Dying-well: The contribution of leisure services to hospice care

Leisure has suffered a neglect in the palliative care literature, with clinically driven narratives often overlooking the pivotal role leisure plays within this landscape. A problem inherent in much of the existing literature is that although scholars agree about the blending of hedonia and eudaimonia, the lines between them are blurred. Therefore, this paper contributes to the existing literature by fleshing out the middle ground of the hedonia and eudaimonia continuum. Here, the authors’ term this point of equilibrium *transitional leisure*, which projects a liminal state of well-being. Interview data is collected from in/day/out-patients, families, and the bereaved (n=140) associated with multiple hospices (n-5). Findings detail the contribution of therapeutic services, therapeutic spaces and therapeutic places to well-being. Conclusions add a further dimension to the well-being literature, an appreciation of ‘dying-well’ and the middle ground of transitional leisure. Practical implications for enhancing service delivery are presented.

Keywords: hospices; hedonia; eudaimonia; well-being; therapeutic landscapes

# Introduction

Palliative care services, like other healthcare providers, deliver a service to their users. Care might be delivered at a hospice site, at home or in palliative care hospital based units. The World Health Organisation 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’ (WHO, 2015). To date, little attention has been afforded to the contribution that leisure makes within this environment, the focus more traditionally upon the clinically driven, bio-medical (disease and illness) narratives dominating this landscape (Young et al., 2018). Making the last stages of life as good as possible is a desirable state so that ‘every dying person (…) can live in anticipation of a good death’ (Department of Health, 2016, p 6). Moore et al., (2013) for instance focussed on day care patients (i.e. those that are invited back to a hospice for a day) and found that patients can initially feel lost and alienated when entering a hospice, only to feel more comfortable over time.

Outside the palliative care landscape multiple studies highlight the pivotal role leisure can play within health. Studies for instance have examined therapeutic recreational opportunities (Anderson and Heyne, 2012), the connection of nature, leisure and well-being (Cleary et al., 2017), the adoption of leisure to promote health and well-being (Henderson, 2014), the transformational capacity leisure offers to well-being (Kleiber et al., 2002), the relationship between leisure, physical health and mental well-being (Kim et al., 2018) and the link between domestic animals and leisure (Young and Carr, 2018). Collectively, these studies position leisure as contributing to a ‘living-well’ narrative.

 Within well-being, two concepts have dominated the literature; namely hedonia and eudaimonia (see e.g. Huta and Ryan, 2010; Huta and Waterman, 2014; Kay Smith and Diekmann, 2017. The former refers to pleasure, happiness and enjoyment, whilst the latter entails the implications of self goal pursuits and self-actualisations (Rahmani et al., 2018).

 Well-being is at the crux of hedonia and eudaimonia and individuals grapple and oscillate within a liminal state faced with psychological, social and physical challenges. The constant ebb and flow of hedonia and eudaimonia is what characterises well-being as a very fluid concept and thus, both concepts must be viewed in tandem and not separately. However, a problem inherent in much of the existing literature is that although some scholars agree about the blending of hedonia and eudaimonia (e.g. Lee and Jeong, 2019; Sharma et al., 2017) the lines between them appear blurred. Indeed, critics of the hedonia and eudaimonia distinction support the idea that there is much value in examining the similarities between the two as well as their differences (Lee and Jeong, 2019). Thus, this paper contributes to the existing literature by fleshing out the middle ground of the hedonia and eudaimonia continuum. Here, the authors’ term this point of equilibrium *transitional leisure*, which projects a liminal state of well-being. Individual self-goals and sense of self for example would seem to be in a constant state of flux. They are neither here, nor there and are betwixt and between (Turner, 1974). Contrary to scholars who claim that hedonia is an outcome of eudaimonia (e.g. Huta and Ryan, 2010; Huta and Waterman, 2014; Rahmani et al., 2018), a state of transitional leisure acts as a level playing field. That is, individuals might have positive or negative experiences but not fully capitalise on their own self-goals to achieve a fuller state of eudaimonia. Yet at the same time, they may feel a sense of achievement or paradoxically a sense of resentment or guilt (should the experience be a negative one).

The paper is structured as follows: first, the concepts of hedonia and eudaimonia are discussed followed by literature linked to well-being, palliative and end-of-life care and leisure. The research methods and analysis are then detailed. Findings follow which are structured into three themes: therapeutic services, therapeutic spaces and therapeutic places. The paper ends with concluding comments and implications for service delivery.

**Literature review**

***Conceptualising hedonic and eudaimonic well-being***

 Two traditions have long dominated well-being discussions. The first tradition is hedonia. In this narrative, philosophers such as Aristippus and Bentham associate hedonic well-being with the minimisation of pain, as well as pleasure and enjoyment (Ryan and Deci, 2001). Tenets associated with more recent understandings of hedonia include appreciating the present (Huta, 2016), being at peace with surroundings, pleasure derived from enjoyable or satisfying activities and lower negative affects such as anger or restlessness (Waterman, 2008). Therefore, emotions within hedonia are a reactive response to environmental stimuli such as consumption objects, events, life histories, and the influence of other individuals (Huta and Ryan, 2010; Huta and Waterman, 2014).

