

How People Who Are Dying or Mourning Engage with the Arts

TONY WALTER

Centre for Death and Society | University of Bath | UK*

ABSTRACT

Though death and loss are recognized as significant themes in fine and popular arts forms, we know virtually nothing about how people who themselves are dying or bereaved use the arts – unless they are practising artists or under therapeutic supervision. This article first reviews how established artists have used death/loss themes in their work, along with the work of arts practitioners in palliative and bereavement care and the role of the arts in death education. These literatures tend to privilege the production of artworks over their consumption, and reveal the absence of research into the arts practices of lay people who are dying or grieving. The article goes on to advocate ethnographic research into lay practices, using the author's own personal experiences and observations to indicate the kind of findings that ethnography may produce, in particular the likely importance – at the end as in the rest of life – of meaningful arts consumption. The article then suggests avenues for researching lay arts practices at the end of life, before concluding with some possible implications for professional care of dying and bereaved people.

* Department of Social and Policy Studies, Bath, BA2 7AY, UK

INTRODUCTION

How do those who are nearing the end of their lives or who are mourning the death of others use the arts? This is a topic about which we know surprisingly little, despite there being considerable literatures on the significance of death and loss in the fine, performing, and popular arts. In this article, I first briefly review the relevant literatures which focus on the published works of famous artists and on the therapeutic practices of arts practitioners. In this article, the term ‘arts practitioners’ or ‘arts professionals’ includes arts therapists, arts facilitators and practising artists working within health care. ‘Arts therapists’ includes all trained therapists who use any of the arts, including, for example, music therapists.¹ This review reveals that what is missing is an understanding of ‘lay’ arts practices around the end of life conducted by everyone else – namely those who are themselves dying or grieving, along with their friends and family – in their ‘everyday’ lives outside of formal medical and care situations.

The rest of the article begins to address this gap by examining these lay arts practices around the end of life. I reflect ethnographically on my own personal experiences and observations of how dying and bereaved people use the arts, which are primarily practices of consumption rather than production, from which I make some suggestions both for a research agenda and for end-of-life policy and practice.

This topic is important for two reasons. First, if – as I show shortly – death and loss are significant themes in all the arts, it is important to ask how people who are dying or bereaved use the arts. Second, though this article is primarily about ‘everyday life’ practices at the end of life rather than about end-of-life professional *care*, recognising lay arts practices could help professionals re-think the care they provide for people who are dying or grieving.

In this highly interdisciplinary field, it may be helpful first to situate myself. I am a sociologist who researches dying and bereavement, intensely personal experiences that are nevertheless shaped socially, culturally, economically and politically. I write not as an artist or art historian interrogating dying and loss, but as a death studies scholar interrogating lay arts practices. This work may be characterized as sociological research examining the arts in everyday life.

LITERATURE REVIEW

There are three main ways in which death and the arts are discussed in the research literature: i) death as a theme in art history and in contemporary arts practice, ii) the work of arts therapists and related professionals, and iii) a much smaller literature on the arts in death education. I briefly review each in turn.

¹ The relation between these groups is discussed by a number of authors, such as Bonde (2011) and Sonke (2011).

DEATH IN THE ARTS

We might expect the arts to be relevant to those nearing the end of their life or grieving the death of others because so much of the arts concerns dying, death and grief. Often, artists have drawn on their own personal experience of grief and/or awareness of mortality. This section will sketch the role of death in a range of arts-making first to demonstrate the resonance between death and the arts, and second to illustrate how one specific group of people – practising artists – have used the arts in relation to their own or others' mortality.²

In fiction, plots often rely on the deaths of characters (Garrett, 1984; Skelton, 2009), not least the Victorian consumptive heroine (Meyer, 2003), while other works play on the fear of death, as in Gothic and vampire novels (Twitchell, 1981). Jonathan Dollimore (2001) has shown the links between eros and thanatos in literature from Shakespeare to the present day. From at least as far back as Homer's Iliad and Odyssey, fiction has found loss to be one of the most compelling of human experiences (Archer, 1999). It has been argued that the death of his eleven year old son influenced Shakespeare's later plays (Smith, 2011), while today, phrases from Shakespeare infuse our language of grief, for example: "Give sorrow words. The grief that does not speak / Whispers the o'er-fraught heart, and bids it break" (Macbeth, Act IV Scene iii). Poetry has meditated on death and loss from antiquity (Vermeule, 1979) to the present day (Ramazani, 1994), while twentieth century war poetry has become a genre in itself (Lyon, 2005).

Turning to the visual arts, death is central to Christian painting with its many portrayals of the crucifixion, of the dead and risen Christ, and of heaven and hell (De Pascale, 2009; Hughes, 1968; Kristeva, 1989). Painters, not least Picasso, have portrayed bereavement (Sumner, 1995), death in war (Malvern, 2000; Stansky and Abrahams, 1994; Viney, 1991) and death in other political events (Fraser, 2003). General surveys of death in painting are provided by Gittings (2009) and Townsend (2009). From the ancient Greeks to Michelangelo to Käthe Kollwitz, sculptures – commissioned for private homes, public squares and cemeteries – have portrayed grief (Bertman, 1999; Oremland, 1980; Shapiro, 1991). Since the Renaissance, sculptures have been made both of and from the dead, for artistic, religious and medical education purposes (L. Burns, 2007; Hansen, 1996; Kemp and Wallace, 2000).

Movies contain similar themes to novels, though to some extent the medium requires that they be dealt with in different ways (Hagin, 2010). Though some photography specialises in the dying, dead or grieving body (Schels and Lakotta, 2004), generating in some instances considerable ethical debate, Barthes (1982) argues that photography, by its very nature, captures a moment in time and hence functions as a memento mori, reminding the viewer of change, loss and mortality.

Without death, a great slice of the Western musical repertoire would not exist (Kastenbaum, 2003; Minear, 1987), not least because grief, death and resurrection

² For more substantial overviews, see Archer (1999), Ariès (1985), Bronfen (1992); Gilbert (2006), and Llewellyn (1991).

are central to requiems (Cross, 1994; Robertson, 1967), while loss is at the heart of both spirituals and the blues (Oakley, 1976; Oliver, 1998). As both historians (Ariès, 1985) and psychiatrists (Parkes, 1972) have observed, grief is the inevitable consequence of love, and Romantic love is particularly liable to come to grief, a reality not lost on the composers of both opera (Hutcheon and Hutcheon, 2004) and pop music (Alteg, 1986; Clayson, 1997; DeSpelder and Strickland, 2005; Inglis, 2004). Eternal love in death is purer than any earthly love, as the operas *Tristan and Isolde* (Richard Wagner, 1857-9) and *La Bohème* (Giacomo Puccini, 1896) and the pop song *Leader of the Pack* (The Shangri-Las, 1964) make clear, though of course the precise cause of young death reflects historical times: consumption in the nineteenth century, versus hot rodding it down main street in the mid twentieth. Many composers, from Bach to Brahms to John Lennon to Dolly Parton to Eric Clapton, have written music arising out of their own personal loss and grief (Berger, 2006) and, in the case of Richard Strauss' *Four Last Songs* (1948), his own impending death.

Finally, in addition to these many art historical studies, there is a literature on how contemporary artists encounter their own mortality (Bell, 2006; Radley, 2009; Radley, 2007), some written by the artists themselves (Waller and Sibbett, 2005; Wilke, 1994). As with (auto)biographies of dying (Bingley, 2006), this literature concerns primarily premature death by cancer; it discusses how artists with cancer use the visual arts to make meaning and to galvanise social action, specifically how feminist artists create images to politicise breast cancer.

The scholarly literature is replete with studies of how practising, and especially famous, artists have confronted grief, their awareness and understanding of mortality, and even their own dying. Clearly the arts provide powerful vehicles – historically often as part of religious ritual – for addressing and expressing concerns about mortality, dying, grief and loss. One might even say that mortality and grief provide a motor for artistic practice; if so, we might hypothesise that this may be true in some ways for everyone, not only those who produce art. I will begin to explore what those ways may be in my later ethnographic section.

THE ARTS IN END OF LIFE CARE

There is a considerable literature by arts practitioners working with those approaching the end of their life and (to a lesser extent) those mourning someone else who has died. This literature primarily concerns practitioners' professional work, including numerous case studies of their clients and of the communities with which they work, but says little or nothing about everyday arts practices removed from professional facilitation. It is nevertheless worth presenting, a) because practitioners have clear – if far from uniform – views about the value of the arts for people at the end of life, and b) because it depicts how arts practitioners work with clients and communities at the end of life, which then may become part of lay experience. Concerning b), however, we must note that the literature typically portrays professional practice through the lens of professional ideology; very little ethnographic research has been conducted into how arts practitioners work with

people at the end of life, so there is little independent documentation or analysis of what they do; rare ethnographies include Francis (1992) and Hara (2011). This perhaps reflects the relative newness of arts therapies and arts facilitation in the context of end-of-life care. By contrast, older established professions such as nursing and medicine have been the subject of a considerable number of ethnographic research studies (for example, Hafferty, 1991; Norwood, 2009).

