Social work and suffering in end-of-life care
An arts-based approach

Introduction

Social workers encounter profound human suffering in many fields of service and are called upon to help and support people at critical points in their lives. There are times when the suffering can be alleviated and other times when solutions will be extremely difficult to find. End-of-life care and bereavement are areas of social work practice that call for a response to suffering that goes beyond the usual repertoire of psychosocial interventions. This chapter will explore some of the challenges that social workers face in end-of-life care and bereavement support and, in particular, how the expressive and creative arts can provide resources that enhance coping and resilience for patients, families and for the workers themselves. Case vignettes drawn from my work as an art therapist and social worker in palliative care will be used to illustrate these themes. Arts-based research is a relatively new field of qualitative research and its methods of inquiry are increasingly being used to further understanding of this very complex area of human service and engagement with people who are vulnerable as they prepare for death. The potential of using collage as a particular example of an arts-informed method for research and practice will be discussed in relation to dying and bereavement.

Facing death: a spiritual challenge

As Kearney (1996) reminds us, death remains the ultimate separation and no matter how skilled and humane our care, there is nothing that can make it all better. For some people, he says, ‘dying has become a time of terrified struggle or meaninglessness despite the best efforts of family and caregivers to comfort and palliate their distress’ (Kearney 1996: 23). Social workers may themselves be engaged in ‘terrified struggle’ from time to time as they explore some of the biggest questions about life, death, suffering and fairness – the questions to which Rabbi Harold Kushner (2004) refers in his book, When Bad Things Happen to Good People. Struggling to find meaning in his son’s death from a rare disease at the age of 14, Kushner decided that although life is not always fair, and ‘the wrong people get sick and the wrong people get robbed and the wrong people get killed in wars and in accidents’ (2004: 52), it is the compassionate response to tragedy and the sharing of others’ pain and vulnerability that ultimately helps us to make sense
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of suffering. When we respond to pain and vulnerability in others, it could be said that we enter
the spiritual domain, defined in the broadest sense by Holloway (2005: ix–x) as ‘the inner life of
human beings, all that is left when you have fed or sheltered them, and that’s just about every-
thing that’s important to them’. A more succinct and focused definition of spirituality, arrived
at by a group of palliative care practitioners led by Puchalski, is as follows:

Spirituality is 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: 887)

This is echoed by Eckersley (2007: 54) when he describes spirituality as ‘a deeply intuitive, but
not always consciously expressed, sense of connectedness to the world in which we live’. When
I think about the patients I have met in palliative care over the years it is this connectedness that
stands out. They live the remainder of their life in precious moments with family, friends and
their professional caregivers, often surrounded by special objects and mementoes, acutely aware
of the beauty of nature. While this might sound idealised and not easily achieved in a hospital
environment unless the rooms are specially designed and oriented towards gardens and sky, it is
important to try to create an environment in which the patient feels at home and at peace. For
some people home is the best place to die but for others it can be the worst. It will depend on
the resources and support that is available to them. Although relief of pain and other distressing
symptoms is vitally important if there are to be healing conversations and leave taking, many
encounters in end-of-life care and expressions of love and devotion go beyond words. The
creative and expressive arts can play an important role. Self-awareness, willingness to face one’s
own mortality and give expression to grief that is experienced both personal and professionally
is a vital prerequisite for working effectively in end-of-life care. The reward for this effort,
 apart from enriching encounters with patients and their families, is the development of a deeper
spiritual awareness and appreciation of life for the practitioner.

Spiritual pain

The suffering experienced by people facing their own death has been referred to as ‘spir-
itual pain’. Dame Cicely Saunders, a nurse, social worker and physician who founded St.
Christopher’s Hospice in London in 1967, is recognised as the ‘outstanding innovator’ in the
field of hospice and palliative care (Clark 2002: 905). It was Saunders who established a new
kind of scientifically-based tender loving care for dying people and their families. In contrast to
previous medical neglect, there was a new openness about the terminal condition that recog-
nised the importance of fostering dignity, meaning and the patient’s humanity. Although suffer-
ing was no longer seen as a symptom or a problem to be solved, there was a need for some kind
of acknowledgement and conceptualisation of the complexity of the dying experience. Saunders
developed the concept of ‘total pain’, which included physical, emotional, social, financial and
spiritual pain. She understood the interplay of practical and emotional struggles but also the
pain that comes ‘from the depths of a person’s being’ (Kearney 1996: 14). Saunders (1988) also
acknowledged the needs of staff in this work when she said, ‘It is hard to remain near pain, least
of all an anguish for which we feel we can do nothing. We are wounded healers and we need
the support of our whole group in this work.’

