

**Conceptualizing Experiential Luxury in Palliative Care:
Pathographies of Liminal Space, Cathedral, and Community**

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Abstract

Conceptualizations of luxury usually derive from individuals who are agentic and empowered. Building upon the consumer-centered experiential movement, this paper deviates from researching the typical, listening instead to consumer narratives associated with luxury in contexts where agency is transitioning. We revisit notions of sacred and profane within the liminal space of palliative and end-of-life care. Adopting purposeful sampling, and agency enhancing storytelling, pathographies in particular, consumption experiences are narrated by patients, families, and bereaved users (n=140) of multiple hospices (n=5) in the UK. Findings shift the evolving consumer centric conceptualization of luxury into conceptions of liminal space, place (hospices as cathedrals), and people (community). A psychosocial narrative emerges which conceptualizes experiences as lived, personalized, integrated, familiar, transformational, hedonic, eudaimonic, and (dis)connected. Our discussion extends notions of the sacred and profane into the mundane and illustrates the ways in which those navigating a liminal space encounter unexpected yet astonishing luxury experiences.

Keywords: hospices; sacred; profane; mundane; storytelling; health

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1.0. Introduction

'The china cup clinks gently, reunited with its saucer. 'These are the grandchildren' Grace says, pointing to an array of beaming faces so respectfully presented on the bedside table. The tragedy of Grace's story which unfolds is not that there are only a matter of days remaining in it, but rather the overwhelming poignancy of her palliative care experiences more generally. An ashen, drawn lady arrives and, witnessing 'strangers' around the bed, immediately pales further. 'They're here to ask me about my experiences in here dear'. Shoulders relaxing, Sandra pulls up a chair and smiles. 'Oh, mum, where would we be without it? This is better than a five star hotel' (Grace (75+ patient), Sandra (55-64, daughter), Lily and Paul (Researchers), Blue Hospice).

Luxury is a subjective concept open to multiple interpretations (Cristini et al., 2017). Traditional attempts to define luxury products and brands coalesced around characteristics such as price, quality, uniqueness, unnecessary, heritage, and aesthetics (Hemetsberger et al., 2012), with luxury often being viewed as exclusive for the privileged few (Eckhardt et al., 2015). Recently, the debate has evolved from an economic dialogue to one which positions consumer experience as an important lens through which to appreciate new unconventional luxury. As embodied in our opening vignette, this new approach is consumer, rather than market, centered (Bauer et al., 2012). A small but burgeoning body of research into unconventional luxury is unearthing important experiential insights into luxury conceptualizations which collectively illustrate previously missed meanings (e.g. philanthropic), states (e.g. having, doing, being, becoming), and the special moments and experiences which consumers perceive as luxury (Cristini et al., 2017; Llamas and Thomsen, 2016). This recent research also opens up calls for new research directions (Gurзки and

Woisetschläger, 2017; Kauppinen-Räsänen et al., 2019), providing us with an opportunity to revisit established sacred and profane dichotomies (Belk et al., 1989) within a unique place. That place is hospice.

New experiential insights from a consumer-centric perspective have to date been derived from agentic, empowered consumers seeking satisfying, pleasurable, and positive experiences (Arnould and Price, 1993; Bauer et al., 2011; Tynan et al., 2010). The voices of Grace, Sandra, and many others transitioning through liminal spaces are largely silent. Certainly, the importance of liminal space from a consumer perspective is recognized in some marketing literature from a pregnancy and motherhood angle (Cappellini and Yen, 2016; Thomsen and Sorensen, 2006; Tonner, 2016), but, with the exception of Hemetsberger et al. (2013), luxury per se has received little examination during these transitional periods. Contributing to an understanding of luxury within a consumer-centric, unconventional lens is at the heart of this paper. We apply the well-established sacred/profane dichotomy (Belk et al., 1989) to the emergent narrative. In contrast to previous research, this time the liminal space of palliative care is the backdrop to the investigation, with the focus on consumers who are not actively seeking pleasure, and whose agency is severely constrained.

This research did not originally set out to understand luxury from a palliative care perspective. Rather, the study derives from a larger project that, adopting a constructivist approach, set out to give a voice to those in this transitional period. A certain kind of storytelling, known as pathographies (i.e. narratives of illness), were used to collect the data. Pathographies are particularly suited to the collection of rich narratives as well as providing agency and a voice to those transitioning through terminal illness (Frank, 1991, 1995; Turley and O'Donohoe, 2016). It soon became apparent that embedded within these pathographies were emergent narratives that contribute to the line of unconventional luxury enquiry which places the consumer, rather than the market, at the center of luxury conceptualizations.

Hospice is a philosophy, a type of care delivered in multiple settings, including patient's homes, in care homes, and within specifically designed hospice or hospital units. In the study location (UK), over 200 hospice units exist, collectively supporting around 200,000 patients annually, free at the point of service. They receive an average of 32% of funding from the government, with the rest coming from fundraising (Hospice UK, 2015). With each unit autonomous, the term 'hospice' provides a unifying identity. Access is via a series of gatekeepers including doctors, nurses, and other healthcare practitioners, each unit supporting those resident within a loose geographical patient footprint. Services are delivered through inpatient units, outpatient and day care centers, programs (e.g. Living Well, Bereavement), and clinics (e.g. Breathlessness Clinic and Lymphoedema Clinic), with the combination of services unit specific. Our respondents comprise people receiving palliative care, and their families, from 5 different hospices in the UK. Palliative care is "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" (World Health Organization, 2015). In this liminal space, agency is compromised as the healthcare dialogue and associated services shift away from curative treatment to a transitional middle stage. Here the rite of passage focuses upon pain and symptom management (Bainbridge and Seow, 2016; Giovanni, 2012).

Rarely the subject of marketing enquiry, this paper shares parts of the pathographies of those attached to specifically designed hospice units. First, our literature review briefly synthesizes the indicative themes embedded within conventional luxury, before we turn our attention to examining the emergent themes contained in unconventional luxury within which our enquiry is positioned. Second, we detail the methodological particulars of research design, data collection and analysis, and ethical considerations. We then chronicle the

emergent experiences within an extended sacred/profane language. They feed into a new conceptual framework comprising conceptions of unconventional luxury in a liminal space, where luxury emerges in a place (hospices as cathedrals) and people (community). A psychosocial rather than economic, management oriented narrative emerges. Conclusions and opportunities for future research are presented.

2.0. Literature review

This literature review comprises two sections. The first includes a brief review of conventional luxury, providing a contrast to the second discussion in which we examine unconventional luxury. The latter section introduces a consumer-centric experiential lens, and provides emergent themes that form the basis of our empirical data discussion.

2.1. Understanding Conventional Luxury: Indicative themes

Whilst a consensus on defining luxury remains to be realized (Cristini et al., 2017; Ko et al., 2019), conventional luxury has long been associated with an economic narrative focused on luxury brands and synonymous with goods that can be owned (Llamas and Thomsen, 2016). Positioned as high quality, desirable, and exclusive, luxury goods are superfluous insofar as “not having it would cause no particular pain” (Berry, 1994, p. 24). For a brand to be considered a luxury, it is typical for consumers both inside and outside the user group to ‘code’ it as so (Kapferer and Bastien, 2009). The move by some brands to develop positioning strategies where the level of inconspicuousness is so high that only those that purchase it can recognize the luxury code is observable (Han et al., 2010).

As society and markets have evolved, so too have views on the symbolic associations of what luxury represents. Different cultures, social classes, and generations have viewed luxury as a driving force of excellence in the arts and in production, creating jobs and

economic well-being (Cristini et al., 2017). Others have positioned luxury as a marker for social status which uses consumption-based boundaries to separate those with privilege and rank from those without (Eckhardt et al., 2015). The inference in such writings is that ownership of conspicuous luxury brands was traditionally reserved for the ‘happy few’ (Kapferer and Laurent, 2016). Conspicuous consumption enabled those with surplus disposable income to spend lavishly on products and services with the intention of having a higher social standing (Veblen, 1994 [1899]).

