

Live Well, Die Well: The Development of an Online, Arts-Based Palliative Care Programme in the Shadow of the COVID-19 Pandemic

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journals.sagepub.com/home/ome**Amanda Roberts**^{1,2} **Abstract**

The Covid-19 crisis led to an increase in the ‘total pain’ of many terminally ill patients who faced a reduction in support, due to the temporary closure of front-line palliative day therapy services. A hospice volunteer, I instigated an online day therapy programme for patients previously attending face-to-face day therapy. Participant feedback revealed the importance of providing a space for ongoing peer support for participants’ changing sense of identity, an issue for time-limited day therapy programmes. An exploration of key concepts associated with palliative care established the multiple connections between such changing identity and arts-based approaches to living well. This article charts how I used this understanding to develop an alternative, online arts-based support programme, *Live well, die well*. It explores the links between ongoing mutual support, arts-based activity and the reactions to a shifting identity in patients with a life-limiting illness.

Keywords

palliative care, day therapy, identity, communication, arts-based

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After a career in education in schools and universities, I decided in 2018 to pursue a new interest in palliative care. I became a teacher because I wanted to improve the life chances of young people. My aim, within this broader moral purpose, of enabling individuals to achieve their potential, seemed applicable to end-of-life care. I therefore began volunteering in the day therapy team of a local hospice. Palliative day therapy is a rapidly expanding model of provision, with over 90% of hospice care provided through day services or at home (Hospice UK, 2015). Day therapy offers the opportunity for re-habilitation within the boundaries of a patient's disease (Low et al., 2005). This re-habilitation, or development of the abilities and dispositions needed for everyday life, is supported by day therapy services such as occupational therapy, physical therapy, sharing and monitoring of symptoms and activities which offer psycho-social support for those with a terminal diagnosis (Kilonzo et al., 2015). Enhancing quality of life, through focusing on a patient's individuality and addressing their specific needs, is a central aim (Hearn & Myers, 2001, in Fisher et al., 2008).

Patients accessing palliative care often experience some degree of what has been termed 'total pain', the physical, mental, social and spiritual pain which can make up the totality of a patients' suffering at the end of their life (Saunders et al., 1995. p.45). The term 'total pain' reflects the complex nature of care needed to support such individuals. An editorial in *The Lancet* (2020) argues that a global pandemic such as COVID-19 amplifies suffering, through physical illness, the exacerbated threat of death, an increase in general levels of fear and anxiety and financial challenges. Alleviation of such suffering is clearly a priority in palliative care and beyond.

The response to the Covid-19 crisis unfortunately meant the temporary closure of the majority of front-line palliative day care services. Day therapy provision at the hospice where I volunteered was suspended, in common with many hospices seeking to reduce virus spread (Powell & Silveira, 2020). This necessary withdrawal of services is, however, increasing levels of patient distress nationally (Cawley, 2020), with individuals deprived of support for their emotional and physical well-being (Andersson Svidén et al., 2009). Seeking to fill this gap, I designed and facilitated an online day therapy programme for patients previously attending face-to-face day therapy at the hospice where I volunteered.

An Online Day Therapy Programme

The online day therapy programme allowed patients to meet weekly online for an hour to share conversation, mutual support and recreational activities and to access clinical guidance where needed. Supported by the hospice day therapy team leader, I decided to involve participants in the design of this new venture, incorporating participant feedback, including suggestions for programme content, from the outset. This feedback led to a re-visiting of the programme's

guiding principles, leading to a statement of aims, developed and agreed with participants.

Through our online day therapy programme we aim to empower participants to live well, within the boundaries of their condition. We work together to achieve this through:

Providing Social Support

Providing opportunities to share experiences, memories, issues and stories to support one another in living well.

Facilitating Exercise

Exercising together to build our physical and mental well-being.

Advising on Symptom Management

Providing advice on symptom management through personal expertise or through signposting other available services.

Building Understanding Together

Learning together about illness, wellness, about us as individuals and the world around us through talking, taking part in games and creative activities and having fun together.