 The second tradition is eudaimonia. This is favoured by philosophers such as Aristotle. Well-being is viewed as living purposefully and living in accordance with ones’ personal values (Norton, 1976). It is associated with engaging in meaningful activities, being self-reflective, developing ones’ best potential, and being virtuous (Aristotle, cited in Broadie and Rowe, 2002). From a similar perspective, Sharma et al. (2017) view eudaimonic well-being as individual attempts to continuously better oneself in order to be able to experience and exercise individual potential, purpose in life, personal growth or self-realisation, strive for excellence, autonomy, and good relationships with others (Huta, 2016; Huta and Waterman, 2014). In this way, when individual selves are repeatedly challenged, a sense of ‘life purpose’ evolves as a result and individuals experience greater authenticity (Laing and Frost, 2017).

 A further line of inquiry advocates well-being as relational. Here, well-being is not seen as belonging to an individual but instead emerges during encounters with other people, objects, and places (Atkinson, 2013; White, 2017). Sharma et al. (2017) also observe three types of roles that involve individuals co-creating with each other. These are: co-producer, strategic partner and community citizen. All three roles have hedonic and eudaimonic well-being outcomes. Individuals might participate in an experience, a service or activity and experience pleasure, which heightens the more they become involved. An organisation or provider of this pleasure can augment the level of participation and thus contribute to enhancing eudaimonic well-being. As a strategic partner, individuals participate for the purpose of benefitting others and encourage them to reach their self-fulfilment goals. This permits a sense of emancipation while co-creating together and along with it, comes happiness and pleasure. For community citizens, here individuals attempt to enhance access to an experience, service or activity. For example, Sharma et al. (2017) reference the reduction of stigma associated with mental health services. Thus, a sense of community allows other individuals to be better informed, make better reasoned choices and greater autonomy over their overall well-being.

When considering the dying well narrative, existing research would seem to focus on more formulaic leisure contexts, whereas a paucity of studies have discussed well-being in relation to palliative care and indeed death in relation to hedonia and eudaimonia. This is of some concern, particularly as there are service users who frequently experience aspects of leisure whilst receiving care. Stewart, et al., (1999) interpret aspects such as psychological well-being and social functioning differently when considering patients and families at the end of life. There is a greater emphasis on immediate self-esteem for example. Closeness to others, finding daily activities meaningful, having privacy, being able to make choices, accepting circumstances, and feeling at peace are also considered important (Stewart et al., 1999). Other authors (see for instance Kellehear (2013)) question well-being, finding depression, isolation, stigma, and spiritual dilemmas to represent some of the multiple challenges at this end of life stage. Taken together, these studies signal that leisure provides some source of self-fulfilment. As Graham (2011) suggests, those with limited agency, as is the case in palliative care, are more likely to experience hedonic well-being by focusing on the more immediate, day-to-day considerations. In contrast, insights from other literature resemble tenets of eudaimonia (see for example Rahmani et al., 2018). Lavoie et al. (2011) for instance, consider how autonomy is experienced by attendants of a palliative care day centre. Issues such as feeling too dependent on others when capacities decline can evoke undesirable feelings. Nonetheless, having supportive and close relationships with others, having values and choices respected, and maintaining hope, are significant.

Common throughout the literature is a sense that when terminal illness strikes, ways of living change, values change, and once insignificant things become more important (Morris et al., 1986). This temporal dimension to well-being is often overlooked in existing conceptualisations of hedonia and eudaimonia. As Beng et al. (2015) note in their study of in-patients in a Malaysian hospice, happiness can be experienced from reflecting on life achievements. Supportive communications with family and friends, experiencing less pain, engaging in activities such as sleeping, eating, praying, cleaning and exercising are also meaningful as they generate a sense of normality (Rasmussen and Edvardsson, 2007). Having discussed hedonic and eudaimonic well-being, the next section examines how leisure experiences affect health outcomes.

***Leisure and health***

 It has long been recognised (see for example; Hull, 1990; Iso-Ahola, 1997; Kim et al., 2018; Mannell and Kleiber, 1997) that leisure experiences, active and passive, induce positive moods, improve cognitive functioning in humans, especially the elderly, reduce depression, improve self-esteem and self-concept and can have a beneficial effect upon various medical problems commonly associated with the sedentary lifestyles of modern industrialised society (Iso-Ahola, 1997). Indeed, Iso-Ahola (1997) further contends that leisure influences health in two principal ways: ‘…first, in and of itself, leisure is conducive to health. The mere existence of leisure in a person's everyday life has consequences for health (…). Another way is where leisure is used as a tool to achieve certain outcomes…’ (p 132). For Iso-Ahola (1997), both leisure and health vary on a continuum; some leisure experiences are more valuable than others and some illnesses are more problematic than others.

An increasing volume of research acknowledges the role that different leisure pastimes may play in the rehabilitation process and their sub processes such as physical (Davies, 2018; Denovan and Macaskill, 2017; Duquette et al., 2016) and cognitive (Duquette et al., 2016; Hood and Carruthers (2007). Indeed, Carruthers and Hood (2007) argue that by participating in leisure activities, individuals can enhance their own personal capacities and resources that are relevant to their own sense of meaning making and personal growth. Several studies have also documented psychological benefits of leisure activity (Lundberg et al., 2010; Szabo, 2013; Szabo et al., 2018) and social benefits (Duquette et al., 2016; Iwasaki et al., 2013, 2015).