However, contemporary thinking exposes the increasing difficulties attached to intelligently associating affluence and social class with luxury consumption (Hemetsberger et al., 2012; Eckhardt et al., 2015). For instance, consider the change to access-based consumption which allows consumers to rent, share, or collaborate to gain access to luxury brands for a few days or hours rather than opting for outright purchase (Belk, 2014). Additionally, brands that were positioned as luxury in a more traditional sense have reduced exclusivity with increased product ranges that include entry level offerings that are affordable to more (Cristini et al., 2017), effectively moving them from luxury to mass prestige (Kapferer and Laurent, 2016). Indeed, “even third-world countries are often attracted to and indulge in aspects of conspicuous consumption before they have secured adequate food, clothing, and shelter” (Belk, 1988, p.104). Individuals could always choose to do without some meaningful thing in favor of purchasing conspicuous luxury should they wish to portray an identity of themselves belonging to an elevated position of privilege (Eckhardt et al., 2015) regardless of their social standing.

In sum, despite luxury consumption now being available to the many rather than limited to the few, the conventional perspective nevertheless views luxury as products that are desirable rather than necessary, often denoting membership of a particular social group, and associated with the portrayal of an elevated social standing. Often-cited dimensions

inherent to luxury goods tend to reflect these themes of exclusivity (e.g. limited, special, superior, prestige), as well as including descriptors relating to high quality (premium, outstanding), aspects of hedonism (fun, enjoyment, pleasure), aesthetics (beautiful, elegant), heritage (craftsmanship, unique, authentic), indulgence (comfort), and escapism (out of the ordinary) (Atwal and Williams, 2009; Hemetsberger et al., 2012; Stiehler, 2016).

2.2 Understanding Unconventional Luxury: Emergent Themes

In contrast to the preceding traditional perspectives on luxury, a new narrative is emerging. There are several interrelated ways in which this new perspective differs from conventional luxury discourse, with shifts in emphasis from communication with others to a focus on the self; from tangible goods to intangible experiences; from marketing led to consumer defined; from enduring to transient; and an emerging recognition that understanding consumer's lived experiences is integral to understanding luxury.

2.2.1 From communication with others to a focus on the self

While traditional views of luxury focused on group membership or social standing, the new perspective interprets luxury as something enjoyed and celebrated primarily for the self rather than necessarily as an outward communication to others (Bauer et al., 2011; Eckhardt et al., 2015). This shift goes beyond the trend from conspicuous to inconspicuous consumption (Wu et al., 2017). Rather, luxury experiences can generate special moments in private spaces (Bauer et al., 2011), a view which contrasts sharply with the traditional marketing literature on luxury (Eckhardt et al., 2015). These hidden moments of luxury can be extremely valuable to the consumer because they can support consumers' selves, potentially contributing to an array of ways in which individuals navigate and construct coherence within self-identity (Hemetsberger et al., 2012).

The importance of possessions to self-identify in terms of learning, defining, and reminding ourselves of who we are has long been established (Belk, 1988). Decoupling luxury from conspicuous consumption (Eckhardt et al., 2015) and even inconspicuous consumption provides us with an extended perspective on the relationship between luxury and the self, where luxury products can be both extensions of the self (Belk, 1988) and self-transformational, representative of processes of becoming rather than possessing. Indeed, though much of the experiential marketing literature traditionally focused on the pursuit and attainment of hedonism (Holbrook and Hirschman, 1982), there is some emerging recognition that luxury is also eudaimonic wellbeing which focuses on self-realization (Hemetsberger et al., 2012; Iloranta, 2019). This new lens enables us to view the ways in which luxury consumption can aid navigate identity in times of transition (Hemetsberger et al., 2012), and perhaps even be tied to a sense of meaningfulness and sense of self-value and wellbeing (Iloranta, 2019; Kauppinen-Räsänen et al., 2019) though this is yet to be considered from the perspective of transition in a liminal space such as hospice.

2.2.2 From tangible goods to intangible experiences

Understanding luxury is no longer restricted to functional products; embedded within the unconventional luxury narrative are experiences and experiential consumption. Some work examines the importance of sensory pleasure such as touch, taste, and smell in luxury product consumption (Bauer et al., 2011) with engagement of the senses playing an important role in differentiating luxury from banality due to a deeper sensory involvement (Featherstone, 2014). However, there is now a recognition that luxury experiences can go beyond product-related dimensions. Building upon Pine and Gilmore's (1999) contention that services are very distinct to tangible products, Atwal and Williams (2009) introduce an experiential luxury framework that demonstrates the ways in which experiences, especially

what they term escapist experiences (those comprising high involvement and high intensiveness), can generate strong emotional feelings. The hospitality and tourism literature similarly contributes multiple insights into luxury as intangible experiential values such as service, aesthetics, escapism, and interactions with others all significantly impact perceptions of luxury (Walls et al., 2011; Wu and Liang, 2009). Indeed, even in luxury studies that focus on tangible products, when examined from a consumer perspective, the place where product purchase and/or consumption occurs emerges as an important experiential dimension that adds to the luxury experience (Bauer et al., 2011; Brun and Castelli 2013; Featherstone 2014; Masvelt et al., 2015).

2.2.3 From marketing led to consumer defined

The new paradigm asserts that the individual's authentic core-self, rather than the marketer, defines luxury (Bauer et al., 2011; Tynan et al., 2010). In the same way as there is now a recognition that value is uniquely and phenomenologically defined by the beneficiary (Vargo and Lusch 2016) so too is luxury uniquely and phenomenologically defined by the consumer (Kauppinen-Räsänen et al., 2019). This perspective has two major consequences. First, studies of luxury should no longer focus on expensive products or services positioned as luxury by the marketer: rather there is a need to widen our lens in order to include those dimensions of any consumption experience within which the consumer perceives luxury (Kauppinen-Räsänen et al., 2019; Mansvelt et al., 2015). From a consumer's perspective, luxury is often in the seemingly small aspects of an experience, or even the elements that the marketer would consider the detritus elements of consumption (Feathersone 2014). Second, because consumption experiences extend beyond the marketer's influence and into their lifeworld contexts (Helkkula et al., 2012) interpretive methodologies are required to identify and evaluate luxury from the consumer's perspective (Kauppinen-Räsänen et al., 2019).

2.2.4 From enduring to transient

Though Ko et al. (2019, p. 406) argue that luxury codes “are consistent across disciplines and ages”, luxury is in fact a relative concept. Luxury changes over time and, like the brands it describes, consumer perceptions at a particular moment in time define luxury (Kapferer, and Laurent, 2016). This perspective, in line with the thinking that luxury is inherently experiential, acknowledges that luxury is not permanent, but is transient and can change across time and place (Mansvelt et al., 2015). The authentic core-self is not fixed and so the individual’s perceptions of luxury change over time as their needs and desires vary based on the context of specific situations (Belk, 2013; Eckhardt et al., 2015; Ruvio and Belk, 2018). Indeed, luxury perceptions can oscillate when consumers switch between selves, thereby aiding them to adapt to different circumstances (Bauer et al., 2011; Hemetsberger et al., 2012). There is also a recognition that within wider experiences occur extraordinary and intense, if fleeting, moments of luxury (Diaz Ruiz et al., 2015).