Programme activities were designed to support the achievement of these aims. Rather than positioning the service on the social/medical continuum of service models (Fisher, 2008), we adopted the “layers” (p.284) of activity model (Higginson et al., 2000), meshing medical and social aims. The key features of the service were:

- online engagement with participants
- short session length – 1 hour each week
- arts-based activities and seated exercise as a regular feature of sessions
- volunteer and clinically-trained day therapy lead as the programme team
- process-based, spiral curriculum, responsive to patient need
- patient expertise drawn on
- patients linked to other services where appropriate
- resource-light
- flexible programme length
- supported by bespoke website

I facilitated sessions, which typically began with a sharing of individual news, in which I invited each participant to speak about events during their week,

things that were concerning them etc. Seated exercise activity followed, led by my colleague. My colleague would demonstrate the exercise, asking participants to take part in the exercise alongside her. Participants were advised to work only at the level they felt comfortable with. I then facilitated an arts-based activity. For example, we enjoyed quizzes and word association games and wrote a communal poem, with each participant contributing one line. We also made a 'Pride and Hope' tree, when each participant shared a source of pride and a hope, which I then wrote onto a paper leaf and hung onto a twig tree. After sessions, a summary of the session with photographs of the results of arts-based activities would be posted on the programme website to allow those who could not attend to maintain a connection with the community.

An Evaluation: Learning From Participants' Feedback

The online programme was conceived as a short-term response to an acute crisis, the COVID-19 pandemic. As the pandemic developed, it became clear that face-to-face day therapy services would remain suspended for the foreseeable future. I wanted to understand the impact of the online programme at this stage, in order to both understand and improve it. This ongoing, illuminative evaluation approach (Partlett & Hamilton, 1972) to service evaluation allowed me to clarify how the online day therapy programme worked, portray this practice (Roberts, 2020) and then develop it further, rather than simply measure its impact at its conclusion.

Whilst such service evaluations do not require external ethical approval (Health Research Authority, 2017), ethical considerations guided the programme design and ongoing evaluation. Adherence to the 'Declaration of Helsinki' set of ethical principles, adopted by the World Medical Association (2013), ensured that participants' wellbeing was prioritised. The aim and scope of the evaluation was shared with participants, with the voluntary nature of participant feedback emphasised. Draft evaluation questions were shared in advance with participants, who were encouraged to add areas for discussion. Participant reactions to the draft evaluation report were also sought. Such actions were particularly important given the potentially vulnerable nature of participants. However, I agree with de Laine's (2000) view that the evaluators' intentions, motivations and ways of being are better indicators of an ethically sound approach than superficial adherence to a given ethical code. The adoption of a virtue-based approach to ethical dilemmas (Macfarlane, 2010), that is, attempting to act in accordance with my conscience, underpinned the programme's development and evaluation.

Of the 10 patients regularly attending face-to-face day therapy, 7 regularly attended the weekly online sessions. All patients had a terminal diagnosis, with 5 suffering from cancer and 2, from a neurological condition. In addition, 1 carer attended the sessions, to support a participant with speech difficulties. Feedback

was collected from participants in June 2020. An online focus group was used as the vehicle to gain this feedback, as part of one of our weekly online sessions. Such an approach seemed congruent with the values and philosophies of palliative care, (Seymour & Skilbeck, 2002), offering participants equal opportunity to share their views, to have the right to be consulted if they so wished (Foster, 2001), whilst not making additional demands on them.

Participants' comments were illuminating, with thoughts around identity dominating reflections. Participants underlined the importance of being in contact with people in a similar situation who understood what it was like to live with a terminal illness. One participant's comment 'this is my tribe now' captured the sense of a changed, shared identity. In everyday parlance, identity refers to particular characteristics and attributes of an individual by which we distinguish one person from another - the human capacity to know who is who (Jenkins, 1996). A central feature of this view of identity is that it is fixed and inflexible. Exemplifying Erikson's (1975) work on identity crisis, participants challenged this understanding, seeing identity not as a fixed state but as a process of development. The disrupted sense of self experienced by some patients as their condition progresses and their capacity for their usual activities diminishes (Exley & Letherby, 2001) endorses this fluid view of identity.

The shifts in who patients are, caused by their illness, are not always easily accepted either by themselves or by friends and family. A change in perceived role and position in family and friendship groups, for example, can contribute to a sense of identity shift, with patients suffering a social death before the physical one their illness ultimately brings (Lawton, 2000). Palliative day therapy can support a patient in acknowledging and accepting a new sense of self (Lawton, 2000). In choosing to associate themselves with others with a terminal illness, patients seem to find a sense of belonging, understanding and comfort, a world in which it is easy to be themselves, whatever that now means. Indeed, respondents in Goodwin et al.'s (2002) study cited meeting people as the most important aspect of day therapy. In attending, and adopting the accepted practices of, an online day therapy group, our patients exemplified Gee's (2001) understanding of identity development through affinity. New kinships appear to partially fill support gaps created by concerns about sharing potentially uncomfortable truths with family and friends (Exley & Letherby, 2001). Relationships with staff and volunteers facilitating day therapy were also seen to be important, resonating with Hyde et al.'s (2011) assertion of the centrality of a holistic sense of community to day therapy patients' well-being.