 Positioning the hospice as a homely environment adds a sense of familiarity and normality. Within this familiar setting for dying/death, objects are also found to be particularly valuable for creating a sense of familiarity and homeliness (Kellehear et al., 2009). Whether this be bedside objects (Kellehear et al., 2009) including photographs (Collier,et al., 2015), personal clothes and bathroom items to CD players and books (Hilário, 2016). Each play a symbolic role. Photographs for instance, bring comfort and can serve as a reminder of other times and places, whilst the arrangement of flowers or careful handling of clothes are emblematic of support (Cleeve, et al., 2018).

Moore, et al., (2013) interprets leisure when drawing upon the concept of ‘therapeutic landscapes’ to explore ‘home’ within hospice day care. Therapeutic landscapes ‘are those changing places, settings, situations, locales, and milieus that encompass the physical, psychological and social environments associated with treatment or healing’ (Williams, 1999, p, 2). Moore et al., (2013) argues that day care patients, who initially feel lost and alienated upon entering a hospice, become more comfortable over time. Relationships with other people, objects, and places to relax and rejuvenate, become appreciated, contributing to a sense of safety, positivity, and purpose (Moore et al., 2013). In turn, patients are able to ‘venture’ (ibid, p155) to some extent and move forward in a meaningful way, whether that be by undertaking new opportunities, making new friends, having complementary therapies, or avoiding places associated more greatly with dying. What is less clear and as will be argued in this paper is what hedonic and eudaimonic well-being looks like during this life stage and whether or not there is a middle ground on the hedonia and eudaimonia continuum. Next, the palliative and end of life care landscape in the UK is charted before moving on to discuss the study methods. This is followed by the findings and discussion sections.

***Understanding the palliative and end-of-life care landscape***

In the UK (the study location), recognition of the particular characteristics of this landscape in support of a ‘dying well’ narrative has been marked by a number of influential documents in the UK over the past decade, well-being an integral part of each (see for instance The Choice in End of Life Care Programme Board, 2015; Parliamentary and Health Service Ombudsman, 2015; Department of Health, 2016). Collectively, these documents provide valuable insights into the range of people and technologies acknowledged as important in supporting palliative care. This dying well narrative recognises that experiences of palliative care are impacted by aspects which are not commonly apparent in other areas of healthcare i.e. psychosocial, spiritual, and holistic support for instance.

 There are over 200 hospices in the UK, supporting around 120,000 palliative care patients annually and receiving an average of 34% of their funding from the government with the rest coming from fundraising (Hospice UK, 2015). Hospices aim to provide emotional and physical comfort to patients as they reach the end of their life, taking a holistic view of the needs of the patient and their family (Department of Health, 2016). Admission into a hospice implies that the patient's focus has shifted away from curing an illness, towards acceptance of end of life, leaving them with hope (Hospice UK, 2015) for the best quality of life in their final days (Myers, 2002; Waldrop and Rinfrette, 2007).

Literature suggests that having support from others, having respectful relationships with carers, and being able to still set and reach goals fosters hope (Buckley and Herth, 2004). This is contrary to problems such as being in pain, or experiencing isolation from poor communication (Buckley and Herth, 2004). In summary, it is clear that there is much to be unearthed from more closely examining hedonia and eudaimonia in palliative care in an under researched leisure context (Young et al., 2018). Having reviewed the literature, the aim of this paper is to therefore better understand the relationship between leisure and palliative care and its contributions to the well-being of those experiencing palliative care. Few studies have problematised the dominant clinical narrative of ‘dying well’. A second aim is to examine the fluidity of hedonia and eudaimonia. Within the literature to date, there are polarised views toward both concepts. Some scholars agree about the intermingling of hedonia and eudaimonia and that the latter follows the former (e.g. Beng et al., 2015; Lee and Jeong, 2019; Rahmani et al., 2018; Sharma et al., 2017). Contrary to scholars who claim that hedonia is an outcome of eudaimonia (e.g. Huta and Ryan, 2010; Huta and Waterman, 2014; Rahmani et al., 2018), we observe a state of *transitional leisure* which acts as a level playing field. That is, individuals might have positive or negative experiences but not fully capitalise on their own self-goals to achieve a fuller state of eudaimonia. Yet at the same time, they may feel a sense of achievement or paradoxically a sense of resentment or guilt (should the experience be a negative one). The next section explicates the study methods, before moving to the findings and discussion sections.

**Methods**

 This study examines the contribution of leisure to the well-being of those experiencing palliative care. It draws upon data collected within a multi-site study designed in collaboration with five hospices who are geographically dispersed throughout the UK. Full ethical approval was granted for each unit through a University Central Ethics Committee. Three independent researchers collected qualitative, in-depth ‘interview’ data (n=140) within these units with patients, family members and also the bereaved.

 An adaptation of the seven point Touchpoint Trajectory Technique (TTT); a methodology for mapping out the patient and family journey which has previously been applied within palliative and end-of-life care environments was developed by Sudbury-Riley et al. (2020). The TTT affords patients the opportunity to tell their (untainted) story from their own perspective and permits the researcher to gain more rich and in depth qualitative insights. A full discussion of the development and testing of the technique falls outside the scope of this paper. Please refer to Sudbury-Riley et al. (2020) for further detail. A limitation of research into palliative care is that studies tend to rely on retrospective views of family members (the bereaved) (Lendon et al., 2015) and therefore miss out on narrative accounts of those patients receiving end of life care. There is also a recognition that it is difficult to fashion an empirical tool that is “feasible, actionable, and patient centred to directly assess the patients’ perceptions of hospice or palliative care” (Meier, 2011, p.352). In this regard, the TTT was easy to use for all hospice patients, regardless of illness.