There is considerable variation between arts practitioners as to the scope and purpose of their work. The literature of art therapy (narrowly defined, *i.e.* not including music and other therapies) has a marked tendency to encourage clients to produce their own painting, sculpting, creative writing, etc. as a means of expressing fears and anxieties, not least around death and loss, which are difficult to put into everyday speech (Nichols and Lister, 1999; Pratt and Wood, 1998). As one authority on the contribution of art therapy to palliative medicine puts it:

The art therapist's task is to facilitate the patient's expressive capacities...The ultimate aim of art therapy is to enable the patient to change and develop on a personal level. Art therapy does not aim to distract or divert a person from their difficulties. (Wood, 2004, p. 1063)

There are two key elements in this process: *expressing* difficult emotions through *producing* an artwork of your own (rather than through consuming someone else's). Art therapy tends to distrust the soothing pleasure found in enjoying a fine painting or piece of music or favourite novel: these can be distractions and diversions from the work of therapy.

A number of schools of thought within music therapy, however, indicate more diverse practices (Aldridge, 2000, 1999; Berger, 2006; O'Callaghan, 2004). Music therapy can be not only active (*i.e.*, expressive) but also receptive; the relaxation and distraction from pain provided by listening to pleasurable music are validated as well as the hard work of personal transformation, and the value of commercially recorded music for reminiscence work is recognised (Dileo and Dneaster, 2005; Lee, 2001; Watson, *et al.*, 2009). A wide range of methods is employed from improvised music making as in Nordoff-Robbins therapy, where the aim is to create a sense of being accompanied or met by the therapist, to listening to recorded music as in GIM (Guided Imagery and Music) where "the client images to recorded sequences of classical music while interactively dialoguing with a guide" (Abrams and Kasayka, 2005, p. 160; Banks, 2011). The community music therapy movement promotes lay musical creativity and performance (Pavlicevic and Ansdell, 2004b).

In musical work with the dying, the music may be not only composed, but also played, by professionals. Music *thanatology*, for example, entails the playing of live, especially harp, music to a person in their final hours (Freeman, *et al.*, 2006; Shroeder-Sheker, 1994). A wide range of positive effects on patients has been documented by live musicians, ranging from physiological (reduced blood pressure, stabilised heart pattern) to psychological (reduction of anxiety and depression) to aesthetic and spiritual (laughter, joy, thankfulness to be alive) (Bolton, 2008, pp. 120-125).

More general writings on the creative arts and the healing arts at the end of life also demonstrate a variety of goals and methods. For example, while many artists and therapists use creative writing, Markell and Markell (2008) outline how children's fiction can be used to help bereaved children. A number of authorities, however, privilege the act of creation, displaying at best an ambivalence about consuming other people's artworks. Bolton (2008) for example announces that her book *Dying, Bereavement and the Healing Arts* is about "being involved in creating art, rather than observing it", and merely summarises in a page or so the positive benefits of enjoying other people's artworks though she sees value in clients not only writing poetry but also reading other people's (p. 18). Hartley and Payne's (2008) book *The Creative Arts in Palliative Care* gives no examples of patients benefiting from a picture painted by someone else, but the book does contain two examples of a patient being encouraged by an arts practitioner to hang his own painting on the wall at home – in one case replacing a painting hung by his parents thirty years ago (pp. 49, 147). In Rogers' (2007) book, *The Art of Grief*, every chapter focuses on clients creating their own art, except the chapter on music, where it is recognised that the starting point may be existing songs, with clients perhaps adding their own words. When the creative arts are employed within palliative care, for example in day-care, they often entail clients producing art and craft works (Hartley and Payne, 2008; Watts, 2009); likewise Doris Francis has written about older people's frequent re-engagement with the arts, for example by taking up painting or sculpture (Francis, 1992).

To conclude, the literature by and about arts practitioners working with people at the end of life indicates a wide range of benefits from creating, performing and consuming artworks, though a considerable proportion of the literature promotes the therapeutic benefits of creating your own art. Even when committed to ensuring that the patient's voice is heard (Waller and Sibbett, 2005), the literature is silent about how people near the end of life engage with the arts when not assisted by arts professionals. This omission is perhaps not surprising, but it is, as I argue later, problematic in that it overlooks the different ways in which lay arts practices at end of life may be facilitated by family, friends and a wide range of health and social care workers.

DEATH EDUCATION

Death education has been developed in several contexts, not least since the 1970s as an often popular elective in North American colleges and universities (DeSpelder and Strickland, 2005), and since the 1980s in medical and nursing training in Anglophone and north west European countries (Field, 1984, 1986) and less formally in primary and secondary education (Leaman, 1995). Using the arts in death education was pioneered by Sandra Bertman in American medical schools (Bertman, 1991; Pacholski, 1986a, 1986b). Bertman's pedagogy uses recorded music and reproductions of famous paintings, her assumption being that artworks of the highest standard have the power to invoke people's deepest fears and hopes. Death education with children may be different; the St Christopher's Hospice death education project with local primary schools, now being replicated in a number of

countries, engages both pupils and patients in arts creation and performance (Tsirir, *et al.*, 2011).

THE MISSING PIECE

What is missing from the valuable literatures summarised above is any discussion of how people, when not under the supervision of arts practitioners or educators, use painting, photography music, poetry and other arts as they come to the end of their life or mourn the loss of others. For example, though there is a small literature on the arts in bereavement *care* (Berger, 2006; Rogers, 2007), the now vast research literature on the experience of bereavement includes virtually nothing on the arts (Berger, 2006). One notable exception is cases where the bereaved person is a professional artist (*e.g.*, Gustav Mahler, Eric Clapton), in which case the researcher is more likely to be a music scholar than a bereavement researcher. More broadly, the overall bias of the literature on death and art is shown in a major four-volume compendium of death studies scholarship (Doka, 2007). The section 'Death in Music, Art and Literature' comprises eleven academic articles: four on death in formal art, three on death in popular culture (cinema, pop music, novels), two on the arts in palliative care, one on death education, and just one ethnography of lay practices – on music in a tribe in south India. This last is the only non-western piece among the eleven, which therefore include no discussion of lay practices in the modern West.

This lack of research into lay arts practices around the end of life is perhaps comparable to how, until some decades ago, medicine developed without reference to lay health practices, a situation which sociological research has now significantly altered (Blaxter, 2010). Lay musical mourning practices *have* been researched, however, in traditional societies. Ethnomusicology has been quite active in this field (Gammon, 1988; Mills, 2012; Wolf, 2001), and Eastern European laments have been extensively studied (Alexiou, 1974; Danforth, 1982; Holst-Warhaft, 1992, 2008; Kligman, 1988). Rare examples of academic studies of lay musical mourning practices in modern industrial societies include sociologist Grace Davie's (1993) study of the evolution of *You'll Never Walk Alone* as a song of mourning on Merseyside, and Philip Tagg's (1993) comparison of Ghanaian and Swedish funeral music.

In western modernity, arguably since the eighteenth century, the arts have been removed from the lay worlds of merry making, rituals and festivals, and become elitist; for most people today, arts involvement mainly entails reading, looking at and listening to the novels, plays, paintings, sculpture, films and music of an artistic elite (Gaztambide-Fernández, 2008). While some contemporary arts therapists challenge the artist/non-artist distinction (Ruud, 2004), this distinction still structures how many artists identify themselves, *i.e.*, as an artist (Bain, 2005), and how many people engage with the arts.

TOWARD AN ETHNOGRAPHY

In this section, I begin to make some sketches of what lay arts practices in the context of mortality might look like. The sketches are based in part on published information, in part on ad hoc ethnography. Though ethnographic research into the work of arts practitioners would also be valuable, this article concerns what people do when *not under* professional arts supervision or facilitation. In the absence of existing ethnographies, I provide preliminary evidence for the meaningfulness of arts consumption around death through reflecting on my own experience in grief and some experiences of friends nearing the end of life.³ These friends and I are white, British, middle class and aged between sixty and ninety – the age range in which dying and grieving are concentrated in affluent societies. What follows comprises not a systematic or planned ethnography but an indication of the kind of material an ethnography could uncover.