2.2.5 Understanding luxury through lived experiences

Given the preceding discussion, it is clear that embedded in consumers’ sensory, emotional, cognitive, individual, and interpersonal experiences are their definitions of luxury (Atwal and Williams, 2009; Bauer et al., 2011). Consequently, a focus on lived experiences, what Helkulla et al. (2012, p.59) term ‘lifeworlds’ where meaning is found in everyday lived experiences, is required. These lifeworlds encompass experiences of time, space, individuality, community, wellbeing, and any other dimension of life that the consumer perceives as meaningful. Within these lifeworlds exist consumer’s perceptions of luxury (Iloranta 2019). That is not to say objects or grand experiences within opulent spaces are no longer important; it is plausible to juxtapose the new types of luxury with conventional understanding of the phenomena. Indeed, Hemetsberger et al. (2012) contend that consumers

do not honor one type of luxury over another insofar as having and owning can be perceived as just as valuable as doing, being, and becoming. What is important is to recognize that it must be the consumer, not the marketer or the researcher, who defines luxury. For this reason, Hemetsberger et al. (2012) warn against classifications of luxury with predetermined categories as these do not fit with a constructionist perspective. Rather than utilize any of the new luxury typologies (e.g. Atwal and Williams, 2009; Stiehler, 2016) then, we turn to the established work on the sacred and profane as a potentially useful schema for examining unconventional perspectives on luxury.

2.2.6 The sacred and profane

The preceding discussion clearly demonstrates that the developing unconventional view suggests perceptions of luxury can emerge from the tangible and the intangible, and lie in rare occasions and in ordinary everyday situations. However, we took heed of the warnings about the need to avoid predetermined classifications of luxury (Hemetsberger et al., 2012) and instead searched for an alternative schema that could aid us in identifying luxury within our vast data set. The perspective of the sacred and the profane seemed appropriate to use as lens through which to view lifeworlds, which of course comprise multiple interactions with tangible and intangible things as well as rare and ordinary situations. Belk et al.'s (1989) seminal work on the sacred and profane, inspirational to so much subsequent consumer research (Arnould, 2004; Arnould and Price, 1993), explains that the secularization of religion and the sacralization of the secular leads consumers to “enact the sacred/profane distinction” within domains of experience (p. 9). In the realm of consumption experiences, sacred refers to “that which is regarded as more significant, powerful, and extraordinary than the self” while the profane “is ordinary and lacks the ability to induce ecstatic, self-transcending, extraordinary experiences (Belk et al., 1989, p. 13). Logically, then, we argue

that conceptualizations of luxury, embedded with consumer's lifeworlds, are those experiences that are perceived by consumers as inducing ecstasy and being perceived as extraordinary. Because we did not ask any questions about luxury per se, this makes the sacred/profane distinction potentially powerful in this research because such instances of ecstasy and extraordinary experiences emerge naturally throughout respondent's pathographies.

Belk et al. (1989) assert that there are six major categories of potentially sacred domains (places, times, tangible things, intangibles, persons, and experiences) and twelve properties of sacredness which fall into three categories. The first category relates to individual and social treatments of the sacred, and comprises hierophany (manifestation of something sacred), kratophany (fear of the sacred), opposition to the profane (defines and protects the sacred), contamination (spread of sacredness), sacrifice (in preparation to meet the sacred), commitment (strong emotional attachment), objectification (concretization of the sacred), ritual (rules of conduct around the sacred), and mystery (cannot be understood cognitively). The second category relates to social concepts and comprises *communitas* (sense of camaraderie and status equality) and *myth* (speculations surrounding the sacred). The third group, pertaining to the psychological, comprises ecstasy and flow, which refer to peak experience.

The sacred/profane dichotomy clearly provides a potentially interesting field in which to extend our appreciation of the relationship between liminality and unconventional luxury for several reasons. First, it was not designed to study luxury per se, which is important given the warnings about the use of predetermined luxury classifications (Hemetsberger et al., 2012). Second, the literature on unconventional luxury asserts that luxury lies within the tangible and the intangible, and in both rare and ordinary situations. The sacred/profane framework includes a range of tangible and intangible potentially sacred domains, and thus

seemed appropriate as a lens wide enough to encompass luxury experiences within a variety of different aspects of experience. The sacred/profane schema also suggests that “a fundamental distinction structuring social life is between what is set apart and regarded as sacred and what is regarded as profane or ordinary” (Belk et al., 1989, p.2). Hence, those lifeworld experiences that emerge from pathographies as being special and out of the ordinary (or sacred) could be indicative of luxury perceptions. Finally, palliative care encompasses the physical, the psychosocial, and the spiritual (World Health Organization, 2015). It seemed, therefore, that the sacred/profane dichotomy, with its special emphasis on the physical (places, tangible things), the psychosocial (times, intangibles, persons, and experiences), and the spiritual (properties of sacredness), is a particularly apt perspective from which to view luxury in our particular context.

In sum, this literature review shows that traditional perspectives view luxury as products that are desirable as opposed to necessary, have some social status, and defined with descriptions (and their synonyms) pertaining to high quality, hedonism, aesthetically pleasing, authentic, and indulgent. In contrast, the new luxury narrative focuses more on the self, more on experiences, is defined by consumers, and recognized as being transient. Hence, a deeper understanding of perceptions of luxury can come from understanding consumer’s lived experiences. However, to date, this understanding comes from the study of individuals who are agentic and empowered and usually seeking hedonic experiences. We make a contribution by examining the lived experiences of consumers who are not seeking pleasure and whose agency is compromised as they transition through the liminal space that is hospice care.

3.0 Method

The current study derives from a large and extensive piece of research designed to take a ‘deep dive’ into the service experiences of hospice users (patients and their families). The research began when a hospice approached us and tasked us with uncovering those aspects of the hospice experience that were working well, and those that needed improvement. The success of the initial stage of the project led to a snowballing of the research and soon included four further hospices throughout the UK. The data we use here is a part of the extensive data generated from the larger study.

3.1 Research design

Adopting a constructivist approach, our multi-site study was designed in collaboration with a number of hospices and hospital-based palliative care providers across the UK. The current research comprises findings from 5 specifically designed hospices, selected on the basis that they are geographically dispersed, comprise both chain and individual hospices, and include both adult and child hospices. Three independent academic researchers collected qualitative data within these units across a 4-year period. Enabling those with compromised agency, in a state of flux, to share their voice was a central driver in formulating the mechanics of the research design. Two inter-related tensions were tackled from the outset of the study: research instrument and ethics.

3.2 Research Instrument

Cognizant of previously acknowledged research limitations in palliative and end-of-life care research (Lendon et al., 2015), a particular type of storytelling known as pathographies (illness narratives) were adopted. Applied to many healthcare contexts (Greenhalgh, 2006) including palliative care, pathographies are an established and humane

method of data collection, providing the voice of patients and carers who may otherwise have been unable to participate in research (Gysels et al., 2008). Pathographies take many forms, with three main overlapping types common: quest, chaos, and restitution (Frank, 1991). Chaos is particularly central to this study, a type which chronicles the experiences of those most vulnerable, overwhelmed by the intensity of their illness. Their pathographical nature can act as a mechanism for reclaiming agency (Frank, 1995; Picardie, 1989). When applied to terminal illnesses, storytelling can offer deep insights into the interplay between markets and mortality (Turley and O'Donohoe, 2016).

We applied a specifically designed Trajectory Touchpoint Technique (TTT) to collect stories in a systematic way (The Authors, 2017; The Authors, in press). The TTT utilizes a series of cartoon rich pictures (Bell et al., 2016), each depicting possible 'touchpoints' (Zomerdijk and Voss, 2010), or points of contact or interactions with hospice, that act as an aide memoire for participants as they narrate their stories. To ensure systematic data collection, these sets of touchpoints comprise seven distinct stages of the hospice journey: pre-arrival; arrival; clinical care and support; facilities; shared spaces; little extras; discharge and aftercare. In addition to literatures and policy documents pertaining to palliative and hospice care, the antecedents of the TTT comprise service design and customer experience literatures and methods. While a full explanation of the development of the TTT is beyond the scope of this paper, Table 1 summarizes the processes involved in identifying potential touchpoints. Table 2 summarizes the different theoretical and methodological antecedents and explains how each contributed to the design of the TTT. Figure 1 provides an example of one of the groups of touchpoint images.