Initially, the researchers paired up to conduct the first five to six ‘interviews’ together in each setting so as to ensure, as far as practical, a consistent data collection style occurred throughout. Given the goal of listening to service user voices, the ‘interviews’ were deliberately structured as conversations around a set of pictorial prompt ‘touchpoint cards’. These prompt cards utilised clip-art pictures, cartoons, or easy-to-recognise signs and symbols to act as an aide-memoir for users as they told their story of their hospice care. They were designed to reflect the different tangible and intangible aspects that service users would commonly come into contact with during the service delivery process. The seven distinct sets of ‘touchpoint cards’ comprised: *pre-arrival; arrival; clinical care and support; facilities; shared spaces; little extras; discharge and aftercare.*

The conversations began by inviting participants to ‘tell us about how you are today’. This was designed to provide an opening and contextual setting for the interview. As the researchers moved from card to card, two specific questions were asked: ‘What happened next?’ designed to move the story along the journey of hospice care; and ‘how did that make you feel?’ designed to gain a deeper understanding of the significance and meaning of the comment offered. Whilst well-being data was embedded throughout conversations, the most relevant to the questioning of leisure services emerged within the ‘shared spaces’ and ‘little extras’ touchpoint cards in particular.

 Purposive sampling was used (Morse, 2006) to collect data on-site from all categories of participants utilising the service (n=140) i.e. day patients, out-patients, in-patients, discharged outpatients, families and the bereaved (see Tables 1 and 2 for demographic data). Some of the hospices were located across the UK in leafy suburbs serving high socioeconomic groups and some in inner cities that are significant for health inequality gaps. The enlisting of hospice organisations came about through referrals after others had heard about the study and expressed interest to participate. Each hospice also acted as ‘gatekeepers’ and handled the recruitment of participants. Their gatekeeper role was relevant insofar as determining which patients were well enough to take part. The researchers provided all the information about the study to the hospices such as participant information sheets and consent forms.

Conversations lasted on average from around forty-five minutes to an hour long, the timing entirely participant led, in-line with ethical approval. All transcripts were anonymised using either letters or numbers and securely stored on a University password protected drive, thus making it impossible to relate back to an individual participant. Conversations were recorded (with permission) and then immediately destroyed after transcription (which was two weeks after interviews had taken place). The transcripts were only accessible by the authors. A minimum of twenty participants were sought, per setting, cognisant that the data offered saturation and similar common themes across the organisations around this point Sudbury-Riley et al. (2020).

Following the lead of Braun and Clarke (2006) the data was coded via a manual thematic analysis in six distinct phases including (familiarisation with the data, generating initial themes, (free themes), searching for themes, reviewing of themes, defining and naming themes and producing the manuscript). In phases two to four, core and sub-themes were identified by each of the researchers individually. To check for thematic consistency, the dominant themes were collectively discussed in phase five by three of the researchers. For example, there was some disagreement over the placement of ‘spiritual support’. Therefore, a cross-check coding approach was performed, which helped to minimise potential bias (Guba and Lincoln, 1994) and it identified that spiritual support for instance would be better placed under ‘therapeutic places’ given that it was used not just as a space but also as a place of worship.

**Findings**

Of the 140 participants in the study sample, 67% were female and 33% were male. Most participants tended to be 65-74 years old (29%) and 27% (those aged 75+). The vast majority of these age groups tended to be either inpatients, day patients or outpatients. Table 1 and 2 provide more details on the definitions of these patient groups and also demographic information.

INSERT Tables 1 & 2 here

The findings which follow celebrate the non-clinical leisure services available for hospice service users. Common points of reference which emerged where linked to a number of areas: arts therapy; music; feel-good treatments; feel-good services; relaxation services; spiritual support; and shared spaces. These are reviewed under three themes: therapeutic services, therapeutic spaces and therapeutic places. Participants also identified gaps in service provision, highlighting opportunities pivotal to well-being which would enhance service design and delivery.

***Therapeutic services***

*Feel-Good Services*

*Art therapy*

 All of the five hospices advocated a combination of either day hospice services, art therapy, baking options, music, animals, trips out, relaxation services such as Tai Chi and Yoga and Jacuzzi and Spa treatments. For many, these options provided a sense of pleasure, self-nourishment and self-care. With art therapy for example, many patients commented about the way that art allowed them to express themselves but also how it allowed them to foster closer friendship ties with others. As underpinned in the following quote: ‘*I like the painting and I did that and I made new friends. It was fabulous’* (inpatient 4, hospice unit 3). Here, the effects of hedonia begin to shine through the patients’ willingness to find aspects such as art therapy enjoyment. It also signals a move to eudaimonia with the wider aim of establishing friends, taking a sense of responsibility on board in co-creating activities in the hospice as well as elevating patients to find meaning in new accomplishments. Many of the patients had never encountered art therapy or indeed deemed themselves ‘non-artists’ beforehand. However, regardless of artistic flair, the emphasis was on making connections with others and not the art therapy itself.