A linked theme in our day therapy participants' comments was the difficulty in talking explicitly about death and dying, 'a continuing taboo' in the words of one participant. Results of a national survey commissioned by the Co-op Funeralcare organisation in 2018 similarly found only 7% of people to be very comfortable in talking about their own mortality. Such responses are perhaps to be expected amongst the general public. What is more surprising is the

reported reluctance of the medical profession to discuss death. Evans et al. (2014) found that where discussions of end of life care did take place, doctors focused on physical complaints and primary diagnosis rather than spiritual and existential issues. Living well until death was not generally a key feature of discussions (Sinuff et al., 2015).

Its inception as short-term response to an immediate crisis meant the online day therapy programme had no fixed end point. Participants' comments emphasised the importance of the curriculum fluidity this offered. They felt a sense of agency in bringing concerns for discussion and accessing the expertise of staff and peers. Many issues were returned to weekly, driven by individual need. Participants appreciated this democratisation of the curriculum and appeared to value a process-based approach, in which learning focuses not on specific outcomes but on flexible processes and activities which supported their changing interests and concerns. Participant expertise could be confidently drawn upon in whole group discussions, where any misconceptions regarding symptom management etc. could be addressed by the clinically-trained team member.

The Development of a New Online Support Programme

After the online day therapy programme had run for four months, the hospice Senior Leadership Team paused the programme to review it. The review led to the introduction of a re-shaped, nine-week education programme, with patients discharged back to their GP at the end of this period, although some flexibility in individual cases was considered. Although this development was understood by patients, it was a cause of concern to some. Patients had developed an effective peer support system, encouraging of the new ways of being which they were attempting to develop and own. To fracture relationships through an artificial cut-off point necessitated by a fixed-term programme seemed inappropriate. I decided to develop a new online support programme, independent of the hospice, to allow patients to continue to connect with one another once their access to time-limited, hospice-based day therapy sessions ended.

Exploring Key Concepts

My intention to develop an independent online programme raised several key questions: What should the programme aim to achieve? What curriculum design would enable the achievement of these aims? Who should be the programme's target participants? How should it be facilitated and evaluated? Reflection on these issues led me to notice some of the assumptions which underpinned my practice. I decided to examine the concepts which had arisen in planning and facilitating the hospice-based online programme, to help me to challenge my assumptions and to move my planning of a new programme forward.

Palliative Care, End of Life and Quality of Life

In everyday parlance, the term palliative care is frequently used to refer to care given at the later stage of a life-threatening illness (Van Mechelen et al., 2012). However, such usage limits palliative care to an end of life intervention, a position unsupported by medical policy and practice (Williams & Wheeler, 2001). Instead, the General Medical Council (2010) sees palliative care as appropriate at any stage of a progressive illness. An assumed dichotomy between treatment for curative purposes and palliative purposes is challenged through this position, which better reflects the reality of the continuum of patient care (Byock, 2000; Faul, 2012).

Whilst potentially empowering for patients and clinicians, such a broad conceptualisation of palliative care challenged my thinking about the target audience for the new programme. I had imagined potential participants would have been discharged from a hospice-based palliative day therapy programme and thus be entering the last stage of their lives. The broad definition of palliative care made me wonder about this assumption. I wondered if I should broaden the programme's scope and offer it to any individual with a life-limiting, progressive illness. Developing a clearer understanding about what is meant by 'end of life' seemed a sensible next step.