[Insert Table 1, Table 2, and Figure 1 here]

We printed each group of touchpoint images onto large laminated cards and uploaded them onto tablets. We invited participants to share their experiences of hospice care linked to

each of the seven groups of touchpoints, effectively eliminating the need for predetermined questions. Instead, only three specific questions were asked: 1) Tell us about how you are here today – designed to provide an opening and contextual setting for the conversation; 2) What happened next? – designed to move the story along the journey of hospice care; 3) How did that make you feel? – designed to gain a deeper understanding of the significance and meaning of comments offered in relation to various touchpoint images. Participants were free to use all, none, or some of the pictures in order to guide their storytelling. Interpretive methodologies are well suited to evaluate customer experiences (Helkkula et al., 2012) and narrative and stories are the most powerful way of accessing healthcare experiences, too (Bate and Robert, 2007). The TTT images encouraged people to reveal their personal stories of their hospice journeys deeply, extensively, and in great detail.

3.3 Ethics

Engaging the terminally ill in research brings forth issues of vulnerability. Marked as high risk, the full institutional ethical process took in excess of six months to complete and included University attendance and defense. Eventually granted, the ethical approval was subject to multiple conditions. The central research ethics considerations of anonymity, confidentiality, voluntary participation, informed consent, and vulnerability took on elevated scrutiny for this study. Specific data capture difficulties pertaining to hospice care were also key concerns. Magnified is the hesitancy among society to discuss mortality (Giovanni, 2012) when participants are locked in the liminal space that is palliative care. Also spotlighted is anonymity due to the well-documented tendency for palliative care patients to form strong personal bonds with their care providers, which often manifests in a reluctance to speak candidly or to suggest that the care they receive is anything but responsive to their needs (Churchman et al., 2014). Most importantly, many people receive palliative care only when

their health is deteriorating to the point where death is often imminent, with many physically incapacitated and/or emotionally drained. Consequently there is a prevailing view that many hospice patients are too vulnerable to participate in research (Sandsdalen et al., 2016).

To address the aforementioned ethical considerations, all our communications (written and verbal) stressed both guarantees of anonymity and our independence from the hospices. All communications also stressed that participants were free to stop their narratives at any point, and without incurring any disadvantage. We allowed, and encouraged, patients to have a friend or family member with them when they narrated their pathographies, if they so wished. We designed a distress protocol which afforded participants the opportunity to contact the hospice counsellor, their family doctor, or their mental health provider. The protocol also included steps to enable us to refer to the hospice counsellor, with the permission of the participant. As a tight-knit research team, we had regular de-briefs and candid discussions between ourselves, and we too had access to counsellors if needed.

Our ethical approval demanded that clinicians act as a gatekeeper before we approached patients. For inpatients, this involved doctors, during the morning ward round, assessing the patient for their fitness to participate in the research. For outpatients, a senior nurse conducted this assessment during clinic. Robust, rigorous and as intent upon protecting participants as these systems are, it was interesting to observe instances where patients subsequently questioned ethical conditions by actively seeking permission from gatekeepers themselves to become involved in the research. On several occasions a patient, previously deemed too unwell to be a potential participant, heard about the study via word-of-mouth and asked the research team for details before requesting permission to participate. Such instances are an important challenge to presumptions of vulnerability inevitably embedded in systems designed to protect.

Finally, and perhaps most noteworthy, we developed the TTT with these issues at the forefront of our methodology design decisions. One acknowledged limitation of research into palliative care is that a significant proportion relies solely on retrospective views of family members (Lendon et al., 2015) and misses key inputs from patients. There is also a recognition that it is difficult to fashion an empirical tool that is “feasible, actionable, and patient centered to directly assess the patients’ perceptions of hospice or palliative care” (Meier, 2011, p.352). The TTT was easy to use for all hospice patients, irrespective of illness: we used the TTT with patients with different types of cancer, heart disease or chronic obstructive pulmonary disease (COPD), and motor neuron disease where one patient narrated her pathography using speaking software. The TTT was also easy to administer, from the bedside of patients, to the homes of bereaved families. Our cartoon images put people at ease and made them smile, enabling us as researchers to be perceived as friendly, informal, and non-threatening. We also used the TTT with children, the very old, and two people who were illiterate. Hence, our TTT proved both easy to use and inclusive, with neither vulnerability nor disability creating a barrier to inclusion.

3.4 Sample

Pathographies were collected from a minimum of 20 participants per hospice, reflecting the pilot study’s data saturation point. A purposeful sampling approach was adopted with data collected from all categories of participants utilizing the service (n=140) i.e. day patients, out-patients, in-patients, discharged outpatients, families, and the bereaved (see Table 2). Clinicians helped to recruit patients and their families over a 3-4 week period within each unit. Bereaved families received invitation letters, explaining the purpose of the study and how to participate. To ensure a consistent style of data collection was adopted throughout, researchers paired together to collect the first five 5-6 pathographies in each unit.

A small number of bereaved family members who lived some distance away opted to talk over the phone, but the vast majority of pathographies took place face-to-face. Patients narrated their stories on site at hospice, while in-line with University ethics on lone working with vulnerable populations, two researchers visited the homes of bereaved families.

[Insert Table 2 here]

3.5 Data Analysis

Conversations averaged 45 minutes, the timing entirely participant led, in-line with ethical approval. All conversations were recorded (with permission) and transcribed verbatim. The data set exceeds 2 million words of individual stories. Luxury was not directly questioned in the study. Rather, as the pathographies unfolded, one of several immediate and striking themes to emerge was the focus on how luxurious the hospices were, particularly in contrast to the many prior experiences with hospitals. The uniquely human and subjective nature of stories enabled us to not only take a deep dive into the lived experiences of hospice service users, ratifying and enriching understanding of known factors, but also confirmed the ability to bring new factors into view (Thomas, 2005). One of these new factors was a clear theme of luxury – albeit unconventional – that ran through so many of these pathographies.

Consequently, while we knew that luxury was a strong theme within the data, in order to fully extract all relevant sub-themes we applied manual data mining methods, utilizing keywords and phrases emergent within the traditional luxury literature. These included the descriptors (and their synonyms) pertaining to high quality, hedonism, aesthetically pleasing, authentic, and indulgent, as outlined earlier. These could relate to tangible products or intangible experiences. We also manually re-examined the transcripts for themes identified in the review of the unconventional luxury literature. Hence we looked for any examples of private moments indicative of navigating self-identity or enhancing wellbeing, and we re-read transcripts whilst open to excerpts of pathographies suggestive of any sensory, emotional,

cognitive, individual, and interpersonal experiences, however fleeting, perceived as luxury. We also kept our minds open to examples of the sacred and profane.

Adopting the approach outlined by Braun and Clarke (2006), we applied manual thematic analysis to the data. Three researchers separately identified core and sub-themes embedded in the data. Next, we shared these themes and reviewed them, relating back to the themes from the literature. Finally, the dominant themes that emerged formed the basis of the results which follow.

4.0 Results and Discussion

Embedded within pathographies thrived an abundance of examples of sacred and profane properties, with this framework proving a major assistance when analyzing the data. As a result, three major core themes emerged: the crisis of liminal space, place (hospices as cathedrals), and people (community). Eight major sub-themes emerged to underpin the ways in which these three major elements influenced experiences. Figure 2 illustrates these major themes and sub-themes, discussed next. Entrenched within our discussion are examples of properties of the sacred and the profane.