*Baking*

 A similar sentiment was experienced in the leisure of baking. In many cases, patients had never baked before. As lamented in the following quote: ‘*I’ve never baked in my life, and we’ve had such a laugh’* (inpatient 2, hospice unit 1), enjoyed by all participating. Baking as a therapeutic and hedonic mechanism provided the impetus for patients to once again network amongst each other and share their own life histories and experiences; both of which point in the direction of heightened psychological and social aspects of eudaimonia.

*Music*

 Music too helped to raise the spirits of many. The following quote is typical of many others: **‘***He does music therapy, and it’s wonderful (…) he’s doing something he enjoys, he likes music’* (relative 3, hospice unit 3)*.* Music seemed to ignite a unique vibe to the hospice and like other feel-good services, brought pleasure and enjoyment. In one setting, a music band brought great support: *‘Yes in fact we have got somebody coming in this afternoon to er, they play the guitar’* (day patient 1, hospice unit 5)*.* Like other feel-good services, retention for music therapy was high with many patients revelling to hear more music bands. Music functioned as a form of emotional escapism and acted as a cognitive decoy in providing symptomatic relief from pain. This form of hedonia like other feel-good services extended to eudaimonia as patients appeared to use music to channel their experiences via get social get together’s with others and a minority, who preferred listening to music in their own space, found solace in music allowing them to reflect on the past and also their life achievements.

*Animals*

 Several of the hospices examined had their own animals. These animals brought comfort and functioned as a close friend to others. This is exemplified in the following quote: ‘*I had a doggy visitor yesterday, she sat here by me, she was lovely’* (inpatient 1, hospice unit 4)*.* Some hospices even had chicks and would enlist patients to help them through their hatching journey come Easter. Others had dogs and/or rabbits. In any case, animals brought a sense of pleasure and satisfaction. They instilled confidence in patients by providing companionship. Patients appeared to feel overjoyed in their presence. Such as was the symbolic nature of animals that, in some instances, patients felt temporarily suspended from any pain woes whilst interacting with them and eudaimonia was experienced in feeling a sense of ownership and self-responsibility in contributing to their looking after.

*Trips*

 Trips out were also appreciated. These included trips to the beach, nature parks amongst others. Trips out helped further develop friendships and gave patients something to enjoy and look forward to participating in. This sentiment is reflected in the following quote: ‘*I mean they do these lovely outings as well which is really nice (…). And you’re well supported and cared for (…) it was really good. It’s a special disabled boat and it was really good’* (day patient 9, hospice unit 3)*.* As a feel-good service, trips out provided a sense of escapism from the norm (i.e. the hospice environment) and brought eudaimonia via social and psychological well-being.

*Relaxation Services- Tai Chi, Yoga*

 Patients welcomed opportunities to take part in classes where Tai Chi and seat yoga were offered, as expressed in the following quote, which is typical of many others: *‘Yes Monday mornings I come to yoga (…) I think it is really good’* (bereaved family 4, hospice unit 1)*.* Tai Chi and Yoga also afforded patients the opportunity to reflect on their inner being with many commenting that they did not expect it to be so enjoyable. They also allowed patients to defy their own expectations of exercise (particularly for several who had not experienced Tai Chi or Yoga before).

*Reading*

Whilst reading traditionally was recognised as a relaxing leisure pastime, seldom was a library facility popular. Probing as to why this may be the case revealed a recurring theme. Illness had reduced the amount of reading it is possible to enjoy: ‘*She loves reading but she can’t as she can’t concentrate anymore’* (relative 4, hospice unit 3). Indeed, concentration was an issue that came up time and again, prompting discussions around possible alternatives to reading. Notions of self-fulfilment were detected in the use of books and talking books in either a shared space or individual space: ‘*Talking books…would be nice’* (inpatient 5, hospice unit 4).

*Jacuzzi and spa treatments*

Well-being was also enhanced through the range of tangible amenities available. These were unit specific and included a Jacuzzi bath in more than one unit, which was readily appreciated. The following view expressed by a relative exemplifies the sentiment of other relatives toward family members receiving palliative care:

*She feels safe here (…). She hasn’t been able to have a bath or anything (…). She came here and they give her the lovely Jacuzzi every day. So little things that we take for granted mean a lot when you, I mean, she is terminally ill* (relative 3, hospice unit 2)*.*

 For many, spa facilities provided a sanctuary: *‘She absolutely loved the aromatherapy’* (bereaved 4, hospice unit 2), ‘*It feels lovely’* (inpatient 8, hospice unit 2) with access to such all too brief as the words of one bereaved relative indicate: ‘*Yes, he loved that. It wasn’t enough, you don’t get enough time’* (bereaved 1, hospice unit 2). Massage sessions also proved to be popular among inpatients: ‘*I had a massage, things I never knew existed! (...) It seemed very nice’* (inpatients 1-3, hospice unit 1). Multiple outpatients discussed the pleasure of receiving massages at their will when in the hospice centre. For example: ‘*They come round and do your arms and shoulders whenever you want’* (outpatients 7, hospice unit 1). These seemingly luxury activities appear in high demand amongst patients, but many were too sick or did not have the time to experience them. For the lucky few who had the opportunity to sample spa facilities, they brought a sense of conspicuousness to their hospice stay. That is, they functioned as a leisure site of luxury and an aspirational place to reach for many.