Michael Kearney, an Irish palliative care physician, uses the term soul pain to describe a
particular form of suffering for the dying person. He has written that ‘We may fear anticipated
physical pain and distress, the emotional pain of separation from those we love and the dependency and loss of control, which, we imagine, lie ahead’ (Kearney 1996: 15). However, soul pain refers to a deeper layer of fear, an ‘existential and primal fear of the unknown that is more like our fear of the dark’ (Kearney 1996: 15), and Kearney goes on to describe soul pain as a ‘wasteland of meaninglessness and hopelessness’ (1996: 1).

Eckhart Tolle (2003) says that it is a great privilege and a sacred act to be present at a person’s death as a witness and companion. Yet, social workers are not always comfortable with this aspect of their helping role and may wish to call on the chaplain or another professional team member to engage with patients and families at such a time. However, the ability to respond to a dying patient is a rare opportunity and Tolle urges us to surrender to every aspect of that experience. He says, ‘do not deny what is happening and do not deny your feelings. The recognition that there is nothing you can do may make you feel helpless, sad or angry … you are not in control’ (Tolle 2003: 111).

As social workers that also offer bereavement counselling and support to individuals and families after someone dies, we need to recognise this helplessness, especially when the death is unexpected or particularly complicated. As Parkes (1972: 175) explains, ‘The helper cannot bring back the person who’s dead and the bereaved cannot gratify the helper by seeming helped’.

Sharing in brokenness

Social workers in end-of-life care are asked to enter into places of pain and to respond with compassion and wisdom based on their professional and personal life experiences. In his exploration of compassion in end-of-life care, Larkin (2016: 4) refers to Henri Nouwen’s belief that compassion asks us to go ‘where it hurts, to enter into places of pain, to share in brokenness, fear, confusion and anguish’. Larkin (2016: 7) argues that compassion requires ‘resilience, fortitude, and sometimes risk taking, but always tenacity and determination’. It is not enough to feel compassion. A compassionate response is an active one.

The extent to which compassionate involvement can be sustained will depend on many things, including the resources available to us in the workplace as we struggle to make sense of tragedy. Skilled supervision and support from our superiors and colleagues can help us to set realistic goals and acknowledge our achievements. We will need a balanced workload with opportunities for creativity or ‘something for the soul’ as a wise senior social worker once suggested. Sometimes there will be a need for personal therapy and healing activities such as meditation or other spiritual practices. At other times, ‘time out’, physical exercise and laughter with family and friends will alleviate stress and cast away thoughts of difficult work encounters. Most importantly and often neglected is the grieving that we need to do ourselves, not only for the actual or fantasised deaths of people close to us but also for the little deaths or dyings we experience in life. The poet Kenneth Patchen (1957: 3) captures this idea perfectly with the words, ‘There are so many little dyings it doesn’t matter which one of them is death’.

David Browning (2004: 22) believes that when we accompany others through tragic life events, ‘our own experiences with suffering and the sense we make of those experiences, constitute both the starting and ending points of these explorations’. Using his mother’s death when he was 13 as a starting point for an exploration of what he has learned as an oncology social worker and in his work with dying patients, Browning poignantly reminds us of our responsibility to understand our personal reservoirs of suffering. Working with a therapist and through poetry writing, he began to find meaning in his mother’s death and this discovery, in turn, helped him to enter fully and faithfully into relationships with clients experiencing significant loss.
Art and healing

In his book, *The Emotional Cancer Journey*, Michele Angelo Petrone (2003) describes his harrowing experience of cancer treatment. He died in 2007, aged 43, after 13 years of struggling with Hodgkin’s disease and involvement in programmes that promoted awareness of the healing power of art. As an artist in residence for a group of hospices in the south of England, he taught fellow patients and their carers about using art to promote spiritual and emotional wellbeing. He believed that the journey of illness was not only about the physical illness but also about the emotional response. It was the human face of care and not just treatment that contributed to the healing of what he described as his ‘tortured soul’ (Petrone 2003: 26). He also wrote about having a ‘guardian angel … a sense of faith in the invisible inner strength, perhaps a combination of everyone who has helped’ (Petrone 2003: 34).