[Insert Figure 2 here]

4.1 The Crisis of Liminal Space

Transition into the liminal space of palliative care is a defining temporal moment. It is situation-specific. All disease trajectories are unique to the patient, and similarly all responses are unique too. What unites these stories is that contrary to other advances in medical care which can help to extend a patients' lifespan, service provision - and therefore patient experience – has in this liminal space moved from curative treatment to pain, medicine, and symptom management. In the UK, policy-level approaches to enhancing end-of-life care have

generated a 'dying well' narrative (Department of Health, 2016; The Choice in End-of-Life Care Program Board, 2015), central to which is the requirement for honest discussions with healthcare professionals, the ability to make informed choices, the development of personalized care plans, the involvement of family (and others important to the patient in the planning process), and signposting to further support and advice. Contrary to this narrative, we found the early days of transitioning into palliative care are in actuality bereft of informed choice, lacking in personalized care plans, and an absence of places to turn to for support and advice. Consequently, distress, denial, variable success with managing symptoms, and little in the way of independence and social participation were characteristic of many lived experiences. Time stands still as people are sucked into a void of endless waiting. Waiting for scans. Waiting for appointments. Waiting for results. Waiting for phone calls. Waiting for more of the same: *"You just are petrified. What's the results going to show? Why haven't we heard? Are they really bad? Have they forgotten about us? Should we ring? Oh, but it was only yesterday and we've got days to wait to hear"* (Jane, 55-64, Relative).

Magnified in this liminal space is fear. Innocuous pains are elevated to signs of something sinister. Change, with all its anxiety inducing attributes, is everywhere. Experiences entail new people and new places due to seemingly endless appointments with different healthcare professionals. Many of these new people and new places are perceived as totally disconnected from each other, *"...this was the problem... we didn't know what they were and where to start"* (Sam, 30-34, Bereaved). There is also a disconnection from familiar lived experiences prior to transition to this liminal space. Grappling, at times helplessly, in a terrifying landscape of disconnected services and diminishing agency, many are beneficiaries of an entirely new language assumed to be spoken by all occupying this space: *"I got a phone call to say that the palliative nurse had been. I didn't know what a palliative nurse was"* (Joe, 65-74, Relative). Ways of living change, values change, and a sense of urgency attaches

to once taken for granted things, listening to music and seeing family for instance (Morris et al., 1986). A state of depression, isolation, stigma, and spiritual dilemmas cocoons the lived experience (Kellehear, 2013).

Kratophany and myth (Belk et al., 1989) dominate this hospice pre-arrival stage. The associated vocabulary, “*The death house*” (Paul, 75+, Day Patient), “*The last chance saloon*” (Mark, 75+, Relative), engineers a firm distance between hospice and home. Kratophany results in a delay to hospice access, with many taking comfort from denying the existence of this experiential offering: “*It’s [hospice care] the thing you don’t want to think about. It’s for people going to die. So, we didn’t want to think about that*” (Jenny, 25-34, Bereaved Relative). Myths prevail, “*I was adamant that I weren’t coming to visit because in my head I just associated it with an old people’s home*” (Michelle, 30-34, Bereaved Parent). Hence the crisis endures as the suspension in this disconnected state persists.

4.2 Hospice as Cathedral

Finally, usually as a result of families approaching breaking point, “*eventually I said ‘look, we can’t manage’*” (Carol, 50-54, Bereaved), dawns a realization, albeit reluctant, that the hospice is needed. Once this transition into hospice is made, and echoing the sentiments of multiple authors (see Hemetsberger et al., 2012; Belk, 2013; Eckhardt et al., 2015; Kapferer and Laurent 2016; Ruvio and Belk, 2018), this time in a liminal space, luxury is indeed found to be a relative concept, situation-specific, and defined by the perceptions of consumers at a point in time. Arrival at, and engagement with hospice services is immediately transformational: “*It was brilliant...everybody was welcoming and friendly and laughter*” (Raima, under 14, Patient). Shrouded in mystery that cannot be understood cognitively (Belk et al., 1989), “*I doubt that anything would have helped much until she [my wife] actually came and saw it and felt the atmosphere*” (John, 55-59, Parent), the magic of

the hospice unfolds, *“Within five minutes... from a closed book to being an open book...that were the magic. The magic of being here”* (Angela, 35-44, Bereaved). To the naked eye the air is seemingly light, filled with bustle and inclusivity. Obscured is the profound reality (and realization) that for all on this journey, patient and family, the hospice is transitioning from a perceived hell to a welcoming place, a cathedral of sacred consumption (Belk et al., 1989).

Examples of opposition to the profane (Belk et al., 1989) abound, *“there’s a calmness as well – I can’t explain it – you’re all chatting but it’s calm”* (James, 55-59, Outpatient), entwined with feelings of reprieve, *“When I got in here what I actually felt was a tremendous sense of relief as the atmosphere was so different from the hospital”* (Ken, 60-64, Inpatient). Intangibles facilitate this transition as many confess to a new fear of life outside the hospice, the ‘other’, sharing an overwhelming sense of relief that they have managed the conflicted journey here, *“it’s [i.e. the hospice] somewhere to come and die if you’re lucky”* (Jean, 55-64, Relative). How quickly have conversations shifted from ‘fearing’ hospices, to fearing ‘other’ healthcare providers, general hospitals most often, with their limited staff and associated resources, *“a totally different world, I couldn’t believe it”* (Barbra, 50-54, Relative). The dawning realization of the peace of this sacred space in an otherwise dank landscape is all consuming, indeed overwhelming for some *“how lucky are we mum”* (Sandra, 55-64, Relative). Grateful that they have escaped the ‘other’, patients worry for those less fortunate in their access. What should be the profane, an ability to access and discuss pain with doctors for instance, becomes the sacred, a major benefit of hospice life. It symbolizes a luxury when compared to earlier service experiences, themselves punctuated by long periods of waiting for access to professional advice.

The familiar becomes elevated in this sacred space: *“as soon as I come in the door, it felt like home”* (Raima, under 14, Patient). Indeed, this finding of normality, the search for the familiar, emerged as a luxury for these people: *“he actually used the word normal, and he*

said *'I just feel like it's home''* (Kathy, 35-39, Patient's Mother). This sense of the familiar brought a great deal of comfort and even hedonic wellbeing to many, *"a home from home... I thought this is where she will be happy and comfortable for the couple of days or however long she has got"* (Jean, 45-49, Relative). This welcoming atmosphere, an atmosphere of safety, and an atmosphere of everydayness, *"Oh right away I felt at home. Right away"* (Jim, 45-54, In-patient) return a sense of normality and calm conceived of as a luxury when contrasted with feelings experienced in other environments. So strong is the desire to feel at home, to enjoy the peace and security so often taken for granted previously, anything which has the capacity to generate a sense of homeliness becomes highly sought after. Echoing the work of Moore et al. (2013) into therapeutic landscapes, even those for whom a sense of the familiar was not immediate, become more comfortable over time, *"Oh I don't like this at all, it's a bit too... I felt... I think you initially feel that anyway. And before I left I thought it was fantastic"* (Sara, 35-44, Relative). Patients, and their families in particular, appreciate fresh flowers, outside spaces, courtyard access, tea rooms and other shared social spaces. Such spaces provide sacred familial opportunities. The family rooms, commonly furnished with toys, contribute to keeping children and grandchildren entertained. The courtyard, an oasis of calm, and the tea room, a good social space. Many stories are woven around the comfort felt by visitors.

Striking are the ways in which perceptions of luxury emerge from what would normally be perceived as the ordinary, the profane. Instead, integrated within the profane were clear perceptions of luxury as the hospice becomes a sacred place. Time flows again helped by new meanings (Belk et al., 1989), new rituals (e.g. mealtimes, tea trolley, drinks trolley) to become accustomed to. The shift is momentary for some (e.g. day patients, outpatients, and families), whilst more significant for others (e.g. in-patients) as they adjust to their new place of dwelling. Options (e.g. single rooms, shared accommodation), choices

(e.g. menu preferences), and a sense of normality “*we had a little puppy...the nurses would...take him around to the patients*” (Stella, 60-64, Relative), all generate a dignified existence which (tragically) is conceived as luxury in this landscape.