Grazian (2004) surveys ethnographic research since the 1920s in one of the arts, namely music, though none of the studies he discusses concern music at the end of life. DeNora's (2000) ethnography of music in everyday life contains, in passing, a few vignettes on mourning and none on dying. Cognate examples of what I am proposing are ethnographies of how people who are mourning or nearing the end of life use material objects and material culture (Gibson, 2008; Kellehear, *et al.*, 2009); what we have hitherto lacked are comparable ethnographies of how they engage in the aesthetic dimension and how they consume, produce or perform artworks. A fine first attempt at this has, however, just been published by DeNora (2012), where she records three musical moments experienced by herself, her dying mother and her subsequently grieving and dying father. She argues for *auto*-ethnography (Stanley, 1993); indeed, within the privacy of a household, it is hard to see how an ethnographer who is not herself part of the household can be present to record let alone interpret such moments. DeNora's auto-ethnography is a by-product of, and certainly not the reason for, her presence in the household. Some of my own observations recorded in the next section are similarly auto-ethnographic.

IDENTITY, MEMORY, COMMUNICATION

I spent many days with Bill while he was dying of cancer at home. One day while he was sitting up in bed, propped up by the pillows as he often was to face straight ahead, he asked me to shift a framed reproduction of a painting for him. "Do you see that picture to my right?" he said, "It was a wedding present 25 years ago, but I can't see it there. Can you hang it on the wall in front of me, so I can see it?" A few minute's work and it was done. Bill's pleasure in the painting was partly aesthetic, partly biographical, and both were to him important. As in the rest of his life, he showed no interest in himself drawing or painting. For him consumption, not production, was what mattered.

This was also the case with Bill's appreciation of music. One reason Bill wished to die at home was so that he could be surrounded by music emanating from his treasured

³ They or their next of kin have given permission for information to be included in this article; pseudonyms have been used.

hi-fi system; normally more a fan of Bob Dylan than of classical music, it was CDs of Mozart, Bach and Tallis that he listened to in his final weeks. Whether with painting or with music, what gave him pleasure, peace and positive memories was his consumption of these commodified mass reproduced art works.

Colin, in his late eighties, could no longer look after his wife as her Alzheimer's disease developed. He visited her regularly in the nursing home and experimented with various ways to regain communication. Eventually he discovered that, though they had never before read poetry together, no sooner had he begun to read a poem with which she was familiar than she would join in and recite it with him. Playing her favourite music on a CD player also brought her 'back to life'. On being told this by their father, the grown-up children too began to use poetry and music to re-establish contact with their mother. This potential of music and rhythm to bring family members back together, recreating for a while their old connection, has been recognised in a number of programmes, including the Alzheimer's Society's *Singing for the Brain* programme, in which sufferers and family members sing and dance together in a group session led by a trained singing leader (Hara, 2011). What is not known is how many families, like Colin's, have discovered this for themselves or have been encouraged by care workers to engage in such activity outside of formally facilitated sessions.

I will now discuss funeral music in some detail because it was the one occasion on which mourners in Britain used to be actively involved in musical performance, but – at least among the majority white population – this is now being rapidly replaced by music consumption. Funerals in many Western countries have recently become more personal (Garces-Foley and Holcomb, 2005) and/or secular (Walter, 1997), and in the UK one major way this is achieved is by listening to two or three of the deceased's favourite CD tracks or to a piece of music that in some way captures the deceased's personality. This is replacing communal hymn singing. Singing hymns was once the norm, but recent surveys in the city of Hull (Adamson and Holloway, 2012) and at one London crematorium (Parsons, 2012) indicate hymns now being sung at only a quarter of funerals.

In the vast majority of instances, the congregation do not sing but listen to the non-hymn music – whether it be a recording of Elton John or the Orchestra of the Age of Enlightenment.⁴ Over the years, I have attended as a mourner about forty funerals in the UK, and though some have included listening to recorded music (and some memorial services have included a live solo or duet), none included congregational singing of a secular song. Of 46 funerals researched in the city of Hull in 2009 (Adamson and Holloway, 2012), though three included a mourner playing a musical instrument, none included secular congregational singing.⁵ An experienced humanist celebrant, who has conducted over a thousand funerals in South London involving all social classes, can recall only two secular songs congregationally sung. Religious singing together is being steadily replaced by listening to secular (and occasionally

⁴ See for example: <http://www.mylastsong.com>, which provides advice for families wishing to select personalised funeral music.

⁵ Sue Adamson, personal communication, 6 Sept 2010.

religious) CDs, driven by personalisation and secularisation, but also reflecting the general decline of communal singing in England.

Abandoning communal musical performance is thus a *consequence* of the choice to include personally meaningful music in the funeral, not its motive. As I discuss in a later section, it is a probably unintended and possibly unnecessary consequence; but it is a consequence nonetheless. And it is remarkable. Singing together was once the main way in which the whole body of mourners participated in the funeral, engaging together in one of the performing arts to perform words of sorrow and hope. According to Davies (but he may possibly here be influenced by being Welsh), “Singing is, fundamentally, a community activity which sets group hopes and power over those of the individual” (Davies, 1997, p. 58) But with the decline in church attendance and the familiarity with hymns that goes with it, and with the small numbers at many elderly people’s funerals in Britain, many people report finding singing hymns at a funeral to be excruciating, embarrassing and/or tedious (Caswell, 2012). So, British funeral-goers are turning their backs on this communal ‘performance of hope’, in favour of listening to a commercially produced CD. Moreover, they often report that this is the most meaningful part of the entire rite (Adamson and Holloway, 2012). Far from passive, their listening can be deeply meaningful.

Precisely how this ritual playing of the deceased’s favourite CD produces meaning needs researching, but a working hypothesis might be that contemporary funerals worship at the altar of individual personality, finding meaning and thus hope in the individual identity of even the most mundane of lives (Garces-Foley and Holcomb, 2005), so the CD capturing the essence of the deceased individual becomes the funeral’s emotional powerhouse. In other words, instead of Davies’s communal singing that “sets group hopes and power over those of the individual”, cited above, listening to the commercially produced, biographically meaningful CD subjects the mourning group to the power of the deceased’s individual identity and thereby, perhaps, sustains the mourners.

In the months and years after the funeral, recorded music can continue to retain powerful associations with the deceased. I am doubtless not alone in going happily about my business when a track comes on the radio that reduces me to tears, reminding me of someone I care for who has died, years or even decades ago. DeNora provides of examples of particular pieces of music that, for the listener, are associated with a person they love who is either absent or dead (DeNora, 2000 pp. 58, 63, 65; DeNora, 2012). Sometimes the association may be so painful that the piece is avoided, as with the mother whose daughter died of an overdose and who could no longer bear to hear the song *Sweet Caroline* (Gibson, 2008, p. 5). Music, along with photography, is the art form that for many is most associated with memory and biography (Keightley and Pickering, 2006). Toward the end of life, particular pieces of recorded music can be intensely pleasurable, recalling memories and confirming identities, and are used for this purpose by some music therapists (O’Callaghan, 2004). Though in some instances individuals may themselves sing or play the piece they treasure, in far more cases is a recording heard. Further, a

recording – especially of non-classical music – has the potential to be *exactly* as heard decades before, and therefore to hold a veracity of memory for the individual, an emotional connection that only photographs can match. Music and photographs thus provide powerful mediums through which the living may encounter the dead, and through which continuing bonds with the dead may be accomplished.

From these anecdotal observations, we may conclude two things. First, as one would expect, it is not hard to find examples of people in grief or toward the end of their life consuming commercially reproduced artworks. Second, their consumption of paintings, poetry and recorded music prompt and confirm memory and identity, connecting consumers to significant others from their past (and on either side of the grave). Arts consumption (or perhaps I should say arts appropriation) in death, as in life, is a part of how people create identities, and this identity construction is social as much as private (Arnould and Thompson, 2005; DeNora, 2000, 2012; Storey, 1999).

BEAUTY AND LIBERATION

Another possible meaning of arts appreciation is based more on philosophical speculation than on my own observations. Havi Carel, a philosophy lecturer who has a disabling and life threatening lung disease, writes in her philosophical monograph *Illness: the cry of the flesh*:

Even in cases of extreme disability there is always a freedom of thought, imagination, emotion and intellect. Freedom and imagination can enable even those who are unable to be in one way to be in a new way....The worlds of literature, film and art may not be real, physical, corporeal, but within them the imagination can roam free and liberate the unable body, albeit temporarily, from its inability to be. (Carel, 2008, p. 70)

Carel is suggesting that arts consumption (reading novels, watching movies, etc.) can profoundly transcend the limitations of the body, and make life worth living. This is much more than the ‘distraction’ or ‘occupational therapy’ to which arts consumption is sometimes reduced in the palliative care literature. The finer the work of art, the more its potential to liberate the imagination, to transport us to a higher world.