The General Medical Council (2010) suggests "patients are 'approaching the end of life' when they are likely to die within the next 12 months" (p.8). Death may be due to advanced progressive incurable conditions, general frailty and co-existing conditions, an acute crisis or life-threatening critical conditions caused by sudden catastrophic events. Despite the clarity of this definition, determining when an individual fits one of the given categories can prove problematic (Christakis & Lamont, 2000). The National Institute for Health and Care Excellence (NICE) (2017) therefore offers a range of tools to assist clinicians in timely identification of people approaching the end of life. The Gold Standards Framework Prognostic Indicator Guidance (PIG) (NICE, 2016), one such tool, offers 'the Surprise Question' – would you be surprised if the patient were to die in the next year, months, weeks, days? – as a key step in assessing nearness to death, in addition to specific clinical indicators and general indicators of decline. Questions around the effectiveness of the PIG (e.g. in White et al., 2017) fail to acknowledge the tentative nature of claims made. Advice on the Gold Standards Framework (2020) website clearly proposes the PIG as a means to predict needs rather than a precise prognostic tool. The impossibility of knowing exact disease trajectories for individuals (Meghani, 2004) and an attendant lack of consistency in defining who counts as a palliative care patient (Van Mechelen et al., 2012) challenged my assumptions around the targeted audience for the new programme. A consideration of the purpose of palliative care rather than its timing helped me to think more clearly about this issue.

The World Health Organization (WHO) (2020) defines palliative care as an approach that ‘improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’. The WHO here echoes Saunders’ (1964, in Clark, 1999) earlier articulation both of the combined physical, psychological, social and spiritual pain associated with terminal illness, the ‘total pain’ of the dying process, and of the role of palliative care in relieving this pain. Palliative care thus aims to affirm and enhance quality of life whilst acknowledging death as a normal process within it. Meghani’s (2004) phrase “the holistic relief of suffering” (p.158) encapsulates this ambitious scope.

I wish to design a programme which contributes to this holistic support. Understanding the features of effective palliative care approaches is therefore crucial. Luckett et al. (2014) focus on structural features, offering co-ordination of services within and beyond the healthcare system, specialist outreach services and managed clinical networks as the components of an effective service. More helpfully for my work, Meghani (2004) encapsulates effective care as total, active and individualised patient care and family support, provided by an interdisciplinary team which communicates well internally and externally, with patients and their families.

A focus on enhancing ‘quality of life’ led me to wonder about the meaning of this term. Some initial reading pointed towards a lack of consensus, which could be partially explained by the concept’s development across a range of disciplines (McCaffrey et al., 2016). However, the inherent subjectivity in what each individual values in life (Barofsky, 2012) is a more obvious explanatory factor. Saunders’ articulation of her driving vision in setting up the first modern hospice recognises this individuality. Saunders movingly articulates her belief in palliative care’s core purpose of supporting unique, precious individuals in living well, whatever that might mean to them, before supporting them through their death.

You matter because you are you, and you matter until the last moment of your life.
We will do all that we can to help you not only to die peacefully, but to live until
you die.
(<https://www.stchristophers.org.uk/about/damecicelysaunders/tributes>)

Unlike Albers et al.’s (2010) work which preceded it, McCaffrey et al. (2016), in a systematic review of literature, follow Saunders’ lead in focusing on the patients’ interpretation of quality of life. McCaffrey et al. (2016) found this quality to be affected, positively or negatively, by patients’ cognitive abilities, their emotional state, access to appropriate healthcare, personal autonomy, physical health, including adequate symptom control, preparation for death, relationships with others and spiritual aspects of life such as hope, comfort, meaning and purpose.

The predominance of psychosocial factors echoed my participants' focus on identity in their evaluation of the hospice online day therapy programme. This concept therefore seemed worthy of further exploration.

Identity

The literature which seeks to explain the development of identity in the socially-constructed world, that is, to explain how one comes to be 'the kind of person one is recognised as being, at a given time and place' (Gee, 2001, p.99) seemed relevant to my understanding of the importance of identity to individuals with a terminal diagnosis. I wondered how the participants in the day therapy group had become the people they were. Erikson (1975) makes a compelling argument for identity as a work in progress, not a fixed state but a process of development. At any given point in time then, we are not so much 'someone' as we are between being 'one kind of someone', on our way to being 'the next kind of someone'. The kind of person we are can therefore develop from one moment to another as we move between situations and contexts. Brubaker and Cooper's (2000) proposal of the active term 'identification' seems more helpful than the passive term 'identity' because it builds on this conceptualisation of identity as activity. It allows us to ask the question, how do we identify ourselves? How do others identify us? It also allows us to propose that the answers to these questions change in response to changing circumstances.