Objectification, to concretize the sacred (Belk et al., 1989), results in perceived luxury integrated within a range of normally profane tangibles. “*It is those little personal touches that are lovely and make all the difference, yeah, lovely*” (Maureen, 60-64, Bereaved). Time and again emerged the ways in which the little things became important: “*They ushered us down to the accommodation, down at the bottom and said, ‘this is your space, that’s all yours just use it as you want. Do you want anything bringing down, any cereals, any toast?’ There was actually a basket of things on the table like shampoo and toothpaste and yes, just normal basic things what you think, ‘actually, I didn’t get any of that, and I needed those’. They made all the difference*” (Paula, 35-39, Bereaved). For Grace and Sandra, introduced in the opening vignette, the China cup and saucer and bedside photographs are symbolic. They provide a conduit, tangibles, objectified, creating a sense of warmth. They serve as a reminder of other times and places as well as being emblematic of family support (Cleeve, et al., 2018). Objects are significant in other ways too. How flowers are arranged, how clothes are handled, or how food is prepared are indicative of signs of care, all of which take on elevated meanings: “*The other day I had egg and chips which was great as I can’t swallow that much and egg goes down well*” (Max, 65-74, In patient). Integration of care that includes the family within this sacred place also adds to perceptions of luxury: “*the whole family get looked after which takes a lot of stress off the family, and just makes it a happier place for everyone*” (Jan, 40-45, Relative).

Examples of hedonic experiences abound, “*‘they’re not just here for the medical needs. I [mother] got a bath and they [child and nurse] are having a pamper session and she were having her nails files and painted*” (Silvia, 35-44, Patient’s Mother). Time and again

the words ‘fun’ and ‘laugh’ emerged, *“the trampoline outside...she was like, come on it mummy. And I’m like, really? So, then we were going on it and then Harry, the hospice dog, he’s lovely, and he comes on the trampoline with us!”* (Amy, 45-49, Patient’s Mother). The basic taken-for-granted ordinary activities, the profound, *“She hasn’t been able to have a bath or anything She came here and they gave her a lovely Jacuzzi every day. So little things that we take for granted mean a lot when you, I mean, she is terminally ill”* (Cathy, 40-45, Relative), become luxury.

4.3 Hospice as Community

Forms of hierophany emerge throughout many narratives, *“Honest to God this place...all the nurses are Angels”* (Pete, 45-54, Inpatient). Manifestations of the magical are not limited to the sacralization of the secular (Belk et al., 1989), however, with hospice nurses also described as *“superheroes in capes”* (Pauline, 60-64, Bereaved). Service users attach sacred and magical meanings to staff which detract attention from the profane reasons behind their terminal illness. Staff are selfless, capable of responding to individual needs and, in delivering a personalized service, they ameliorate the consequences of illness, their commitment consistently central to this experience. Ironically, sacred status is for staff, with the importance of being human - being a person - emerging as crucially important for patients, *“I don’t think they see the patient as a patient... they see them as, you know, a human being that has got families”* (Shelly, 30-34, Bereaved). Evidence of personalization of service, treating individual needs, abounded, and were clearly perceived as luxury: *“and you think, wow, they are actually treating him as an individual, she said is there “anything you want?”, and she just looked at him holistically, and I think the fact that she said is there anything we can do for you, anything, right now... that just gave you the benchmark for what was to come”* (Amy, 50-54, Relative). Personalized service extended to meeting the needs of

relatives, too, with the following quote particularly indicative of a personalized service to meet the particular, and extremely sad, needs of patient siblings *“they did us a cinema night, they opened the cinema up, got us some popcorn, put a movie on. That was good, because my girls...well, they've never been to a cinema. They've never done anything like that. Yes, they've opened up to a lot. Gave the girls a bit more of a childhood rather than they need to be adults. They've been able to be who they are”* (Joanne, 35-39, Relative). For many patients, personalization begins to return a sense of agency, *“Out there I did what I was told, basically! I think that was one of the things I found most difficult, I had no control over what was happening....you just feel really helpless, really, and I haven't felt that here, so that's been really good”* (Ada, 65-69, Inpatient).

Unlike ‘out there’ with its disconnected services, ‘in here’ in this special community, experiences are connected, *“Absolutely wonderful....on the button. Sometimes you don't have to say anything, she just assesses you and the next minute – boom, boom, boom – things are done”* (Doris, 75+, Inpatient). Language helps to verbalize the intangible and experiential markers of luxury characterized by safety, purpose, and positivity. Luxury is connected service, *“She [hospice doctor] was like an instant GP [doctor] and consultant all rolled into one”* (Cathy, 65-74, Inpatient); tailored service, *“It is so much faster here getting stabilized than the hospital because they have the one-to-one. I think it is a lot different. I really do”* (Ted, 65-74, In-patient); and accessible service, *“Anything I needed all of a sudden I could have”* (Pete, 45-54, Inpatient) enhance these lived experiences. Connections go beyond joined up services. Human connections are crucially important here, a luxury in comparison to what has gone before, *“It's safe here, you're safe because no-one's going to look at you, no-one's going to judge you”* (Carol, 35-39, Relative). Experiences, shared in communion with others, also bring a sense of returning agency and belonging, *“It helps too because a lot of people don't have good days and you learn that you're not the only one”* (Annie, 65-74,

Outpatient). Sharing takes multiple forms including both the intimate sharing of food, “*I ordered a takeaway one night and had all the family around in the conservatory area and it was brilliant. Just perfect*” (David, 45-54, Inpatient).

Sharing takes on elevated meaning in this community. Characteristic of people experiencing liminality together, it transcends to *communitas*: “*the comforting thing is that they’re all here for the same reason, so you can talk because we’re all here for the same reason, and we laugh, we cry, we swear, do you know what I mean, and it’s just like ‘this is so unfair’ and what have you, but we always support each other*” (Kathy, 35-39, Relative). This *communitas* is a crucial contribution to psychosocial wellbeing, “*these people have given me a strategy for coping*” (Charlie, 65-69, Relative), enabling some to ‘venture’ (Moore et al., 2013) and move forward in a meaningful way, “*the bereavement group was worth its weight in gold. Yeah I’m glad I went and of course since then we’ve got all these friends, it’s really helpful and well you’ve sort of got to make a life again*” (Sally, 75+ Bereaved). *Communitas* often comes in the direst moments of the life of a person (Turner, 2012), yet through this we can identify contamination. As Belk et al. (1989) note, unlike contamination in medical usage, in this situation it refers to the spread of positive sacredness. Contamination examples materialized among countless bereaved families who now volunteer for the hospice, they organize fundraising activities, and they spread the word and attempt to bust the negative myths which persist around the word ‘hospice’.

Wellbeing, with all its ‘dilemmas of definition’ (Gillett-Swan and Sargeant, 2015, p. 137) plays a pivotal role. Though an earlier study by Graham (2012) concluded that those with limited agency experience limited wellbeing, the converse emerges through narratives. While hedonic wellbeing, most commonly associated with the minimization of pain, and associations of happiness as pleasure and enjoyment, emerged in narratives attached to shared spaces and the uptake of relaxation treatments and services, *eudaimonia* emerges from

communitas, a luxury for capacity to set aside the pain, anguish, and emotional rollercoaster of illness and manage the practicalities of living with illness in a humane way. Hospice also brings a sense of comfort and wellbeing to the bereaved, “*she’d died. Where do I go now? And then I wentand she was beautiful. I thought, “Oh, thank goodness that she’s like that”* (Eileen, 55-59, Bereaved); “*at the end he was very peaceful and there wasn’t any discomfort never mind pain there wasn’t any discomfort so I was really pleased, we still find comfort in that every day and it almost helps the grieving process”* (Jamie, 45-49, Bereaved).