This hints at a somewhat old fashioned view of aesthetics (Gaztambide-Fernández, 2008). Conservative philosopher Roger Scruton argues that:

We all know what it is like in the everyday world to be transported by the things we see – a flash of sunlight, a remembered melody, the face of someone we love – these dawn on us in the most distracted moments and suddenly life is worthwhile. These are timeless moments in which we feel the presence of another, a higher, world. From the beginning of western civilisation, poets and philosophers have seen the experience of beauty as calling us to the divine...Through beauty we come to understand ourselves as spiritual beings. (Scruton, BBC2TV)

Scruton goes on to denounce modern art (and architecture) for abandoning this spiritual calling:

But our world has turned its back on beauty...The beautiful work of art brings consolation in sorrow and affirmation in joy. It shows human life to be worthwhile. Many modern artists have become weary of this sacred task; the randomness of life cannot be redeemed by art... Since the world is disturbing, art must be disturbing too. (Scruton, BBC2TV; see also Scruton, 2009a)

Thus Scruton is against conceptual art, which uses art to explore ideas rather than to create beauty. Significantly, this is precisely also what much art therapy is about: exploring difficult feelings and difficult ideas (such as, 'I am going to die') (Wood, 2004). This synergy is not coincidental; it is taught. The concept of art as exploring ideas and feelings rather than creating beauty is taught in art colleges in the UK, and a first degree in art is a normal pre-requisite in the UK for postgraduate training in art therapy.⁶ Add a dose of Freud, and you get a self-referencing ideology: art, whether created by artists or by the clients of therapy, is about expressing the difficult, the inexpressible; it is not about creating or appreciating beauty.⁷

This synergy between art therapy and the art school idea of art is shown in phototherapist Rosy Martin's account of the death of her father, which she photographed. For her, both the practice of photography and the practice of therapy entail "challenging taboos, representing the un-representable", both offer "a means of thinking through feelings, feeling through thoughts" (Martin, 1995, p. 74).

Drawing on Carel and Scruton, however, we could hypothesise that, notwithstanding the merits of conceptual art and of art therapy, many people find in the arts not challenging thinking but transportation through beauty (among other things). It is too late to ask him, but I suspect that is why my friend Bill wanted Mozart and Haydn as he lay dying. Outside of certain art therapy practices,⁸ it seems likely that the arts are used in death, as in life, rarely to gain psychological insight or to face mortality, but more usually to enjoy the aesthetic dimension and, as one gets older, to enjoy the biographical connections evoked and to share memories (DeNora, 2012). In this view, there is no reason to suppose people change just because they are dying.

An alternative hypothesis, drawing on symbolic interactionism, notes that terminal illness or bereavement disrupt self-identity (Bury, 1982). This could lead some people to use the arts in a conceptual way to explore the new, disrupted, self; some people in this situation may well value arts therapies that allow them to explore difficult thoughts and painful feelings. Alternatively, other people may retain habitual practices of arts consumption in order to strengthen and comfort their threatened self. Or biographical disruption could lead to a mixture of these two strategies, as perhaps with Bill who continued his familiar practice of listening to music on his hi-fi but who found comfort in a new situation by modifying the repertoire.

⁶ For information on UK art therapy training programmes, see: <http://www.baat.org/training.html>.

⁷ Verney and Ansdell (2010) do discuss beauty in relation to their Nordoff-Robbins music therapy work, but acknowledge they are unusual in so doing.

⁸ It is vulnerable groups such as children, psychiatric patients and the dying who are usually expected/allowed to express difficult feelings through picking up a paint brush or banging a drum. More powerful people are left alone to attend operas and pop concerts, to visit art galleries, to buy novels and download music off the internet, *i.e.*, to be arts consumers. Which is better could be a matter for debate.

SOME CAVEATS

The tentative conclusion I draw from my observations, from trends in funeral practice, and from Carel and Scruton above, is that in everyday settings when people are dying or mourning in contemporary societies they typically engage with the arts as they do in the rest of their lives, by *consuming*. Moreover, what they mainly consume are the mass produced and mass distributed capitalist art products that saturate everyday life (Benjamin, 1973/1936). That is to say, they listen to digitally recorded music more often than they perform music themselves, still less compose music; they watch movies far more often than make them (even in the YouTube era); they read fiction more often than write it; and they have reproductions on the wall at home more often than they visit an art gallery or themselves paint.

I do not want to overstate this argument. In terms of surface area, the world's largest piece of community folk art is probably America's AIDS Memorial Quilt, comprising thousands of panels quilted by friends and family mourning someone who has died of AIDS. These many thousands of mourners, drawing both on the long-standing American tradition of quilt making and the creativity of the late twentieth century San Francisco gay community, have been highly creative in constructing the panels.

Nor is all the art consumed or commissioned by mourners mass produced; some is individually commissioned from craftsmen. Though most gravestones are now mass produced, with inscriptions requiring little skill other than manipulation of a computer keyboard, there is nevertheless a minority market for individual commissions of hand carving (Frazer and Oestreicher, 1998; Robinson, 1995), if on a more modest scale than in the eighteenth and nineteenth centuries (Robinson, 1995). Memorial tattoos are increasingly popular, by definition an individually commissioned craft production (Langellier, 2001).

Though gravestones are purchased from a commercial provider, in grave maintenance mourners can show considerable creativity, just as they do in decorating both spontaneous shrines and formal memorials. Occasionally, as with the Vietnam Veterans Memorial in Washington, D.C., the authorities collect and archive tributes left at the memorial. More often, authorities charged with the management of graveyards and memorials are frustrated when the creativity of individual mourners conflicts with official regulations (Doss, 2010; Francis, *et al.*, 2005; Santino, 2006).

As noted earlier, driven by the twin forces of individualisation and secularisation, mourners at British funerals are fast moving away from singing together. It need not necessarily be, however, that they do not *want* to sing together; it may be that most clergy and secular celebrants never offer the option of secular congregational singing. Simon Smith is a funeral celebrant who thinks differently; he e-mailed me with a list of 22 secular songs he has led at recent funerals, including *Pack Up Your Troubles*, *You'll Never Walk Alone*, *What A Wonderful World*, *Blowin' In The Wind*, *Where Have All The Flowers Gone*, *Swing Low Sweet Chariot*, *Let It Be*, and *Fire And Rain*. He told me, "I usually say 'Let's raise the roof for X' - and they do." His company Green Fuse runs training courses for funeral celebrants, in which they are taught to

lead congregational singing; however, Smith does not know how many celebrants actually encourage this once so qualified, and we should note that Green Fuse funerals are markedly more participatory than most in a number of ways (Morrell and Smith, 2007; Smith, 2009). Other celebrant training courses with which I am familiar offer no training in how to lead congregational singing.

One other minority experience of arts participation at a funeral concerns dancing. At only one funeral have I ever danced; actually it was not at the funeral itself, but at the post-funeral refreshments, and it was for Mary, an elderly Scots woman who had been living in England. If one function of the post-funeral gathering is to re-energise the mourners through eating, drinking and talking together (Bloch and Parry, 1982), for me this was remarkably amplified through having to galvanise my mourning body into motion as the band struck up and the caller invited us to the first reel. This experience hints at national variations, even within the British Isles: England has no popular equivalent of Scottish country dancing, or of Irish communal singing within the family, or of Welsh community singing. Arguably, these non-English practices are ways of affirming Scottish, Welsh or Irish identity in the face of the British Isles' dominant English culture; this was certainly the case with Mary's wake. Various sub-groups within the UK may well dance and sing at funerals, but it is not common among the white English.

As far as close family are concerned, the contemporary white British funeral is increasingly a co-production between family and clergyman or celebrant (Holloway, *et al.*, 2010; Morrell and Smith, 2007). Family members or close friends may read a poem, play an instrument, use Adobe PhotoShop to insert a picture of the deceased onto the front cover of the service sheet, or set up a PowerPoint loop of photographs of the deceased that can run during the funeral service or during the subsequent refreshments. The main body of mourners, however, remain an audience, consuming the family's co-production.

In the 19th century, post-mortem photography was a craft production, with the commercial photographer commissioned by the family to photograph the deceased (S. B. Burns, 1990; Ruby, 1995). This practice was superseded in the twentieth century largely because mourners already had photographs, taken by family members of the deceased while alive (Beloff, 2007; Edwards, 1999; Riches and Dawson, 1998). Digital photography greatly expands the possibilities of lay creativity in modifying images after they have been taken (Lee, 2010) and re-purposing them years later (Banks, 2011), not least at the funeral. Photography is – increasingly – the one art form which millions create as well as consume.

So, it is too neat a distinction to say that at the end of their life or in grief people are not producers but only consumers of the arts. The two can be intertwined. Consider this:

Hours before her mum Debbie died of cervical cancer, sixteen year old Sarah Phillips recorded a version of *Autumn Leaves*, one of her favourite songs, for her on her mobile phone...Family friend, Charlie Mole, subsequently added the musical

accompaniment. This was played as a tribute at her funeral... The recording was later shared with friends via YouTube. What Sarah and her dad didn't realise was that allowing the world access would turn this home-recording into an instant internet hit and attract a torrent of messages of shared grief. (BBC, 2010; Phillips, 2010)

Sarah took a commercially recorded pop song her mother had liked, performed it herself, and then released it on YouTube. Was she consuming, performing, or creating?