*Personal Grooming Services- Beauty treatments and hair care*

 Like spa facilities, beauty treatments, too, were welcomed by many service users for their feel-good effects. The following comment was typical: ‘*she loves coming down and getting her nails (…) done and that has cheered her up in some ways’* (relative 2, hospice unit 2). Hair care was particularly dominant in conversations, with access to hairdressing services varying considerably. Where absent, patients longed for a mobile hairdresser: ‘*she was always fussy about her hair (…) she would say look at the state of my hair!’* (bereaved 4, hospice unit 2)*.* Relatives also worried that their male relatives were not getting shaved properly: ‘*I sometimes think he could do with a proper shave which he doesn’t get’* (relative 2, hospice unit 3).

 For some, there was a reluctance to use haircare treatments because of illness or worries about what the products may contain: ‘*She is very nervous about any beauty products, and I think she has the impression that the girl responsible for the hair salon isn’t as nervous about the health products as she is’* (relative 7, hospice unit 2). Reluctance also stemmed from a worry about being disloyal to a regular hairdresser: ‘*She will do my hair in July before I finish. She said I don’t want to step on your hairdresser’s toes’* (outpatient 6, hospice unit 2). Beauty and hair services on the whole typified hedonia, yet for the loyal few, a sense of eudaimonia as patients recalled familiar hairdressers whom they were comfortable with. Similarly, such feel-good services created symbolic meanings for patients and, despite their own illnesses, they found solace in looking and feeling beautiful.

***Therapeutic spaces***

*Shared Spaces*

*Family Rooms and day rooms*

 Shared spaces outside patient rooms, wards and day centre facilities were pivotal to enhancing well-being. Such included multiple leisure opportunities: family rooms, commonly furnished with toys, contributed to keeping children and grandchildren entertained. The importance of family rooms and day rooms went some way in providing entertainment and collaborative bonding amongst fellow patients. It also permitted comfort and allowed patients to feel appreciated and well looked after; almost mimicking the home environment. Such views are reflected in the following quotes: ‘*There’s loads and loads of toys and she has to look at absolutely everything all the time’* (relative 11, hospice unit 5)*; ‘Our Louise was only little (…) so the room for the kids (…) very helpful’* (bereaved 3, hospice unit 5)*.* The day room was also appreciated as a good social space: *‘I think it’s very good. And I think like they get to know each other. They talk with each other. And they don’t just sit here looking at each other. They’re talkative, friendly. And have a laugh. Good laugh’* (inpatient 6, hospice unit 2). Many visitors reflected upon how the facilities enabled them to feel comfortable, even when patients had a lot of visitors at once: *‘Well I like it, and I think Julie likes that hustle and bustle, but yeah, I know Julie likes that’* (relative 1, hospice unit 4)*.* Beyond providing comfort and recreating aspects of the home environment, such shared spaces helped contribute to eudaimonic well-being and specifically aided symbolic interactions with others, self-realisation and they afforded patients greater autonomy in the hospice.

*Garden spaces*

Like the family room and day room, external spaces were particularly appreciated. One bereaved for instance, voiced their pleasure over the beautiful gardens they had easy access to:

***‘****you do appreciate the surroundings (…) it is nice to have the lovely gardens’ (day patient), ‘We’ve had massive comfort from the gardens. We used to wheel mum out into the gardens (…). For me, the garden is special’* (bereaved 8, hospice unit 3)*.*

*C*ourtyard space was acknowledged as just as important, recognised as peaceful and lovely to look out onto: ‘*We used to sit in the courtyard and here and watch the birds as he loved nature and all that’* (bereaved family 5, hospice unit 2)*.*

Shared spaces also helped prevent feelings of isolation: *‘In the day room it’s very nice. It has chairs in the top half where we all sit around and then a table in the bottom half’* (day patient 4, hospice unit 4)*.* However, not all service users had positive experiences of socialising with other patients. For some, this was due to personality, illustrated by comments such as: ‘*she was not particularly social’* (inpatient’s family 6, hospice unit 3)*.* For others, problems arose because their illness caused communication difficulties, or more often because some found it difficult to watch other people decline:

*I made some really good friends who have sadly passed away, so I tend to shy away from going to a set group now, it is hard watching people decline as you get better and move on, as I say, I made a couple of really good friends so it was really difficult* (discharged outpatient 4, hospice unit 2)*.*

 It is moments likes these where patients faced illness complications and difficulty in watching others decline that blur the lines between hedonia and eudaimonia. The findings signal that when health deteriorates in particular, it becomes less clear when hedonic and eudaimonic feelings begin and end and if and when they do start again.

***Therapeutic places***

*Spiritual Support*

 This is a crucial area for some people in their everyday lives, the following comments echoing common narratives here: ‘*She is religious (…) so that is important to her’* (relative 1, hospice unit 3)*.* The on-site location of a spiritual place was appreciated by many for reasons shared here:

*Yeah. I mentioned something about when you get plagued with a lot of illness you don’t always feel like keeping your faith up. But it hasn’t escaped me completely. And being here with there being a chapel in here it’s been able to put a few things into context for me. Give me a bit more spiritual awareness that I’d lost* (inpatient 4, hospice unit 1).