5.0. Conclusions

This paper has adopted a constructivist approach, set within an unconventional luxury consumer-centric lens, to seek further understanding of what consumers conceive as luxury when experiencing palliative and end-of-life care services. Hospice consumers have, for the first time in experiential luxury research, played a pivotal role in the data collection process, sharing their illness narratives through a specifically designed storytelling tool, the TTT. The deep dive nature of the TTT has, unintentionally, generated pathographies rich in experiential luxury data. Examination of the emerging experiences through the sacred and profane consumption lens (Belk et al., 1989) enabled us to uncover perceptions of luxury within a liminal space. In so doing, we extend understanding of unconventional luxury within a setting where need rather than choice drives consumption. This is sharp contrast to previous research, where conceptualizations of unconventional luxury, premised upon experiential consumption, are derived predominantly from studies examining the discretionary activities, holidays or leisure for instance, of consumers who exert control over their own patterns of consumption (Atwal and Williams, 2009; Walls et al., 2011). For hospice consumers the converse is true. Needs rather than choice take precedence here. A need to manage illness. A need to return agency. A need to reinstate some semblance of normality and the ordinary to

everyday life experiences. A need felt not by one consumer, but rather a family of consumers, including patients and their relatives. All are included in holistic care pivotal to the palliative care ethos, yet each experience the same environment in unique ways.

The drivers that inform what consumers conceive of as luxury when experiencing palliative care leads to a new conceptualization of experiential luxury (Figure 2) predicated upon eight experiential categories: lived experiences, personalized experiences, integrated experiences, familiar experiences, transformational experiences, hedonic experiences, eudaimonic experiences, and (dis)connected experiences, all bound in notions of liminal space, place, and community. Prior to accessing hospice, people's experience of transition is dominated by the chaos caused by disconnected services, a lack of informed choice and personalization, an absence of support and advice, and a void of seemingly endless waiting. Exacerbated by kratophany and myth around hospice care, fear and anxiety dominate and the crisis is prolonged.

Eventually, hospice comes and the magic that is impossible to understand cognitively unfolds. The hospice is a sacred place, a cathedral of sacred consumption (Belk et al., 1989) within which dimensions of experiential luxury abound. Conversations shift from a fear of hospice to a fear of other places, entwined with a dawning realization that there is a feeling of normality again – certainly a luxury given their recent experiences. The hospice becomes a place of sanctuary, a home from home, where tangibles are objectified and spaces provide sacred familial opportunities and even hedonism in the form of fun and pampering. Here every day, usually mundane activities take on new connotations that separate them from the profane. People make this sacred place even more special. Hierophany elevates care staff to sacred and mythical beings while, importantly for patients, they themselves begin to feel human again. Here, the luxury of personalized, connected services are a stark contrast to what

went before, while *communitas* brings refuge, support, and much needed eudaimonic wellbeing. This support continues beyond the death of the patient to comfort the bereaved.

Unlike the extant experiential luxury research that finds escapism in the form of escaping everyday life and seeking the extraordinary to be an important dimension of unconventional luxury (Atwal and Williams, 2009; Hemetsberger et al., 2012; Stiehler, 2016), within the liminal space that is palliative care, the hospice provides an escape founded in the ordinary rather than the extraordinary. Studying experiential luxury in this liminal space also challenges original conceptions of the sacred and profane (Belk et al., 1989). These challenges often emerge as a consequence of the disconnected service systems experienced outside the hospice environment. Ordinary everyday objects and experiences no longer sit comfortably in the profane domain, a bedside table covered in photographs, egg and chips served to assist illness complications. Instead they are elevated in status to the sacred, so symbolic are they of identity, care, and humanity. Clearly, something else is going on in this healthcare space not easily unpicked within a sacred/profane dichotomy. Exploring unconventional experiential luxury in this liminal space leads us into a further appreciation of a sacred/profane middle ground, that of the 'mundane'. This 'mundane' space is occupied by recurring activities which may be tedious, tiresome and pedestrian, neither extraordinary nor ordinary, but entirely necessary for transitioning consumers. For consumers who reside outside this liminal space such experiences would represent neither the ordinary (profane) or extraordinary (sacred). For hospice consumers, whilst the distinction is less clear-cut, few would welcome, or self-assess their categorization as ordinary. These actions verge on the edge of this profane space. They speak to the existence of a 'mundane' space, a space populated by experiences which are monotonous and humdrum, yet so fundamental to quality of life in this environment.

Another interesting ‘middle’ dimension also emerges from the current study. To suggest luxury is either conventional or unconventional is misleading. Rather than juxtaposing each as in the work of Bauer et al., (2011), this study suggests that really a middle ground between conventional and unconventional luxury literatures exist. For instance, a nuanced appreciation of the coding of luxury, found commonly in conventional luxury literatures (Kapferer and Bastien, 2009), seeps into the unconventional luxury space too. Echoing the conventional luxury work of Kapferer and Laurent (2016), perceptions of unconventional luxury are relative, modeled by the period of time in question. Perceptions of hospices pre- and post-arrival illustrate this. Pre-arrival, all associations are negative, undesirable, an environment to be avoided. Arrival on-site saw this transition to an appreciation of the luxury offering in place. In many instances, these transitions were immediate, luxury defined by the individual’s core self, common to unconventional literature (Hemetsberger et al., 2012; Tynan et al., 2010). Uncommon to the literature, however, is the finding that unlike many sacred objects for which consumers enlist marketers to help transform from the profane (Arnould, 2004) this transition occurs naturally and almost immediately when people reach that sacred place.

An interesting extension to this understanding is that whilst hospices, once consumed, might be coded by the core self as a luxury offering, this coding is understood only by those experiencing it, once experiencing it, and not before. It is unanticipated, not sought out in a celebratory or enjoyable way as so often the case within the unconventional literature (Bauer et al., 2011; Eckhardt et al., 2015). Indeed, for those experiencing this environment, hospices symbolize anything but luxury pre-consumption. Not only are perceptions of luxury relative to the period in question, there is a further layer to this relativity, a temporality worthy of further study, both in extremis, and within studies of experiential luxury more generally.

Finally, in this consumer centric conceptualization of luxury, whilst economic narratives have been replaced by psychosocial factors, interesting questions linked to social status, often a marker of luxury in conventional research (Eckhardt et al., 2015; Cristini et al., 2017) also arise. Consistent with the view of other scholars (Arnould, 2004; Tynan et al., 2010), sacred things cannot be bought and sold, the hospice is part of the shared economy, a collaborative space which is not wholly owned by any one individual. Technically, it is available to all who reside in this liminal space. Yet the air is heavy with an unspoken exclusivity. Many fear for those less fortunate, less connected somehow to this offering, their experiences tinged by anxiety for others and an overwhelming sense of relief for themselves. Despite no monetary barriers being in place (free at the point of service), the findings confirm an exclusive dimension (Table 3) is present here. Hence, we challenge Bauer et al.'s (2011) suggestion of disconnecting consumer-centered unconventional luxury from social class. Analyzing the profile of the participants in this study does not support this thinking, with 84% of the sample in the higher socio-economic grouping. Particularly as the sampling strategy sought representation from all types of hospice users, this suggests that social status does play a role in the luxury that is hospice consumption. Whilst exploring the particulars of this role is beyond this study, a question instead for further research, it does add an important dimension to our understanding of unconventional luxury, suggesting that social markers are actually embedded further into luxury experiential consumption than previously acknowledged. Even where luxury consumption is something to be enjoyed primarily for the self (Bauer et al., 2011; Eckhardt et al., 2015), this opportunity may be compromised by a lack of access to experiences in the first place.