Many caveats need to be made in drawing the conclusions and asking the questions above, not least that some individuals are simply more artistically creative than others. Regardless, I suggest that the dominant pattern remains: toward the end of life and in mourning most people engage with the arts as consumers more than as creators. This is a different emphasis than that reviewed earlier in the professional literature on the arts in end of life *care*, and may be hard for some of those professionally involved in the creative arts to hear. After two conference presentations of early versions of this paper, I was struck that several comments from the audience did not address what I had been talking about – everyday arts consumption practices at the end of life. Instead, the comments concerned artists who were dying, or projects initiated by artists; how lay people use or consume mass-reproduced art products seemed to be of little interest.

IMPLICATIONS

So far, I have reviewed various literatures on death and the arts, and noted that there is virtually no research into the lay arts practices of people facing their own death or mourning that of others. I have drawn on my own experiences and those of friends to suggest the potential of ethnographic work to fill this gap in the literature. I have hypothesised from this that lay arts practices are likely to be mainly of arts consumption rather than production, at the end as in the rest of life. There are alternative hypotheses, however, as to whether arts practices may change as an individual's sense of self is disrupted. In this section, I suggest some ways in which such hypotheses might be explored more systematically.

RESEARCH

There is an elitist tendency amongst intellectuals to sneer at consumers and consumption, as if consumption is mindless, and consumers are dupes (Miller, 1995; Storey, 1999). This was reflected in the Frankfurt school's critique of mass culture, not least the commodification of popular music (Grazian, 2004). Since the 1970s, however, cultural studies research into consumption has consistently shown that consumers are not dupes but active co-creators of meaning; that they consume within specific contexts; and that careful ethnography can reveal the meanings they give to commodities (Storey, 1999), including popular music (Grazian, 2004). Ethnographic studies of high art, in contrast, have tended to research how artworks are created or performed, whether by general populations (Finnegan, 1989) or by sub-populations such as the elderly (Francis, 1992) or the sick (Radley, 2007, 2009). Researchers need to follow DeNora's lead and explore how people, not least in the context of

mortality, engage with the arts (DeNora, 2000, 2012). Small's (1998) concept of music(k)ing, referring to all kinds of musical practices (including listening to recorded music), has helped bring consumption onto the agenda of those researching music; an equivalent concept is needed for the other arts.

I have already mentioned differing theoretical understandings of how the arts are used when life is dramatically disrupted, for example using the arts conceptually to explore the new self or using the arts biographically to maintain continuity with the old self; the concept of biographical disruption could illuminate research into lay arts practices at the end of life. More specific questions abound. First, many anthologies of mourning poetry have been published in the UK in recent decades (Atwell, 2005; Benson and Falk, 1996; Whitaker, 1984). Do grieving people read them? In what circumstances? How do they feel when they read them? How, if at all, do they appropriate published poetry into their own grieving? Second, people's consumption of the arts changes over the lifespan. In what ways do grief and the impending end of life provide catalysts for changing tastes and behaviours? When a frail person no longer has the strength to hold a book, do family members sit and read to them? How does being read to by a loved one change the listener's experience? Third, an observational study of bedside objects in a hospice revealed about half the patients had CD players, DVDs and other sound equipment (Kellehear, *et al.*, 2009). How do the patients use such bedside equipment? What meanings does music have for them? How many play music in their heads without the need for mechanical or electronic equipment? Fourth, have bereaved African-Americans, whose musical heritage includes spirituals and the blues that express loss, sorrow and hope, found themselves more likely than Anglo-Americans to sing as well as to listen? Or is music now so globalised that the musical heritage of every social group is not only available to all but also embraced by all? Fifth, how do those who *do* create or perform art manage when failing health means they can no longer sing or blow the notes or hold a paintbrush? Sixth, the one occasion on which British people are routinely expected to make artistic decisions in relation to end of life care is the expectation that the family choose the music for the funeral; this is almost always facilitated not by a musician or other arts professional but by a clergyman or celebrant who has received little or no musical training. One ethnographic study has observed this process (Adamson and Holloway, 2012; Holloway, *et al.*, 2010); but more study of this important decision-making process would be useful. Seventh, it is possible that practices vary in countries other than Britain, for example Ireland, where singing together within the family is not unusual, in bereavement as in the rest of life. In the Netherlands, different relationships pertain between artists and the public and the visual arts are integrated into both everyday and ritual life very differently than in Britain, leading to some innovative arts-based rituals for mourners.⁹ Researching such cross-national variations could be instructive (Walter, 2012).

These suggestions are merely indicative and far from exhaust the possibilities for a research agenda that takes seriously the aesthetic dimension at the end of life, in the way that research is now taking material culture at the end of life seriously. Such an

⁹ See for example the artistic reinvention since 2005 of All Souls Day: <http://allerzielenalom.nl>.

agenda needs to examine what arts professionals and other professionals do in relation to the arts at the end of life. But at present, the main need is for a significant rebalancing of research effort in order to generate knowledge about the *everyday* aesthetic practices of people as they live in the face of their own or a significant other's mortality; at present, this is an entirely new area for research.

POLICY AND PRACTICE: END OF LIFE CARE

This article has been primarily concerned with people's experiences as they face either their own or a significant other's death, and the need to research this topic from a variety of angles. If my tentative finding is correct that at the end of life artistic engagement happens mainly through consumption and that this is or can be meaningful in a number of ways, then there are several implications for those who deliver professional care. Specifically, palliative and elder care workers might be advised to see the arts not only as a part of formal end-of-life professional *care* but also as a part of everyday life. As well as referring service users to arts practitioners, care workers can also validate and support everyday practices. For example, an occupational therapist assessing a dwelling to enable a patient's return home to die may suggest that given his love of music, the hi-fi system needs moving to his bedroom, and invite the family to identify someone with sufficient technical expertise and physical strength to move it. Whether the client is living at home, in a residential care setting or in a hospital or hospice, 'the arts' are not solely the territory of arts professionals. The arts are engaged with every time a patient listens to music on her headphones, every time a mourner turns to one of the many published collections of bereavement poetry, every time she re-runs his favourite movie, etc.

Health care, and particularly palliative care, is in danger of professionalising the arts. Most publications on the arts in health are written by arts practitioners. They describe special projects, day care craft sessions, memory work in residential care and music therapy, but hardly any describe how their clients use the arts outside of such sessions, *i.e.*, when they are not clients. The First National Symposium for the Arts in End of Life Care, held at St Christopher's Hospice, London, in November 2010, comprised many presentations by art and music therapists, none of which described arts activities outside of professional facilitation or described lay practices of arts consumption; rather, practitioners' presentations described cases or projects in which practitioners facilitated creative arts productions or performances by dying clients or death education sessions with school pupils. Such presentations and publications, and they are increasing in number, may succeed in promoting the services provided by artists and therapists in palliative care, thus balancing the medicalisation of palliative care and moving it in a more holistic direction. But in the process, such writings also serve to professionalise the arts: raising the status of arts practitioners within palliative care may paradoxically also eclipse all sight of how patients themselves use the arts when not being facilitated by an arts professional.

This reflects processes of professionalisation within palliative care happening on a much broader level. Palliative care's key concept of caring for the whole person and not just a patient's medical needs invites an ever-increasing diversity of professionals

into a ‘multi-disciplinary team’. Each new profession needs to prove its worth by demonstrating the value of its work with patients and communities, and to build occupational capacity. Allan Kellehear (1999, 2005) has argued that building occupational capacity is an inevitable consequence of holistic care, and can be at the expense of building community capacity (the capacity of households, neighbourhoods and communities to care for those who are dying). In his view, there needs to be a refocusing of resources toward building up families and communities. This ‘health promoting’ approach is a response not so much to current financial pressures as a response to what dying *is*, namely a social, community and family event (in which of course professional expertise has its place). This is not to romanticise communities, many of which are fragmented – leaving many elderly people isolated toward the end of life. There is some evidence that a health promotion approach to end of life care can actually help build communities (Johansson, *et al.*, 2012), and that it can facilitate everyday arts practices (Batt-Rawden, 2007).

As an example of what I am advocating, one may ask why my friend Colin had to discover by trial and error that his wife, suffering from Alzheimer’s disease, responded so positively to poetry and music? Did the (in general, rather good) residential home where she lived not routinely inform relatives of this possibility? If not, had the home not received any training in such matters from arts practitioners employed locally in palliative care? Might this be a better use of practitioners’ time, or at least some of their time, than one-to-one or even group sessions with clients?