Robert Pope was a Canadian artist who died of Hodgkin’s lymphoma in 1992 at the age of 36 after a 10-year battle with the illness. He also described his experience in his paintings, many of which have been used extensively in medical education since his death. In ‘Sparrow’ Pope painted a man lying in bed gazing through a window at a sparrow sitting on the branch of a tree:

> One haunting memory of my illness is spring. From my window all I could see were the tops of horse-chestnut trees, covered with beautiful blossoms. These blossoms seemed to say to me all I was feeling. They became for me encouragement to persevere, a symbol of recovery. This image also shows the sparrow. I have tried to contrast a number of opposites: outside and inside, the horizontal man with the vertical bird and trees, passiveness and activity, illness and health. The man and the bird share the same vulnerability and strength. (in Stewart 2005: 794)

Metaphors and symbolic language

Listening with a third ear to symbolic language is very important when working with dying and bereaved people. The capacity to tune in and to be moved by something that is profound and meaningful has been referred to in the expressive arts therapy literature as ‘empathic attunement’ (Kossak 2015: 3). Attunement is described as an immersion in the present moment and a sensory awareness of ourselves, others and the spaces we inhabit. Being attuned to our own ‘sensory presence and internal pulse’ (Kossak 2015: 105) is regarded as very important in establishing rapport and working empathically with patients in end-of-life care. Being fully present in this way requires a more imaginative and heart-felt involvement than traditional psychosocial assessment and intervention—based on the biomedical model.

It has been more as an art therapist than as a social worker that I have become aware of opportunities for this kind of empathic attunement through art making, non-verbal communication and connectedness through symbols and metaphors. The word metaphor is derived from the Greek *meta* meaning above and beyond, and *phorein*, meaning to carry from one place to another. Metaphor can be regarded as a way of knowing that engages the imagination. Art therapy and other expressive arts approaches such as poetry, movement and creative writing are not always recognised as tools for healing and spiritual development, and yet there is growing evidence of the need for a more imaginative approach to suffering, or what Levine (1997: 2) refers to as ‘the healing of the imagination by the imagination’. Allen (1995: 3) goes even further when she says that our imagination is the most important faculty that we possess and that it is through our imagination that we discern possibilities and options. It represents the ‘deepest voice of the soul’.
Art therapy in palliative care

The following vignettes show that art therapy can lift patients’ spirits when they are very ill. An art-making opportunity with a trained therapist can provide respite from a focus on medical problems and on everything that is ‘wrong’. Drawing and painting can be used for reminiscence and life review as patients recall happier times. Sometimes the colours, materials and actions that are chosen can convey strong feelings of anger, sadness and regret. The process of creating the image is seen as an end in itself and its meaning is not necessarily interpreted nor discussed.

James was an 85-year-old man with lung cancer who was very distressed about his shortness of breath. As I accompanied the doctor on her daily round, I heard James say, ‘What happens now, doctor. If I can’t breathe there’s nowhere to go, is there?’ In other words, if I can’t breathe I will die. He was afraid of running out of breath. As a sensitive palliative care physician, the doctor was able to listen to James who began to weep as he spoke of his fears and sadness about leaving his wife behind. She was very frail and he had been her carer. He never expected to be the first to ‘go’. Not having picked up a coloured pencil since childhood, James was not sure about doing any kind of art activity. However, when he told me that he had always been interested in black and white photography I suggested that he might try drawing with a stick of charcoal. After I showed James how to make simple squiggles to get the feel of the charcoal on paper, he spent many hours sketching the tree outside his window and various objects in his room. He said that ‘it took his mind off things’ and he felt more at peace. He proudly showed his sketch book to his visitors.

Audrey, a 65-year-old woman whose husband had died two years previously in the same unit confided in me: ‘No one thinks I’m capable any more. I feel so useless.’ Her adult children were very protective and highly anxious given that they had already lost one parent and were facing the death of another. She had been on a cruise when she became ill and the next thing she knew she was dying from ovarian cancer. When offered an opportunity to do some painting, she began to make cards for her grandchildren and chose an image for each child. A horse for one child, a boy playing cricket for another and a dancing ballerina for her granddaughter. She was able to lose herself in this activity and said, ‘This is fun!’ When the grandchildren came to visit her, I provided materials for them and they created cards and drawings for her in return. These were attached to the wall in front of her hospital bed to remind her of this very special family connection.

