sang the 23rd Psalm*" and *singing phrases from songs like Pink Floyd's 'Comfortably Numb'*.

Several soul carers referred to being engaged in advocating for those at the end of life through workshops and talks and also providing training to potential soul carers – both these activities contribute to raising awareness and promoting spiritual care in the broader society.

The research did not invite reflection on the socio-political context within which soul carers are doing their work. A possible line for future enquiry might be to study the affordances and constraints and

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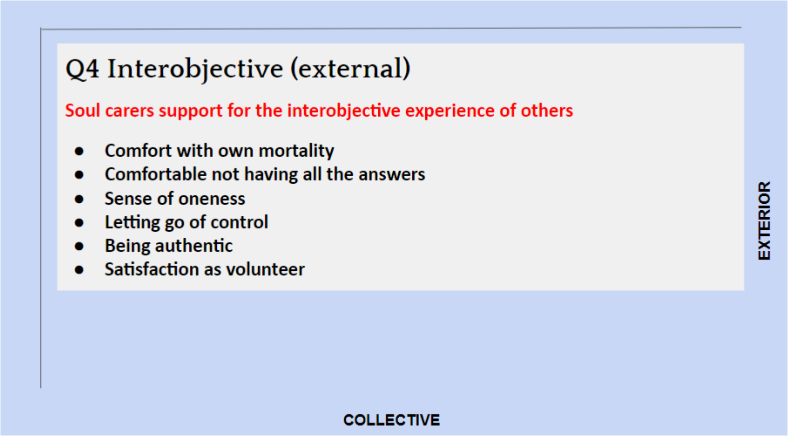
[15] Trauma research describes the process of co-regulation where the carer's "warm, calming presence and tone of voice, verbal acknowledgement of distress, modelling of behaviours that can modulate arousal, and the provision of a structured environment that supports emotional and physical safety" (complextrauma.org).

challenges that are present in end-of-life care in the context of South Africa at this time – both for the patient and the soul carer.



Q4 Interobjective (external)

Soul carers support for the interobjective experience of others

- Comfort with own mortality
- Comfortable not having all the answers
- Sense of oneness
- Letting go of control
- Being authentic
- Satisfaction as volunteer

Figure 12 Soul carers support for the interobjective experience of others

Soul carers were asked to describe what they had learnt in doing this work. *What wisdom have you learnt from this work in spiritual care?* A range of responses emerged.

Comfort with one's own mortality

Soul carers described feeling comfortable with their own mortality and hence were able to do this work without being fearful or resistant to death: *"I have come face to face with my own mortality, beliefs, values and what creates meaning in my day-to-day life"; our being, and our passing are sacred moments of transition"; "I know that everything is constantly changing, reaching its end"; "we will all be at this point in our lives, that is part of life, that it's ok"; "one day it will be me"*. Soul carers also acknowledge that they are *"not afraid of death" and that the* lack of fear "*can be a wonderful gift to bring to those at the end of life".*

Comfortable not having all the answers

A common thread in responses from soul carers was being comfortable in the place of 'not-knowing' and not always having answers, expressed as: "*there is so much that is mystical, inexplicable and unfathomable – sometimes there are no words, just experience*". In short, soul carers are comfortable with not having to know everything.

Sense of oneness

Some soul carers expressed a sense of oneness and connection to the whole in being with another at the end of life: "*there is a sense of oneness of myself with the universe*"; "*we are all connected", "we are all one"; "[I had] an overwhelming sense of one-ness with another human being … [that we shared] a common humanity connected through the dying process; within the Kin-dom we are one with each other and nature*". In short, soul carers are comfortable with the mystical and have a sense of oneness and connection.

Letting go of control

Learning to accept the situation and not to try and control the outcome was expressed by several soul carers, for example: *"some things cannot be fixed"*; "*as a physio, I am there to solve problems; sometimes that is not needed [in this work]. What is needed is that I see and listen without being ready with solutions*"; "*[I] also need to just 'be' with the person, not to try to fix things*"; "*to let things be what they are*"; "*my way is to think I have to find solutions and I had to suspend my ego in it…which is very hard*". A soul carer remarked that she had learnt *"to see people from an end-of-life lens",* another that *"it is not [my] wisdom that matters"* and yet another that he/she has developed *"the wisdom to let go and surrender".*

Being authentic

Being authentic with oneself and the person and trusting one's inner knowing was a thread for some, expressed as "*speak your truth, guided by my intuition, that grounded me"; "showing my vulnerability and fear*;" and "*tears*". In sum, soul carers have learnt not to try to fix things, to trust in their own and a higher wisdom as well as show their vulnerability.

Satisfaction as volunteer

While not all soul carers are volunteers, a few expressed their deep satisfaction in doing this work in a voluntary capacity, saying, "*I love the volunteer work I do;*" and "*[I choose*] *not to charge and to give freely of my time*".

Findings and Conclusion

In this study we set out to profile the work of a group of non-medically trained carers (known in our study as soul carers) to provide spiritual care in non-traditional settings to people at the end of life, including those who were naturally ageing or those with a terminal diagnosis. Non-traditional spaces include people's homes, elder care facilities, and other community spaces like churches. Operating in these non-traditional spaces helps to extend the palliative model of care beyond hospices and palliative wards in hospitals into broader society.

We introduced the term 'minding the gap' to suggest the role spiritual carers play in working alongside and supporting other medical and professional staff and also in providing support to family members and other members of the person's circle of care.