Or to give a related example: Lee’s (1996) well-regarded book on music therapy records the author-therapist’s 33 sessions with a terminally ill client who was a musician; by contrast, one *Singing for the Brain* leader can facilitate scores of families a week. Lee uses a professional model of therapy, while *Singing for the Brain* uses a community model of public health. Similarly, community music therapy aims to empower people to use music to promote healthy communities, though its emphasis on performance marginalises most people’s everyday practices of music consumption (Pavlicevic and Ansdell, 2004a).

If dying and mourning are to be normalised and re-centred in the community (Kellehear, 2007), everyday arts practices during these life stages must be brought into clearer focus. The Befriending Network, which provides volunteer ‘befrienders’ to people who would otherwise be isolated through ill health, disability or social disadvantage, provides an example of community normalisation of dying. Given that the dying person not the befriender sets the agenda, one possible role of a befriender is to enable or share in the service user’s arts practices. Susan had advanced motor-neurone disease and listened to recorded music together with her befriender, both her own favourite music and new music introduced to her by the befriender. Another befriender in the same local network is a practising musician.

It is increasingly recognised, at least as an aspiration, that beauty is important in the architecture and design of hospitals and hospices (Worpole, 2009). Here is a recognition that patients and families benefit from beautiful surroundings, created by professional architects and artists. In other words, patients’ and families’ appreciation

of artworks produced by others has value. Yet, there seems to be something of a failure to recognise the many ways in which people dying and mourning consume the arts in more everyday settings, not least their own homes. This gets eclipsed – in the literature at least – by the emphasis on more participatory, creative and therapeutic engagements with the arts, typically in institutional settings such as hospice day-care. The problem is not what gets written and spoken about, but what is not written or spoken about – a sin not of commission but of omission – even though what is omitted may have the potential to empower more people at less cost.

My argument has been based on direct though unsystematic observation in Britain of lay arts practices around the end of life, and on published literature. I have not observed the work of arts practitioners working in end-of-life care, and it is entirely possible that their work is not accurately reflected in the literature; as noted, there is as yet virtually no ethnographic research into arts professionals' practices in end-of-life care. It has been suggested that some practitioners who use pre-existing art and music with patients have kept quiet about their practice because it deviated from the professional ideology of arts therapy at a time when a united front was needed for the profession to establish itself (Pavlicevic and Ansdell, 2004a). That such practices are now more widely written about may reflect an increased degree of professional confidence. How end-of-life care workers who are not arts specialists facilitate the arts is very rarely discussed in the literature, so it is also possible that some of the facilitative practices I advocate are already taking place but are not perceived as valuable enough to publicise. An audit would illuminate how, if at all, health and social care workers facilitate their patients' everyday arts practices.

CONCLUSION

This article has identified a new area of research, namely the everyday arts consumption practices of lay people as they approach the end of their life and as they mourn the deaths of significant others. This is important as both death and the arts are part of being human; research into this interface should not be limited to researching works by established artists and the activities of arts practitioners and educators. I have provided some hints as to what an ethnographic approach to researching this new field might look like, and sketched some research questions. Finally, I have suggested that professional end-of-life care needs to take lay arts practices more seriously than the literature indicates it has so far done, and spelt out some possible implications of this new emphasis for policy and practice.

REFERENCES

- Abrams, B., and Kasayka, R. (2005) Music imaging for persons at the end of life. In C. Dileo and J. V. Loewy (eds.), *Music Therapy at the End of Life*. Cherry Hill, NJ: Jeffrey Books, 159-170.
- Adamson, S., and Holloway, M. (2012) A sound track of your life: Music in contemporary UK funerals. *Omega: Journal of Death and Dying*, 65(1): 33-54.
- Aldridge, D. (2000) *Music Therapy in Dementia Care*. London: Jessica Kingsley.
- Aldridge, D. (ed.) (1999) *Music Therapy in Palliative Care*. London: Jessica Kingsley.
- Alexiou, M. (1974) *The Ritual Lament in Greek Tradition*. Cambridge: Cambridge University Press.

- Alteg, T. (1986) Death themes in adolescent music. In C. Corr and M. McNeil (eds.), *Adolescence and Death*. New York: Springer.
- Ansdell, G., and Verney, R. (2010) *Conversations on Nordoff-Robbins Music Therapy*. Gilsum, NH: Barcelona Publishing.
- Archer, J. (1999) *The Nature of Grief: The Evolution and Psychology of Reactions to Loss*. London: Routledge.
- Ariès, P. (1985) *Images of Man and Death*. Cambridge, MA: Harvard University Press.
- Arnould, E., and Thompson, C. (2005) Consumer culture theory: Twenty years of research. *Journal of Consumer Research*, 31(4): 868-882.
- Atwell, R. (2005) *Remember: 100 Readings for Those in Grief and Bereavement*. London: Canterbury Press.
- Bain, A. (2005) Constructing an artistic identity. *Work, Employment and Society*, 19(1): 25-46.
- Banks, R. (2011) *The Future of Looking Back*. Cambridge: Microsoft Press.
- Barthes, R. (1982) *Camera Lucida: Reflections on Photography*. London: Cape.
- Batt-Rawden, K. B. (2007) *Music and Health Promotion*. Unpublished PhD thesis, University of Exeter.
- BBC. (2010) *i-shrine*: Radio 4, May 21.
- Bell, S. E. (2006) Living with breast cancer in text and image: Making art to make sense. *Qualitative Research in Psychology*, 3(1): 31-44.
- Beloff, H. (2007) Immortality work: Photographs as memento mori. In M. Mitchell (ed.), *Remember Me: Constructing Immortality*. London: Routledge, 179-192.
- Benjamin, W. (1973/1936) The work of art in the age of mechanical reproduction. In W. Benjamin (ed.), *Illuminations*. London: Fontana, 211-244.
- Benson, J., and Falk, A. (1996) *The Long Pale Corridor: Contemporary Poems of Bereavement*. Newcastle-upon-Tyne: Bloodaxe Books.
- Berger, J. S. (2006) *Music of the Soul: Composing Life Out of Loss*. New York: Routledge.
- Bertman, S. (1991) *Facing Death: Images, Insights, and Interventions: A Handbook for Educators, Healthcare Professionals, and Counsellors*. New York: Hemisphere.
- Bertman, S. (ed.) (1999) *Grief and the Healing Arts: Creativity as Therapy*. New York: Baywood.
- Bingley, A., McDermott, E., Thomas, C., Payne, S., Seymour, J., Clark, D. (2006) Making sense of dying: A review of narratives written since 1950 by people facing death from cancer and other disease. *Palliative Medicine*, 20(3): 183-195.
- Blaxter, M. (2010) *Health*. Cambridge: Polity.
- Bloch, M., and Parry, J. K. (eds.) (1982) *Death and the Regeneration of Life*. Cambridge: Cambridge University Press.
- Bolton, G. (ed.) (2008) *Dying, Bereavement and the Healing Arts*. London: Jessica Kingsley.
- Bonde, L. O. (2011) Health musicing - music therapy or music and health? A model, empirical examples and personal reflections. *Music and Arts in Action*, 3(2): 120-140.
- Bronfen, E. (1992) *Over her dead body: Death femininity and the aesthetic*. Manchester: Manchester University Press.
- Bull, M. (2000) *Sounding Out the City: Personal Stereos and the Management of Everyday Life*. Oxford: Berg.