Jan, 68, used watercolour crayons to draw and paint a number of her favourite holiday places. She had become ill just before moving into a retirement village with her husband and derived great pleasure from quietly creating and reminiscing. She and her husband had planned their retirement very carefully and were both very sad that the dream would not now be realised. Watercolour crayons are particularly suitable for people who are frail as they are able to use a light touch to draw something on paper and by adding water with a brush there is a flowing movement of colour on the page. It is often experienced as a soothing and pleasurable activity and patients often take delight in seeing a crayon line drawing transform into a watercolour painting with a few brush strokes.

Paul, a 56-year-old architect, enjoyed drawing ships when he felt well enough to join other patients in the main lounge room of the palliative care unit. He was always critical of his artwork and struggled to get the sails ‘right’. Despite all efforts to relieve his symptoms he was in constant pain and was often bad tempered or withdrawn with the nursing staff and with his visitors. One day he invited me to bring some art materials to his room. Choosing dark blue pastel paper and various coloured soft pastels, Paul swiftly and purposefully drew a scene that he described as ‘the cosmos’. He then proudly drew a TARDIS, the time machine from the BBC Doctor Who
television series. With tears running down his cheeks he said, 'I don’t know where I’m going … but I know that I am not staying'. Paul was able to return to his home for a short time before returning to the palliative care unit to die. The name he gave to his drawing was ‘The Journey’.

Fragmentation in bereavement

The idea that grief and bereavement are fragmenting experiences is reflected in the language that is used by bereaved people after the death of someone they have loved deeply. Terms such as ‘falling apart’, ‘broken’, ‘shattered’ and ‘in pieces’ are frequently used to convey the intensity of their grief. Levine (1997: xvi) believes that it is ‘essential for human being (sic) to fall apart, fragment, disintegrate, and to experience the despair that comes with lack of wholeness’ and that it is by moving into the experience of the void that the possibilities for creative living arise and a new form of existence begins to emerge. One of the ways in which grieving and bereaved people can ‘put themselves together again’ creatively is through collage. Moon (2001a: 18) defines the creation of collage as ‘a structured activity that engages a client in making choices and organising materials, and can be symbolic of creating order out of fragmented aspects of life or chaotic feelings’.

Sharon Strouse, an art therapist whose 17-year-old daughter died by ‘falling’ off the roof of her college dormitory, created collages for ‘transformation and healing’ and to ‘reaffirm and construct a world of meaning that had been challenged by the loss’ (Strouse 2015: 187). The name Strouse (2013) has given to this process is ‘artful grief’ and she has published her collages and story in a book by that name. She also conducts workshops for other bereaved people. Strouse (2015: 192) describes her creative process as ‘unlocking doors to unexplored feelings’ and made the discovery that she felt empowered through the act of creating. A further example of the use of collage and creativity for healing of grief and bereavement is offered as follows. It is a fine example of ‘artful grief’.

Cat among the leaves

Emma was a participant in a workshop I conducted for counsellors and therapists on the theme of ‘Loss, Grief and Bereavement: An Arts-Based Exploration’. In the workshop Emma had engaged in a collage activity, which she later described as ‘meditative and therapeutic’ although she had struggled with the set task. I had invited participants to bring a copy of a photograph of a person or place that they associated with loss and grief and had spoken about the fragmentation inherent in bereavement experience. It was an attempt to symbolically explore what was lost or broken and to try to do some repairing and healing through cutting and pasting in a photomontage or collage activity.

I did not know that Emma’s mother had recently died and it was not until we corresponded after the workshop that I learned more about her experience of grief and the creative process she had engaged in. She had been very quiet and fully absorbed in her creative task on that day and had been reluctant to share thoughts with fellow participants after the art-making activity. I had been deeply moved by the image she had created of a small black cat nestling in among golden leaves that she had painstakingly cut out of some wrapping paper.