 Fear was a common emotion: *‘I’m frightened of dying. So I’ve spoken to the chaplain here which has been lovely’* (inpatient 1, hospice unit 1). Evidence of spiritual needs being accommodated was frequently provided: *‘the chapel is nice because you can share communion if you want to or just be in that little space. I’m grateful for that and the people who do that’* (day patient 3, hospice unit 4)*.* People described chapel facilities as ‘*quiet’* and *‘peaceful’* places, appropriately pitched: *‘I took comfort in it (…) some people like to light a little candle’* (relative 5, hospice unit 2). Whilst a number of service users talked about using chapel facilities on-site: ‘*It has become important to mum, the chaplain has visited her every day. And mum has found a lot of comfort from that’* (relative 2, hospice unit 3)*,* it was much more common for patients to appreciate their presence than necessarily utilise them. For those who did not use the chapel, many had been visited by the Chaplain, who provided an introduction that was not overbearing to those who are not religious: ‘*Did not push themselves on you’* (inpatient 3, hospice unit 1).

**Discussion**

The aim of this paper was to better understand the relationship between leisure and palliative care and how it contributes to the involvement and well-being of those experiencing palliative care; an under researched and unusual context when compared to much of the existing literature. Few studies have problematised the dominant clinical narrative of ‘dying well’. Therefore, this paper adds a further dimension to the well-being literature via an appreciation of the contribution leisure plays within the ‘dying-well’ narrative. It has done this by drawing upon extensive empirical data collected from palliative care environments i.e. hospices, giving a voice to hitherto largely absent service users.

Connecting service experiences to a leisure narrative permits a move beyond traditional clinically focused narratives and helps to make sense of what hedonic and eudaimonic well-being looks like in palliative care. With this in mind, a second aim was to examine the fluidity of hedonia and eudaimonia. Within the literature to date, there are polarised views toward both concepts. Some scholars agree about the intermingling of hedonia and eudaimonia and that the latter follows the former (e.g. Lee and Jeong, 2019; Sharma et al., 2017). The findings from the current study detect that hedonic well-being, which is commonly associated with the minimisation of pain, and associations of happiness as pleasure and enjoyment, is found in narratives attached to shared spaces and the uptake of relaxation treatments and services. In hospice care, the influence of family and friends is found to be pivotal to realising this form of well-being (Moore et al., 2013). Not only do previously acknowledged advocacy roles exist, but *all* service users have the potential to gain pleasure and enjoyment out of the services offered, be it massage, spiritual, or beauty treatments for instance. This inclusivity generated a calmness, a peace of mind for patients in particular, with many expressing more concern for their family and friends than necessarily their own circumstances. In turn, this positively impacted upon eudaimonia, often associated with engaging in meaningful activities, being self-reflective, developing ones’ best potential, and being virtuous.

However, this paper also observes that the lines between the two concepts are blurred. Enmeshed within the narratives of the hospice patients are moments and experiences which signal hedonia (e.g. experiencing feel-good services and which lead to some eudaimonia, yet at other times, patients are riddled with illness and neither encounter hedonia or eudaimonia. Thus, the term *transitional leisure* is offered by the authors to determine a liminal state of stasis. Here, patients are betwixt and between (Turner, 1975) and despite indicating a willingness in most cases to partake in hospice provided leisure services, their ongoing illness and sentiments toward them can prevent them. This does not mean that patients refute such leisure services but rather, they have more pressing priorities to grapple with. Therefore, a state of transitional leisure would seem to signal a temporary suspension of hedonia and eudaimonia or in other words ‘the middle ground’ between the two. Contrary to scholars who claim that hedonia is an outcome of eudaimonia (e.g. Huta and Ryan, 2010; Huta and Waterman, 2014; Rahmani et al., 2018), transitional leisure acts as a level playing field. This means that individuals might have positive or negative experiences but not fully capitalise on their own self- goals to achieve a fuller state of eudaimonia. Yet at the same time, they may feel a sense of achievement or paradoxically a sense of resentment or guilt (should the experience be a negative one). What is clear here is that because spiritual support like shared spaces and feel-good services are more transformational for different patients and at different points in their hospice experience, ill health and non-participation in leisure activities (whilst offered) leans toward a state of stasis. That is, feelings of hedonia and eudaimonia are not necessarily experienced simultaneously but are temporarily suspended whilst patients are in a liminal state of being. This temporary suspension can be restarted but only when patients feel ready and willing. Well-being is on their terms and thus, they possess the autonomy and individual agency to curate their own leisure experiences, regardless of whether the hospice provides such feel-good services, shared spaces or not.

On the other hand, this paper also observes that there can sometimes be an overload and influx of leisure services which contribute to some patients feeling a sense of guilt because they might not be able to take part. Within therapeutic leisure landscapes (Anderson and Heyne, 2012; Carruthers and Hood, 2007; Cleary et al., 2017; Hood and Carruthers, 2007; Moore et al., 2013; Williams, 1999) individuals can initially feel lost and alienated but they can become more comfortable over time. The current findings compliment this argument but by extension, reveal that patients can become overburdened with their own illness worries and overwhelmed by the plethora of leisure services on offer. Thus, feelings of alienation are grounded not just upon accessing leisure offerings but also during the leisure experience itself and specifically when individuals enter a transitional leisure state.