- Burns, L. (2007) Gunther von Hagens' Body Worlds: Selling beautiful education. *American Journal of Bioethics*, 7(4): 12-23.
- Burns, S. B. (1990) *Sleeping Beauty: Memorial Photography in America*. Altadena, CA: Twelvetimes Press.
- Bury, M. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4: 167-182.
- Carel, H. (2008) *Illness: The Cry of the Flesh*. Stocksfield: Acumen.
- Caswell, G. (2012) Beyond words: Some uses of music in the funeral setting. *Omega: Journal of Death and Dying*, 64(4): 319-334.
- Clayson, A. (1997) *Death Disks: Mortality in the Popular Song*. London: Sanctuary.
- Cross, E. (1994) Death in war: Britten and the war requiem. In J. Davies (ed.), *Ritual and Remembrance*. Sheffield: Sheffield Academic Press, 124-151.
- Danforth, L. (1982) *The Death Rituals of Rural Greece*. Princeton: Princeton University Press.
- Davie, G. (1993) 'You'll never walk alone': The Anfield pilgrimage. In I. Reader and T. Walter (eds.), *Pilgrimage in Popular Culture*. Basingstoke: Macmillan, 201-219.
- Davies, D. (1997) *Death, Ritual and Belief*. London: Cassell.
- De Pascale, E. (2009) *Death and Resurrection in Art*. Los Angeles: J.P. Getty Museum.
- DeNora, T. (2000) *Music in Everyday Life*. Cambridge: Cambridge University Press.
- DeNora, T. (2012) Resounding the great divide: Theorising music in everyday life at the end of life. *Mortality*, 17(2): 92-105.
- Denyer, P. (1997) Singing the Lord's song in a strange land. In P. Jupp and T. Rogers (eds.), *Interpreting Death: Christian Theology and Pastoral Practice*. London: Cassell, 197-202.
- DeSpelder, L. A., and Strickland, A. L. (2005) *The Last Dance: Encountering Death and Dying* (7th ed.). Boston: McGraw Hill.
- Dileo, C., and Dneaster, D. (2005) Music therapy at the end of life: State of the art. In C. Dileo and J. V. Loewy (eds.), *Music Therapy at the End of Life*. Cherry Hill, NJ: Jeffrey Books, xix-xxvii.
- Doka, K. J. (2007) Death in music, art and literature. In K. Doka (ed.), *Death, Dying and Bereavement* (vol. 1, section 4). Abingdon and New York: Routledge.
- Dollimore, J. (2001) *Death, Desire and Loss in Western Culture*. London: Routledge.
- Doss, E. (2010) *Memorial Mania: Public Feeling in America*. Chicago: Chicago University Press.
- Edwards, E. (1999) Photographs as objects of memory. In M. Kwint, M. Breward and J. Aynsley (eds.), *Material Memories: Design and Evocation*. Oxford: Berg.
- Field, D. (1984) Formal instruction in UK medical schools about death and dying. *Medical Education*, 18: 429-434.
- Field, D. (1986) Formal teaching about death and dying in UK nursing schools. *Nurse Education Today*, 6: 270-276.
- Finnegan, R. (1989) *The Hidden Musicians: Music-Making in an English Town*. Cambridge: Cambridge University Press.
- Francis, D. (1992) Artistic creations from the work years: The New York world of work. In J. Calagione, Francis, D., Nugent, D. (eds.), *Worker's Expressions: Beyond Accommodation and Resistance*. Albany: State University of New York Press, 48-67.
- Francis, D., Kellaher, L., and Neophytou, G. (2005) *The Secret Cemetery*. Oxford: Berg.

- Fraser, E. (2003) Delacroix's Sardanapalus: The life and death of the royal body. *French Historical Studies*, 26: 315-349.
- Frazer, H., and Oestreicher, C. (1998) *The Art of Remembering*. London: Carcanet.
- Freeman, L., Caserta, M., Lund, D., Rossa, S., Dowdy, A., and Partenheimer, A. (2006) Music thanatology: Prescriptive harp music as palliative care for the dying patient. *American Journal of Hospice and Palliative Medicine*, 23(2): 100-104.
- Gammon, V. (1988) Singing and popular funeral practices in the eighteenth and nineteenth centuries. *Folk Music Journal*, 5(4): 412-447.
- Garces-Foley, K., and Holcomb, J. S. (2005) Contemporary American funerals: Personalizing tradition. In K. Garces-Foley (ed.), *Death and Religion in a Changing World*. Armonk, NY: ME Sharpe.
- Garrett, S. (1984) *Death Sentences: Styles of Dying in British Fiction*. Cambridge, MA: Harvard University Press.
- Gaztambide-Fernández, R. A. (2008) The artist in society: Understandings, expectations, and curriculum implications. *Curriculum Inquiry*, 38(3): 233-265.
- Gibson, M. (2008) *Objects of the Dead: Mourning and Memory in Everyday Life*. Carlton, Vic: Melbourne University Press.
- Gilbert, S. M. (2006) *Death's Door: Modern Dying and the Ways We Grieve*. London: W.W. Norton.
- Gittings, C. (2009) The art of dying. In A. Kellehear (ed.), *The Study of Dying*. Cambridge: Cambridge University Press, 163-187.
- Grazian, D. (2004) Opportunities for ethnography in the sociology of music. *Poetics* 32: 197-210.
- Hafferty, F. (1991) *Into the Valley*. New Haven: Yale University Press
- Hagin, B. (2010) *Death in Classical Hollywood Cinema*. Basingstoke: Palgrave Macmillan.
- Hansen, J. (1996) Resurrecting death: anatomical art in the cabinet of Dr. Frederik Ruysch. *The Art Bulletin*, 78(4): 663-679.
- Hara, M. (2011) Music in dementia care: Increasing understanding through mixed research methods. *Music and Arts in Action*, 3(2): 34-58.
- Hartley, N., and Payne, M. (eds.) (2008) *The Creative Arts in Palliative Care*. London: Jessica Kingsley.
- Holloway, M., Adamson, S., Argyrou, V., Draper, P., and Mariau, D. (2010) *Spirituality in Contemporary Funerals*. Hull: University of Hull.
- Holst-Warhaft, G. (1992) *Dangerous Voices: Women's laments and Greek Literature*. London: Routledge.
- Holst-Warhaft, G. (2008) Death and the maiden: Sex, death, and women's laments. In E. J. Håland (ed.), *Women, Pain and Death: Rituals and Everyday Life on the Margins of Europe and Beyond*. Newcastle-upon-Tyne: Cambridge Scholars Publishing, 15-33.
- Hughes, R. (1968) *Heaven and Hell in Western Art*. New York: Stein and Day.
- Hutcheon, L., and Hutcheon, M. (2004) *Opera: The Art of Dying*. Cambridge, MA: Harvard University Press.
- Inglis, I. (2004) A brief life: Broken hearts and sudden deaths. *Popular Music and Society*, 27(4): 477-488.
- Johansson, S., Leonard, R., and Noonan, K. (2012) Caring and the generation of social capital: Two models for a positive relationship. *International Journal of Social Welfare*, 21: 44-52.

- Kastenbaum, R. (2003) "Arise, Ye more than Dead!": Culture, music and death. In C. B. Bryant (ed.), *Handbook of Death and Dying*. Thousand Oaks, CA: Sage, 1008-1018.
- Keightley, E., and Pickering, M. (2006) For the record: Popular music and photography as technologies of memory. *European Journal of Cultural Studies*, 9(2): 149-165.
- Kellehear, A. (1999) *Health Promoting Palliative Care*. Oxford: Oxford University Press.
- Kellehear, A. (2005) *Compassionate Cities*. London: Routledge.
- Kellehear, A. (2007) The end of death in late modernity: An emerging public health challenge. *Critical Public Health*, 17(1): 71-79.
- Kellehear, A. (ed.) (2010) *The Study of Dying*. Cambridge: Cambridge University Press.
- Kellehear, A., Pugh, E., and Atter, L. (2009) Home away from home? A case study of bedside objects in a hospice. *International Journal of Palliative Nursing*, 15(3): 148-152.
- Kemp, M., and Wallace, M. (2000) *Spectacular Bodies: The Art and Science of the Human Body from Leonardo to Now*. London / Berkeley: Hayward Gallery / University of California Press.
- Kligman, G. (1988) *The Wedding of the Dead: Ritual, Poetics, and Popular Culture in Transylvania*. Berkeley, CA: University of California Press.
- Kristeva, J. (1989) Holbein's dead Christ. In J. Kristeva (ed.), *Black Sun*. New York: Columbia University Press, 107-138.
- Langellier, K. M. (2001) 'You're marked': Breast cancer, tattoo and the narrative performance of identity. In J. Brockmeier and D. Carbaugh (eds.), *Narrative and Identity: Studies in Autobiography, Self, and Culture*. Amsterdam and Philadelphia, PA: John Benjamins, 145-184.
- Leaman, O. (1995) *Death and Loss: Compassionate Approaches to the Classroom*. London: Cassell.
- Lee, C. (1996) *Music at the Edge: The Music Therapy Experiences of a Musician with AIDS*. London: Routledge.
- Lee, C. A. (2001) Music therapy. In J. Barraclough (ed.), *Integrated Cancer Care: Holistic, Complementary, and Creative Approaches*. Oxford: Oxford University Press: 144-154.
- Lee, D.-H. (2010) Digital cameras, personal photography and the reconfiguration of spatial experiences. *The Information Society*, 26: 266-75.
- Llewellyn, N. (1991) *The Art of Death*. Edinburgh: Edinburgh University Press.
- Lyon, P. (ed.) (2005) *Twentieth-Century War Poetry: A Reader's Guide to Essential Criticism*. Basingstoke: Palgrave Macmillan.
- Malvern, S. (2000) Memorializing the great war: Stanley Spencer at Burghclere. *Art History*, 23(2): 182-204.
- Markell, K., and Markell, M. (2008) *The Children Who Lived: Using Harry Potter and Other Fictional Characters to Help Grieving Children and Adolescents*. London: Routledge.
- Martin, R. (1995) Memento mori manifest. In J. Spence and J. Soloman (eds.), *What Can a Woman Do with a Camera*. London: Scarlet Press, 67-74.
- Meyer, B. (2003) Till death do us part: The consumptive Victorian heroine in popular romantic fiction. *Journal of Popular Culture*, 37: 287-308.
- Miller, D. (1995) *Acknowledging Consumption: A Review of New Studies*. London: Routledge.
- Mills, S. (2012) Sounds to soothe the soul: Music and bereavement in a traditional South Korean death ritual. *Mortality* 17(2): 145-157.
- Minear, P. (1987) *Death Set to Music*. Atlanta, GA: John Knox Press.