This active conceptualisation of identity informs de Muijnck's (2019) proposed construction of a stable identity during terminal illness through considering past, present and future selves. We may instinctively consider our present identity to be stable. However, chronic illness can disrupt this, leading to a loss of self in interconnected ways, both through manifestations of the physical disease, diminished social and familial relationships and a social death in which we cease to be active agents in others' lives (Mulkay, 1993 in Lawton, 2000). Drawing on theatrical imagery, Goffman's (1959) discussion of front stage and back stage selves is pertinent here. In attempting to shield family and friends from the reality of their changing lives, individuals with a life-limiting illness may adopt a front-stage self, a persona in which they follow the script, the rules about what is expected of them. When friends and family go home, when the audience leaves, the back-stage, more authentic self can come into play. Exley and Letherby (2001) use the connected image of a 'stranger' to sum up the feelings and behaviours of the terminally ill, with their respondents reporting feeling like 'outsiders' or 'strangers', both in relation to their previous identity and in their relationships with others.

The concepts of similarity and difference are helpful in exploring these ideas further. Hall (1996, p. 17) suggests that identities are 'the product of the marking of difference and exclusion', a position supported by Taylor (1998). The concept of 'othering', a process where a person or group is marked as

different to others (Johnson et al., 2004), is also relevant. Finding out who I am appears to include the procedure of finding out who I am not (Butler, 1990). A terminal diagnosis means an individual is no longer a member of the group of people who do not have such a diagnosis. Gawande (2014) underlines the “chasm of perspective between those who have to contend with life’s fragility and those who don’t” (p.99) which such a diagnosis brings. In joining a palliative care day therapy group, an individual can both acknowledge their shift in perspective and gain empathy and comfort from those now like themselves. However, a construction of such services as short-term interventions, with a strong re-habilitative focus, seems at odds with individuals’ need for an ongoing system of psycho-social support. Participants in Lawton’s (2000) study clarified this conflict between the stated aims of the service and their ongoing needs. A reluctance to be discharged evidenced the importance of the new social world they had found, where they did not feel like a stranger and where the back-stage self was welcomed. I wondered how an acceptance of identity shift connected to an interest in talking about death and dying, the other key theme raised by our participants.

Talking About Death and Dying

In the novella *The death of Ivan Ilyich*, Tolstoy (2016, pp. 63–64) captures the intensity of the terminally-ill character’s need for shared, open discussion of death and dying between himself and his loved ones.

Ivan Ilyich’s worst torment was the lying – the lie, which was somehow maintained by them all, that he wasn’t dying, he was only ill, and all he had to do was to keep calm and follow doctor’s orders and something good would emerge. Whereas he knew that, whatever was done to him, nothing would emerge but more and more agony, suffering and death.

Numerous research studies confirm patients’ desire for honest, sensitive communication about end-of-life issues (Anderson et al., 2013). The understanding of loved ones which Ivan Ilyich so fervently craved not only helps patients but also enables families to be better prepared for dealing with death (Costello, 2018), thus avoiding the health issues which not talking about emotional issues can bring (Garland & Garland, 2001). Despite this, both the general public and healthcare professionals alike generally remain reluctant to talk about death and dying (Hanna, 2011.)

The elusiveness of prognostic certainty goes some way towards explaining this reluctance in clinicians (Broom et al., 2014). Many are unclear about the right time to initiate conversations about end-of-life (Hendricks-Ferguson et al., 2015) or fear patients’ reactions to the shift from curative to palliative care, so fail to raise the issue (Broom et al., 2014). However, there is also evidence that

healthcare professionals lack training in this area (Levin et al., 2010; Xafis et al., 2015) and are poorly supported due to a paucity of recommended communication approaches (Hendricks-Ferguson et al., 2015). Such professional reluctance to engage in conversations around death and dying can prove problematic for the patient. Patients can interpret an unwillingness to listen to their concerns as a sign of indifference on the part of medical staff (Xafis et al., 2015), with some questioning the accuracy of diagnoses due to poor communication (Hendricks-Ferguson et al., 2015). Conversely, open and timely communication around end-of-life issues has been shown to help patient understanding, subsequent decision-making and wider quality of life (Evans et al., 2014), whilst also reducing healthcare costs (Abdul-Razzak et al., 2015).

The case for encouraging timely discussion of death and dying seems strong then. Indeed, the setting up of *Dying Matters* in 2008, a coalition supported by the Department of Health, was a clear attempt to change social norms. However, although experts now recommend some techniques to support honest conversations, what these look like in practice remains unclear (Anderson et al., 2013). Whilst not being in a position to influence norms of physician/patient communication, I wondered if my experience as an English teacher equipped me to develop the use of storytelling to support conversations between individuals with a life-limiting disease and their family and friends. An investigation of the relationship between storytelling, illness and communication seemed an appropriate next step.