Emma’s description of the process of creating the collage conveys something of the mystery and beauty that often surprises people when they allow themselves to enter into the unknown or as Allen (2005: 2) puts it, the ‘place of all possibilities’. Emma’s grief about her mother’s death, her own vulnerability, her love of cats and their attachment to her all seemed to converge as she struggled to begin:
How could I even start to put something so big into such a small space? … Then I saw the fabric with the little black cat prints and something clicked in. It tugged at an edge of something I was feeling, though I didn’t try to make sense of it and the creative process had started. Anyway, when I saw the fabric with the little black cat I intuitively picked it up. Then I saw that golden leaf paper and I knew that the cat needed to be inside among them, it was a feeling. Cutting it all out until it fitted my felt sense of it all felt very meditative and therapeutic. Like something was settling into place. I think it was certainly a process that allowed me to symbolise my experience into something tangible. … the grief often feels bigger than me and it has a magical, transpersonal or spiritual element to it. I don’t have ideas to attach to it. I often feel deep sadness. But often I also find myself sitting with a sense of awe at the vastness and intricate nature of it all. I can’t control it … it’s scary and beautiful all at once. I breathe and be and try not to get too overwhelmed. Making it turned out to be a very honest moment for me.

Emma’s feeling about the spiritual element in her art making resonates with Farrelly-Hansen’s (2001) suggestion that art making is inherently spiritual, and spirituality is an important ingredient in therapy or in becoming whole. It is essentially a search for meaning, new answers and fresh perspectives. Allen (2005:2) believes that art making can be a ‘spiritual path’ and can lead us to ‘new places in ourselves, our work, our relationships and our communities’. Through art making Emma was able to develop new insights and a greater acceptance of the grief she was experiencing following her mother’s death. Her love for her cat was a source of sustenance because this was the cat that had ‘rescued her’ when she was at her most lost and vulnerable. For some reason Emma’s collage had moved me deeply and when we exchanged email messages about the process it was interesting to learn that far from being a small vulnerable figure her cat in among the leaves was in fact quite a powerful creature. It was an assumption or projection on my part and a reminder to keep one’s own feelings and thoughts. I began to wonder about strength and vulnerability and the connection between them. Social workers who enter into the places of pain when people are dying or grieving will need to embrace this kind of ambiguity.

Arts-based research

While the interrelationships between research, theory and practice in the field of social work are now well established, there was a time when social workers found it difficult to articulate the complex nature of their interventions with vulnerable populations. Ethical issues aside it was not always possible to capture the uniqueness and efficacy of the helping encounter. Arts-based practitioner-researchers face a similar dilemma in that they struggle to define what they do and what it means. As Hartley (2008: 51) explains, ‘There is about the creative process and the object that is created something of the wordless; no group of words can accurately describe what is seen or heard’.

Arts-based research practices offer qualitative researchers alternatives to traditional research methods (Leavy 2009). They draw on such things as literary writing, poetry, music, dance, visual art and collage, and these media may be used in all phases of the research endeavour, not just in its final representation. McNiff argues that art-making by the researcher should be included in an inquiry and that we need to be able to distinguish between artistic knowing and scientific understanding. He also believes that research methods and questions need to arise from the unique character of the art experience because ‘art is a way of knowing, problem solving, healing and transformation that we marginalize if we do not embrace it as a vehicle for research’ (McNiff 2013: xiii).
Collage, a word derived from the French, coller, meaning to stick, refers to a genre in which ‘found’ materials that are either natural or made up are cut up and pasted onto a flat surface. The use of collage as a form of visual inquiry is particularly appropriate in bereavement given the often shattering and fragmented nature of grief experience. Butler-Kisber describes three approaches for using collage. Collage can be used in a memoing/reflective process, to conceptualise or to elicit writing or discussion or perhaps all three. As she goes on to explain, ‘the researcher works in an intuitive and non linear way using disparate fragments and joining them in ways that can produce associations and connections that might otherwise remain unconscious’ (Butler-Kisber 2008: 270).

Collage can be used to both formulate and respond to a research question, for example by creating art cards or small-scale collages to express themes. In writing an autobiographical dissertation and narrative inquiry, one arts-based researcher made a collage before beginning a new section. Evaluation of arts-informed research using images as well as writing poses further challenges for the field including those related to copyright. It might be helpful for practitioners and researchers (Moon 2001b: 50) to keep an art journal to ‘capture images of daily life’ without analysing or judging them. The images can be about experiences, objects or emotions and Moon suggests working in the art journal for a short time each day.

**Conclusion**

As social workers in end-of-life care, we will be required to enter into the spiritual domain as we empathise, seek to understand and assist patients and their families at the most vulnerable of times. We will be called on to witness their suffering, confront our own mortality and ultimately, try to find meaning in these experiences. I believe that it is through remaining open and connected that the answers will come. I would like to urge readers to explore the potential of the expressive and creative arts to literally make sense of difficult experiences through the senses, through art making and soulful practices that nourish our own spirits as we try to nourish those of others.

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