- Morrell, J., and Smith, S. (2007) *We Need to Talk About the Funeral: 101 Practical Ways to Commemorate and Celebrate a Life*. Bedlinog, Glamorgan: Accent Press.
- Nichols, L. G., and Lister, S. (1999) Using art therapy with pediatric oncology patients. In S. Bertman (ed.), *Grief and the Healing Arts: Creativity as Therapy*. Amityville, NY: Baywood, 99-117.
- Norwood, F. (2009) *The Maintenance of Life: Preventing Social Death Through Euthanasia Talk and End-of-Life Care - Lessons from The Netherlands*. Durham, NC: Carolina Academic Press.
- O'Callaghan, C. (2004) The contribution of music therapy to palliative medicine. In D. Doyle, G. Hanks, N. I. Cherny and K. Calman (eds.), *Oxford Textbook of Palliative Medicine* (3rd ed.). Oxford: Oxford University Press, 1041-1046.
- Oakley, G. (1976) *The Devil's Music: A History of the Blues*. London: BBC.
- Oliver, P. (1998) *The Story Of The Blues*. Boston: Northeastern University Press.
- Oremland, J. (1980) Mourning and its effect on Michelangelo's art. *Annual of Psychoanalysis*, 8: 317-351.
- Pacholski, R. A. (1986a) Death themes in music: Resources and research opportunities for death educators. *Death Studies*, 10: 239-263.
- Pacholski, R. A. (1986b) Death themes in the visual arts: Resources and research opportunities for death educators'. *Death Studies*, 10: 59-74.
- Parkes, C. M. (1972) *Bereavement: Studies of Grief in Adult Life*. London Tavistock.
- Parsons, B. (2012) Identifying key changes: The progress of cremation and its influence on music at funerals in England, 1874-2012. *Mortality*, 17(2): 130-144.
- Pavlicevic, M., and Ansdell, G. (2004a) Introduction: The ripple effect. In M. Pavlicevic and G. Ansdell (eds.), *Community Music Therapy*. London: Jessica Kingsley, 15-31.
- Pavlicevic, M., and Ansdell, G. (eds.) (2004b) *Community Music Therapy*. London: Jessica Kingsley.
- Phillips, S. (Producer). (2010) "Tribute to her dying mother." Retrieved from <http://www.youtube.com/watch?v=jIRQvbhdR58>
- Pratt, M., and Wood, M. (1998) *Art Therapy in Palliative Care*. London: Routledge.
- Radley, A. (2009) *Works of Illness: Narrative, Picturing and the Social Response to Serious Disease*. Ashby-de-la-Zouch: InkerMen Press.
- Radley, A., and Bell, S. (2007) Artworks, collective experience and claims for social justice: The case of women living with breast cancer. *Sociology of Health and Illness*, 29(3): 366-390.
- Ramazani, J. (1994) *Poetry of Mourning: The Modern Elegy from Hardy to Heaney*. Chicago: The University of Chicago Press.
- Riches, G., and Dawson, B. (1998) Lost children, living memories: The role of photographs in processes of grief and adjustment amongst bereaved parents. *Death Studies*, 22(2): 121-140.
- Robertson, A. (1967) *Requiem: Music of Mourning and Consolation*. London: Cassell.
- Robinson, D. (1995) *Saving Graces: Images of Women in European Cemeteries*. New York: Norton.
- Rogers, J. E. (ed.) (2007) *The Art of Grief: The Use of Expressive Arts in a Grief Support Group*. London: Routledge.
- Ruby, J. (1995) *Secure the Shadow: Death and Photography in America*. Cambridge, MA: MIT Press.
- Ruud, E. (2004) Reclaiming music. In M. Pavlicevic and G. Ansdell (eds.), *Community Music Therapy*. London: Jessica Kingsley, 11-14.
- Santino, J. (ed.) (2006) *Spontaneous Shrines and the Public Memorialization of Death*. Basinstoke:

- Palgrave Macmillan.
- Schels, B., and Lakotta, W. (2004) *Noch Mal Leben vor Dem Tod*. Munich: Deutsche Verlags-Anstalt.
- Scruton, R. (2009a) *Beauty*. Oxford: Oxford University Press.
- Scruton, R. (2009b) *Roger Scruton: Why Beauty Matters*. Television Program. BBC 2, 28th November.
- Shapiro, H. (1991) The iconography of mourning in Athenian art. *American Journal of Archaeology*, 95: 629-656.
- Shroeder-Sheker, T. (1994) Music for the dying: A personal account of the new field of music-thanatology – history, theory and clinical narratives. *Journal of Holistic Nursing*, 12(1): 83-99.
- Skelton, J. (2009) Dying in Western literature. In A. Kellehear (ed.), *The Study of Dying*. Cambridge: Cambridge University Press, 188-210.
- Small, C. (1998) *Musicking*. Hanover, NH: Wesleyan University Press.
- Smith, K. (2011) *Shakespeare and Son: A Journey in Writing and Grieving*. Santa Barbara, CA: Praeger.
- Smith, S. (2009) When I'm 64: Music for babyboomer funerals. *Funeral Services Journal*, 124(9): 108-109.
- Sonke, J. (2011) Music and the arts in health: A perspective from the United States. *Music and Arts in Action*, 3(2): 5-14.
- Stanley, L. (1993) On auto/biography in sociology. *Sociology* 27(1): 41-52.
- Stansky, P., and Abrahams, W. (1994) *London's burning: Life, Death, and Art in the Second World War*. Palo Alto, CA: Stanford University Press.
- Storey, J. (1999) *Cultural Consumption and Everyday Life*. London: Arnold.
- Sumner, A. (ed.) (1995) *Death, Passion and Politics: Van Dyck's Portraits of Venetia Stanley and George Digby*. London: Dulwich Picture Gallery.
- Tagg, P. (1993) 'Universal' music and the case of death. *Critical Quarterly*, 35(2): 54-85.
- Townsend, E. (2009) *Death and Art: Europe 1200-1530*. London: Victoria and Albert Museum.
- Tsirir, G., Tasker, M., Lawson, V., Prince, G., Dives, T., Sands, M., and Ridley, A. (2011) Music and arts in health promotion and death education: The St Christopher's Schools project. *Music and Arts in Action*, 3(2): 95-119.
- Twitchell, J. B. (1981) *The Living Dead: A Study of the Vampire in Romantic Literature*. Durham, NC: Duke University Press.
- Vermeule, E. (1979) *Aspects of Death in Early Greek Art and Poetry*. Berkeley: University of California Press.
- Viney, N. (1991) *Images of Wartime: British art and artists of World War 1*. Newton Abbot: David and Charles.
- Waller, D., and Sibbett, C. (eds.) (2005) *Art Therapy and Cancer Care*. Maidenhead: Open University Press.
- Walter, T. (1997) Secularisation. In P. Laungani, C. M. Parkes and W. Young (eds.), *Death and Bereavement Across Cultures*. London: Routledge, 166-187.
- Walter, T. (2012) Why different countries manage death differently: A comparative analysis of modern urban societies. *British Journal of Sociology* 63(1): 123-145.

- Watson, M., Lucas, C., Hoy, A., and Wells, J. (2009) *Oxford Handbook of Palliative Care* (2nd ed.). Oxford: Oxford University Press.
- Watts, J. (2009) Illness and the creative arts. In S. Earle, C. Komaromy and C. Bartholemew (eds.), *Death and Dying: A Reader*. London: Sage, 102-108.
- Whitaker, A. (1984) *All in the End is Harvest: An Anthology for Those Who Grieve*. London: Darton, Longman, Todd.
- Wilke, H. (1994) *Intra-Venus*. Exhibition: 8 January – 19 February. New York: Ronald Feldman Fine Arts Gallery. <http://www.feldmangallery.com/pages/exhsolo/exhwil94.html>
- Wolf, R. (2001) Emotional dimensions of ritual music among the Kotas, a South Indian Tribe. *Ethnomusicology*, 45(3): 379-422.
- Wood, M. (2004) The contribution of art therapy to palliative medicine. In D. Doyle, A. Hoy, N. I. Cherny and K. Calman (eds.), *Oxford Textbook of Palliative Medicine* (3rd ed.). Oxford: Oxford University Press, 1063-1068.
- Worpole, K. (2009) *Modern Hospice Design: The Architecture of Palliative Care*. Abingdon: Routledge.

ABOUT THE AUTHOR

Tony Walter is Professor of Death Studies at the University of Bath. A sociologist, he has written and lectured internationally on a variety of aspects of death and society. For more information see www.bath.ac.uk/cdas/people.