Storytelling, Illness and Communication

Anatole Broyard, in a meditation on his own ill-health, offers storytelling as a natural response to illness. He muses on how it provides an alternative strategy to medical intervention to help an individual cope and to fight the fear, not so much of dying, but of the “diminished self” (Broyard, 1992, p. 25). The connection which Broyard makes between storytelling and identity interested me. Stories can be told on a grand scale; they can narrate the history of countries or societies. However, I was interested in a ‘small stories’ approach, which enables individuals like Broyard to capture their experience, whilst acknowledging the fluid and contingent nature of identity (Georgakopoulou, 2006).

Storytelling appears to provide humans with the opportunity to construct an identity which they can go on to live out (Bruner, 1996; Clandinin et al., 2009; Ricoeur, 1980). This emancipatory power comes from the potential storytelling offers us to create an understanding of the world into which we feel we will fit (Bruner, 1996) and have some control over (McAdams, 1996). Thus narratives link both to being and becoming, allowing an analysis of the present whilst pointing towards future potential (Clandinin & Connolly, 2000). Given that future potential is constrained for those with a terminal diagnosis, I wondered if storytelling remained an appropriate palliative strategy.

Frank's (1998, p. 197) discussion of 'deep illness' was helpful here. Illness is deep when it is perceived by the sufferer as altering their life choices, decisions and identity. Frank (2013) discusses the enriching effect storytelling has on those suffering from deep illness. This arises from stories' potential to 'repair the damage' done to the ill person's sense of identity and life map and to provide a way of 're-drawing maps and finding new destinations' (Frank, 2013, p. 53). A "reconstitution of the self" (Gubar, 2016, p. 4) allows this re-drawing, which helps to address the disintegration of the self which deep illness often brings (Sakalys, 2003).

This pro-narrative argument relies to some extent, however, on a view of all humans as homogenous, narrative beings who recall a past, narrate a present and imagine a future. Remen's (1996) assertion that "everyone is a story" (p.iv) powerfully expresses this view. However, Strawson (2004, in Woods, 2011) suggests many individuals do not see life as a connected narrative but instead as episodic. The injunction to narrate, with its' focus on linked, verbal or written stories, is misguided and possibly harmful for these individuals. Instead, Woods (2011) offers alternative forms of telling, such as music and art, as non-linguistic forms of self-expression. My own experience bears out Polyani's suggestion (1967, as cited in Eisner, 2004) that much of our knowledge is tacit and untold, often due to the difficulty of expressing the most profound knowings in propositional form. Indeed, there appear to be points in life where words are inadequate to explain what is known, felt or believed (Frosh, 2002, as cited in Leitch, 2006). It therefore seemed relevant to consider the opportunity artmaking offers to explore the subtleties of our experience in creative, non-linear ways (Leitch, 2006; Spouse, 2000).

Artmaking, Illness and Communication

Craft activity is a common feature of hospice-based palliative day therapy. The positive impact on patients of doing things for themselves and making their mark on the world through artmaking (Gauntlett, 2011) can help combat the fear and isolation associated with living with a terminal diagnosis. Artmaking in this context can be far more than the distraction suggested by Dalley (2009). It can offer those with life-limiting illness both a voice and a way to explore the meaning of life, death and dying (All-Party Parliamentary Group on Arts, Health and Wellbeing Inquiry, 2017). It can provide a means to externalise something previously not available for overt, conscious consideration (Jones, 2005; Malchiodi, 2007) or, indeed, discussion with others. Where patients' sense of identity is disrupted by their illness, artmaking can be used to maintain continuity with the old self, to explore a new self (Walter, 2012), or to come to terms with the shift from looking for a cure to accepting mortality (Safrai, 2013).