Working within the palliative discourse, with the established place for spiritual care, the research homed in on the concept of 'spiritual pain' or 'spiritual distress' and investigated the contribution that soul carers make in this regard. These contributions were theorised and analysed using Wilber's (2014) 4 Quadrants of the Integral model of human development. In applying this heuristic to the data, a granular description emerged of what these soul carers actually do in this end-of-life space, showing how soul carers 'mind the gap' by providing emotional, spiritual, psycho-social, physical and environmental support to those in their care.

Soul carers describe their contribution to 'minding the gap' in end-of-life care for those in non-traditional settings in the following ways.

On the one hand, they ‘mind the gap’ with their time and availability, supporting often over-busy medical and paramedical professionals who are not able to do more. More importantly, however, ‘minding the gap’ provides the patient with significant scaffolding to navigate the often-difficult terrain of the end-of-life journey. The overriding disposition that soul carers bring to this work is one of ‘being with’ the other in a compassionate and non-judgemental way.

The research illustrates how soul carers support people on an emotional, psychological and spiritual level, assisting people to express their questions, fears and beliefs about what they are going through and to find some meaning and coherence in their life experiences. Through being present and with careful listening, a hospitable environment is created for the person to share something of their inner world and to be affirmed, consoled and witnessed. Spiritual ‘gaps’ minded by soul carers working from an interspiritual paradigm include creating spaces for the symbolic and ‘the mystery’ to be expressed through forms of praying, blessing, reading from sacred texts, singing, facilitating rituals of blessing and forgiveness and vigiling. The phrase ‘hearing another to speech’ in this experience of dying comes to mind (Morton, 1985).

Soul carers mind the gap in the relational world of the person by helping connections or reconnections to be made with family, friends, and others in their community. Where relationships may be wounded, soul carers facilitate reconciliation and healing processes and rituals.

Soul carers are attentive to where more support might be needed for the person physically and to relax and calm the person when agitated. They offer gentle touch and massage, visual and auditory stimulation, as well as relaxation and breathing exercises. Soul carers attend to the spatial and what could make the person’s environment more pleasant and ambient, lighting candles, playing music and infusing the space with calm and peace. Some soul carers ‘mind the gap’ through raising awareness about death and dying and spiritual care in social spaces.

While not all soul carers claim to be doing everything, the composite picture of this work reveals the possible range of care responses that people facing the end of life are being offered.

The research also elicited self-reflective observations on how soul carers viewed their practice, what they learnt and how they were transformed through this work. What emerges from this exploration is a rich tapestry of humble, generous, committed, wise, self-reflective and skilful practitioners, most of whom perform their service either ‘after hours’ in addition to a day job, or integrated into their professional work, or as volunteers. Only a few derive payment for their time and skill. This is a consequence of medical aids not recognising the service spiritual carers provide – for those patients who are on medical aids – or that many people availing themselves of soul carers’ services are not on a medical aid or their funds have dried up. Thus, most spiritual carers are volunteering their service. This raises questions of justice, equity, and sustainability and thus challenges the health sector – private and public – and the medical aids to take seriously the contribution of these practitioners and find ways to accommodate them in the economic model of end-of-life care.

The study has had other useful benefits in firstly raising questions around the relationship between the training programme and the practice: What needs to be enhanced or extended or changed in the training programme to better prepare spiritual (soul) carers for work in the field? And secondly, with regard to the relationship between soul carers and the ‘community of practice’- the Soul Carers

Network: How can the relationship be sharpened so that it effectively supports the transmission of practical wisdom to those doing the work of caring for others at the end of life?

What the research has not undertaken and which we believe to be worthy of further study is to probe the efficacy and the scope of the practice and to examine how this model of spiritual care through ‘minding the gap’ could be extended to address the class, cultural and racial caveats beyond its current delivery.

Few in number, unevenly spread, and unrecognised in the formal hierarchies of the health sector, their work often unnoticed, yet soul carers’ contributions at the end of life are part of what stitches together and helps to hold and heal our hurting society.

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Appendix A: Online survey questions

1. Where do you live and work?
2. What is your understanding of spirituality and spiritual care for people at the end of life?
3. In what capacity do you offer spiritual care (choose as many as apply)
a) as a friend/family member/neighbour
b) as a volunteer carer
c) as an employed carer
d) as part of your professional work as a (state the specific profession, e.g. nurse, social worker, physio, complementary therapist, counsellor, life coach, religious minister etc)
4. With whom do you work? (choose as many as apply)
a) people who are ageing
b) those living with a terminal condition
c) adults
d) children
5. In what contexts do you offer your services (state as many as apply to you)?
a) In people’s homes
b) In a hospice, clinic, hospital or elder care facility
c) In a church or religious community
d) Mention any other sites of practice
6. What form does your spiritual care take (state as many ways as apply to you)?
a) Caring (including personal care, cooking, home managing, health care)
b) Visiting and companioning
c) Assisting with end of life affairs and documentation
d) Legacy work, life story writing
e) Facilitating difficult conversations
f) Reading / playing games / music / art activities
g) Praying, anointing, blessing, reading sacred scriptures, meditating
h) Creating and facilitating rituals (memorials, funerals, bereavement)
i) Training/counselling spiritual carers
j) Raising awareness about spiritual care within palliative care
k) Mention any other contributions

7. When did spiritual care at the end of life become a clear focus in your life? Could you estimate how many people might have received spiritual care from you?

8. Is there one experience that stands out for you?

9. What wisdom have you learned from this work in spiritual care?

10. Is there anything else you would like to say?

11. Is there a question, not asked, that you would like to respond to?