 The strengths of this study are embedded in the application of the trajectory touchpoint technique (TTT- a new methodology for examining patient and family experiences) in fleshing out important voices from service users experiencing palliative care. A further strength is the attention paid toward fleshing out what leisure looks like in palliative care and also theoretically, by fleshing out the middle ground between eudaimonia and hedonia. Like all studies, this one too has limitations. For example, it would be useful for future scholars to test our theorisations of transitional leisure, if only to flesh out further sub categories of it so that theorisations of the ‘middle ground, between hedonia and eudaimonia may be able to advance further. Since the dataset was collected from participants in UK palliative care units, further research might benefit from conducting a similar study in other international contexts. This would seem quite pertinent, as the meaning of leisure for those experiencing palliative care and also palliative care models may differ in other countries. Thus, a cross- comparison study involving several countries may invigorate the extent of eudaimonia and hedonia further and also assist in fleshing out transitional leisure further. As a final note on limitations, future studies could also examine ‘non participation in palliative care’ and why some users might choose to overlook it.

**Concluding comments**

 An aim of this paper was to better understand the relationship between leisure and palliative care and its contribution to the involvement and well-being of those experiencing palliative care. This paper observes that leisure services when embedded within therapeutic landscapes such as hospice care, do have the capacity to provide opportunities for the creation of relationship assemblages and induce a sense of belonging and vitality (Rasmussen & Edvardsson, 2007). Whilst they have been shown to have the capacity to contribute to different forms of well-being, be it psychological or social for instance, it is their contribution to emotional well-being which is amplified in this study and particularly worthy of further research investigations.

 Insights offered in this paper make a number of important contributions to theory and practice. Relating to aim 2 and having examined the fluidity of hedonia and eudaimonia, this paper detects that a state of transitional leisure acts as a level playing field between eudaimonia and hedonia. These findings may be useful to a variety of leisure services to help them adapt and implement changes in service delivery in order to make a difference to service users. For palliative care services, these opportunities might include establishing and operationalising systems with the capacity to: both offer ‘feel-good’ treatments such as beauty treatments, cognisant of the products utilised in them; communicate activity options to service users so that they are able to utilise their time fully during less structured group sessions; consider alternative information sources in the library e.g. audio books and books with large print; and communicate information about what treatments and services are available to all service users. Given the neglect toward leisure in palliative care (Yong et al., 2018), the contribution of leisure in this environment to well-being is considerable. For example, leisure services must recognise the importance of not overwhelming patients with too many services, but ensure equal access to them overall. Future research could also look more closely at offering sub categories of transitional leisure, particularly as leisure more broadly, is experienced at different points in time (Rahmani et al., 2013). This might help further cement closer conceptualisations of the middle ground between hedonia and eudaimonia.

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Table 1: Collaborating Organisations and participant profile (n=140)

|  |  |  |
| --- | --- | --- |
|  | **Participating Organisations** | **Service User Profile** |
| **Hospice Unit**  | **Alias** | **Area**  | **Funding** | **Services** | **In-patients (those admitted to the hospice)**  | **Day (those who return to the hospice for a day visit) & outpatients (those who return to the hospice for follow up appointments)** | **Relatives**  | **Bereaved family** | **Total** |
| 1 | Red Hospice | Towns N England  | 20% Govt.80% charity | Inpatient Unit; Outpatient center | 4 | 14 | 12 | 8 | 38 |
| 2 | YellowHospice | City NW England  | 40% Govt.60% charity | Inpatient Unit; Day center services  | 10 | 6 | 7 | 5 | 28 |
| 3 | Blue Hospice | Towns SE England | 11% Govt.89% charity | Inpatient Unit; Day hospice; Hospice@home  | 4 | 14 | 4 | 9 | 31 |
| 4 | Green Hospice | City NW England | 47% Govt.53% charity | Inpatient Unit; Day therapy unit; Hospice@home  | 6 | 4 | 6 | 5 | 21 |
| 5 | PurpleHospice | City NE England | 10% Govt.90% charity | Children’s Hospice with Inpatient Unit, Respite Services; End-of-Life Bereavement Suites | 1 | 1 | 13 | 7 | 22 |
| N=140 |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Hospice Unit** |  | **Age Range** | **Gender** | **Ethnicity** | **SEG\*** |
|  | N | Under 14 | 15-24 | 25-34 | 35-44 | 45-54 | 55-64 | 65-74 | 75+ | M | F | WB\*\* | NWB\*\*\* | AB | C | DE |
| **1** | 38 |  |  |  | 1 | 7 | 4 | 15 | 11 | 10 | 28 | 37 | 1 | 17 | 17 | 4 |
| **2** | 28 |  |  |  | 2 |  | 3 | 14 | 12 | 15 | 16 | 31 | 0 | 14 | 14 | 3 |
| **3** | 31 |  |  | 1 |  | 6 | 4 | 5 | 12 | 12 | 16 | 27 | 1 | 12 | 12 | 4 |
| **4** | 21 |  |  | 1 |  | 7 | 5 | 5 | 3 | 5 | 16 | 21 | 0 | 9 | 9 | 3 |
| **5** | 22 | 2 | 1 | 6 | 7 | 4 | 1 | 1 | 0 | 4 | 18 | 19 | 3 | 9 | 4 | 9 |
| **n** | 140 | 2 | 9 | 10 | 24 | 17 | 40 | 38 | 46 | 94 | 135 | 5 | 61 | 56 | 23 |
| **%** |  | **1** | **6** | **7** | **17** | **13** | **29** | **27** | **33** | **67** | **96** | **4** | **44** | **40** | **16** |

Table 2: Further demographic information by collaborating organisation

\*Socio-Economic Group \*\*White British \*\*\*Non White British