The dominant Hippocratic medical tradition, based on external medical intervention with evidence-based cure as its goal, seems out of step with this

emphasis on individual sense-making. Artmaking seems to fit more readily with the Asklepiian tradition. Asclepius was the Greek god of healing and medicine who may have been a human healer, later given the status of a god (Hart, 2000). The Asklepiian medical tradition stresses healing in the context of an acceptance of mortality (Downie, 2012) and acknowledges that aspects of the healing process come internally, from the patient. The links between the Asklepiian tradition and art psychotherapy are interesting. Art psychotherapy enables patients to ‘express, discover and play with their own meanings and interpretations of their experiences’ (Tjasink, 2010, p. 75). Tjasink’s research explores the positive impact of artmaking on patients’ experience of agency in a context of possible medical objectification. However, here, artmaking is undertaken in the presence of a professional art therapist. Dalley (2009) suggests this presence provides the medium for patients to achieve the conscious and unconscious expression needed to support potential change. Whilst accepting the importance of trained professionals in an art psychotherapy process, I would challenge the position that artmaking cannot precipitate inner reflection and potential change outside of a discrete art therapy programme. Walter’s (2012) proposition of artmaking’s potential to support the exploration of self remains convincing and leads me to consider artmaking, with appropriate facilitation, as a communication catalyst for those living with deep illness.

This exploration of key concepts helped me to think anew about the programme I was proposing to develop. I explore elements of its design below.

Designing a New Programme of Support for Living Well

I shared earlier several questions which arose as I considered the development of a new programme to support those with a terminal diagnosis, independent of the hospice where I volunteered. I return to those questions here to support an explanation of the design of this new programme, entitled *Live well, die well*.

What Does the Programme Aim to Achieve?

The *Live well, die well* programme aims to empower individuals with a life-limiting illness to live well, within the boundaries of their condition, through learning with and supporting one another in online, arts-based activity groups.

Achieving this aim will enhance participants’ ability to live and die well through:

- making positive connections with others with a life-limiting illness
- gaining validation for a shifting identity as their illness progresses
- gaining understanding and support from those who can empathise with them
- enjoying engaging in arts-based activity which stimulates reflection and learning

- being better equipped to initiate conversations about death and dying, if so desired, with family and friends

Who Are Programme's Target Participants?

I wish to contribute to services which support individuals in coping with the total pain of terminal illness. Although hospice day therapy programmes are often targeted at those in the last year of life, the difficulty in accurately predicting the timing of an individual's death makes this criterion debatable. Moreover, the WHO's focus on early palliative intervention suggests the potential efficacy of this programme for all individuals with a life-threatening illness. Indeed, Nedjat-Haiem et al. (2017) claim that starting a programme too late can mean participants become too ill to complete it, a position supported by Udo et al. (2017).

Given that individuals will self-refer to the new programme, Van Mechelen's (2012) criteria of 'needing additional care' is helpful, as is his discussion of a shared interpretation between individual and caregivers of their status as a palliative care patient. The *Live well, die well* programme is therefore available to any individual with a life-limiting, progressive illness who would like additional support, whatever stage of illness they are at.

What Curriculum Design Supports the Achievement of the Programme's Aim and Objectives?

Achieving the programme's aim and objectives is facilitated by a spiral, fluid curriculum. This enables individuals' interests to be followed and facilitates reflection and learning. However, this fluidity needs to be supported by a clarity of curriculum structure and content which enables programme facilitators to deviate from a sound holding structure with confidence. The multiple connections between storytelling, artmaking, illness, communication and living well have been established above and provide this sound structure. Whilst recognising their interdependence, the curriculum design artificially separates them to enable coherent programme planning and facilitation. The *Live well, die well* programme consists of three workshop series:

Workshop Series 1 – Arty Living: Living Well Through Artmaking

The 2017 inquiry by the All-Party Parliamentary Group on Arts, Health and Wellbeing evidenced the positive impact which the arts can bring to health and well-being. For those coping with a terminal illness, artmaking offers a way of taking control, continuing to make a mark on the world and can help combat fear and isolation (Gauntlett, 2011).

This series of workshops facilitates participants' discussion of existing artworks to extend experience and come to a deeper understanding of the world (de

Botton and Armstrong, 2013). It also supports participants in making their own art, offering the potential for life enrichment and peace (Malchiodi, 2007). Activities include critiquing *The Kiss* by Gustav Klimt and drawing a zentangle inspired by it, drawing an abstract poppy in response to a viewing of Georgia O'Keefe's poppy paintings and discussing the artistic merits of graffiti.

Workshop Series 2 – Gripping Yarns: Living Well Through Storytelling

Men and women are essentially storytelling beings (MacIntyre, 1985), with storytelling seeming to be a natural response to illness (Broyard, 1992). As such it can enrich the lives of those living with a terminal diagnosis, building communities of individuals who understand and support one another (Frank, 2016). This series of workshops supports participants in using words to mine the depths of life, re-draw life maps and find new destinations (Frank, 2013).

Activities include reading and writing of haiku poetry, fables and 50 word stories, both individually and as collaborative group projects.

Workshop Series 3 – Life Rivers: Living Well Through Talking About Life and Death

Numerous studies confirm that honest, sensitive communication about end-of-life issues is very important to those with a life-limiting illness (Anderson et al., 2013), supporting patient understanding, subsequent decision-making and wider quality of life (Evans et al., 2014). The increased stress and health issues for families who avoid talking about death and dying with their loved ones is also clear (Garland & Garland, 2001). However, such open communication is often difficult to achieve. This series of workshops facilitates participants' exploration of life and death through using the metaphor of the flow of a river to explore significant life events (Simić et al., 2017). The depth of reflection which can be encouraged through this metaphor (Taylor, 2011) enables participants to explore how to talk with loved ones about their own life and death. Whilst drawing on a life review process, this workshop series does not promote the systemic approach to seeking resolution of past issues central to life review (Jenko et al., 2007). Instead, it sites memories of the past in the context of the present and uses these to support the planning of future, potentially difficult, conversations.

Activities include the drawing of a life river, plotting memorable events, reflecting on and discussing their meaning and developing strategies to share meanings of the past, present and future with others.

All workshop series take place over four weeks, with a 1-hour online workshop per week. I will initially facilitate all workshops, which can be accessed as a complete programme, in any order, or as a one-off, stand-alone experience. In

the last session of each workshop, time is devoted to exploring how participants might set up their own online mutual support community, if they so wish.

How Will the Programme Be Evaluated?

I needed to consider at this planning stage the evaluation methods I will use to determine the effectiveness of the programme. Clear evaluation will allow me to share learning across the palliative care field. Many palliative care evaluation tools do not appear to take adequate account of the breadth of patient perspectives on living well (McCaffrey et al., 2016). Indeed, there is little agreement about the efficacy of particular outcome measures (de Silva, 2014), perhaps due to the obvious difficulty of ‘measuring’ such a complex set of beliefs, feelings and experiences (Bausewein et al., 2011).

I intend to use patient-centred outcomes measures (PCOMs), as this aligns both with person-centred care approach promoted by National Health Service England (2021) and the programme’s aims. Albers et al. (2010), although noting the lack of sufficiently validated instruments, found the McGill Quality of Life questionnaire to have evaluatory merit with palliative care patients. Although not specifically focused on palliative care, I was also interested in Poulos et al.’s (2019) use of the Warwick–Edinburgh Mental Health and Well-Being Scale (WEMWBS) to evaluate their arts-on-prescription programme. Whilst scientific research provides the frontline in our fight against the pandemic, the insights which qualitative research can bring to an understanding of the impact of widespread infectious diseases (Vindrola-Padros et al., 2020) are also highly valuable at this time. An approach which combines both quantitative measures and qualitative insights should lead to the development of a rigorous evaluation approach for the *Live well, die well* programme.

Moving Forward

In 2000, Byock pointed out the need to develop innovative ways of providing palliative care. This need has been rendered even more urgent by the COVID-19 pandemic. The *Live well, die well* programme has emerged from the opportunity technology offers us to provide alternative forms of support to those with life-limiting illnesses. In facilitating an arts-based exploration of life, in preparedness for living well and for dying well, the programme adds to current palliative care provision. Its online nature means it is accessible during a pandemic and at any time for those who struggle to leave their homes. In supporting participants to set up their own mutual support groups at the end of the programme, it tackles the difficulty of fracturing new identities and friendships when patients are discharged from time-limited support programmes.

Cecily Saunders saw care, education and research as a triad which should underpin hospice policy and practice (Hartley, 2014). As a practitioner and

researcher, this interconnection resonates with me. The dual activities of facilitating the programme and researching its impact on the extent to which its participants can live and die well are my next challenge.

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Author Biography

Amanda Roberts, pedagogic and professional knowledge has been developed through experience in a variety of educational roles, including leadership positions in four secondary schools culminating in headship. She subsequently formed a successful consultancy company, providing support for leadership and learning in numerous contexts. She went on to hold a variety of roles at the University of Hertfordshire, UK which supported the development of her expertise in diverse areas such as quality enhancement and curriculum design. Building on a breadth of research and publications in the area of distributed leadership, her recent research focuses on how to support the development of agential leadership and positive self-image in individuals with a life-limiting illness.