Unconventional luxury needs further research. Inevitably, the current study has limitations: data comes solely from UK consumers in physical hospice units, accessed via gatekeepers as per ethical approval. Whilst this is a common methodological approach, it is

also one which has acknowledged limitations inbuilt. Space limitations means data, already selected from a very large data set, are selective, both in terms of the keywords utilized and the subsequent analysis and interpretation. While we have no reason to believe our findings are atypical, further exploration among palliative care patients in non-hospice units such as hospitals, care homes, @home services, both in the UK and abroad, or those living with chronic illness, would offer further testing ground for the mundane and help reaffirm, or otherwise, the importance of the dominant themes that emerged as dimensions of unconventional luxury in this interpretive study.

References

- Arnould, E. J., & Price, L. L. (1993). River Magic: Extraordinary Experience and the Extended Service Encounter. *Journal of Consumer Research*, 20(1), 24-45.
<https://www.jstor.org/stable/2489198>
- Arnould, E. J. (2004). Beyond the Sacred-Profane Dichotomy in Consumer Research. *Advances in Consumer Research*, 31, 52-54.
- Atwal, G. & Williams, A. (2017). Luxury brand marketing—the experience is everything! *Journal of Brand Management*, 16, 338-346.
- Bainbridge D. & Seow, H. (2016). Measuring the quality of palliative care at end of life: An overview of data sources. *Healthy Aging & Clinical Care in the Elderly*, 8, 9–15.
- Bate, P., & Robert G. (2007). Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design. Oxford, UK: Radcliffe.
- Bauer, M., von Wallpach, S., & Hemetsberger, A. (2011). My Little Luxury. *Marketing ZFP*, 33(1), 57-67.
- Bauer, M., von Wallpach, S., & Hemetsberger, A. (2012). Luxury & myself - how luxury experiences contribute to consumer selves. *Proceedings of 41st EMAC, Lisbon*.
- Belk, R. W. (1988). Third World Consumer Culture. In E. Kumcu and A. F. Firat (Eds.), *Marketing and Development* (pp.103-127). Greenwich, CT: JAI Press.
- Belk, R. W. (2013). Extended self in a digital world. *Journal of Consumer Research*, 40(3), 477-500. <http://www.jstor.org/stable/10.1086/671052>
- Belk, R. W. (2014). You are what you can access: Sharing and collaborative consumption online. *Journal of Business Research*, 67(8), 1595–1600.
<https://doi.org/10.1016/j.jbusres.2013.10.001>

- Belk, R. W., Wallendorf, M., & Sherry Jr, J. F. (1989). The sacred and the profane in consumer behavior: Theodicy on the odyssey. *Journal of Consumer Research*, 16(1), 1-38.
[http://links.jstor.org/sici?sici=0093-5301%](http://links.jstor.org/sici?sici=0093-5301%20160100010001)
- Bell, S., Berg, T., & Morse, S. (2016). *Rich Pictures: Encouraging Resilient Communities*. New York: Routledge.
- Berry, C. J. (1994). *The idea of luxury: A conceptual and historical investigation*. Cambridge: Cambridge University Press.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Brun, A. & Castelli, C. (2013). The nature of luxury: a consumer perspective. *International Journal of Retail & Distribution Management*, 41(11/12), 823-847.
<https://doi.org/10.1108/IJRDM-01-2013-0006>
- Cappellini, B. & Yen, D. (2016). A space of one's own: spatial and identity liminality in an online community of mothers. *Journal of Marketing Management*, 32(13-14), 1260-1283.
<https://doi.org/10.1080/0267257X.2016.1156725>
- Churchman, R., York, G. S., Woodard, B., Wainright, C., & Rau-Foster, M. (2014). Revisiting perceptions of quality of hospice care. *American Journal of Hospice and Palliative Medicine*, 31(5), 521–526. doi: 10.1177/1049909113499441.
- Cleeve, H., Tishelman, C., Macdonald, A., Lindqvist, O., & Goliath, I. (2018). Not just things: the roles of objects at the end of life. *Sociology of Health & Illness*. May 2018. 40(4), 735-749. <https://doi.org/10.1111/1467-9566.12719>
- Cristini, H., Kauppinen-Räsänen, H., Barthod-Prothade, M., & Woodside, A. (2017). Toward a general theory of luxury: Advancing from workbench definitions and theoretical transformations. *Journal of Business Research*, 70, 101-107.
<https://doi.org/10.1016/j.jbusres.2016.07.001>

Department of Health (2016). Our Commitment to you for End of Life Care. Government Response to the Review of Choice in End of Life Care. Department of Health, London.

Diaz Ruiz, C. A., Holmqvist, J., & Penaloza, L. (2015). Consumers' moments of luxury: the case of salsa festivals. 44th EMAC Conference, Leuven, Belgium.

Eckhardt, G. M., Belk, R. W., & Wilson, J. A. (2015). The rise of inconspicuous consumption. *Journal of Marketing Management*, 31(7-8), 807-826.
<https://doi.org/10.1080/0267257X.2014.989890>

Featherstone, M. (2014). Luxury, Consumer Culture and Sumptuary Dynamics. *Luxury: History, Culture, Consumption*, 1(1), 47-69.

Frank, A. (1991). *At the will of the body*. Boston, MA: Houghton Mifflin.

Frank, A. (1995). *The wounded storyteller*. Chicago: University of Chicago Press.

Gillett-Swan, J. K. & Sargeant, J. (2015). Wellbeing as a process of accrual: beyond subjectivity and beyond the moment. *Social indicators research*, 121(1), 135-148. DOI: 10.1007/s11205-014-0634-6

Giovanni, L. A. (2012). End-of-life care in the United States: current reality and future promise—a policy review. *Nursing Economics*, 30(3), 127-134.

Graham, C. (2012). *The pursuit of happiness. An economy of well-being*. Washington: Brookings Institution Press.

Greenhalgh, T. (2006). *What seems to be the trouble? Stories in illness and healthcare*. Oxon: Radcliffe Publishing.

Gurzki, H. & Woisetschläger, D. M. (2017). Mapping the luxury research landscape: A bibliometric citation analysis. *Journal of Business Research*, 77, 147-166.
<https://doi.org/10.1016/j.jbusres.2016.11.009>

- Gysels, M., Shipman, C., & Higginson, I. (2008). Is the qualitative research interview an acceptable medium for research with palliative care patients and caregivers? *BMC Medical Ethics*, 9, 1-6. doi:10.1186/1472-6939-9-7.
- Han, Y. J., Nunes, J. C., & Drèze, X. (2010). Signaling status with luxury goods: The role of brand prominence. *Journal of Marketing*, 74(4), 15-30. <https://www.jstor.org/stable/27800823>
- Helkkula, A., Kelleher, C., & Pihlström, M. (2012). Characterizing Value as an Experience. *Journal of Service Research*, 15(1), 59-75. <https://doi.org/10.1177%2F1094670511426897>
- Hemetsberger, A., von Wallpach, S., & Bauer, M. (2012). 'Because I'm Worth It'-Luxury and the Construction of Consumers' Selves. *Advances in Consumer Research*, 40, 483-489.
- Hemetsberger, A., von Wallpach, S., & Bauer, M. (2013). 'All in Good Time': Narratives of Luxury Experience in Transition to Motherhood. *European Advances in Consumer Research*, 10, 287-288.
- Holbrook, M. B. & Hirschman, E. C. (1982). The Experiential Aspects of Consumption: Consumer Fantasies, Feelings, and Fun. *Journal of Consumer Research*, 9, 132-140. <https://www.jstor.org/stable/2489122>
- Hospice UK. (2015). Facts and Figures About hospice care. <https://www.hospiceuk.org/media-centre/facts-and-figures> Accessed 3 January 2018
- Iloranta, R. (2019). Luxury tourism service provision - Lessons from the industry. *Tourism Management Perspectives*, 32, 1-9. <https://doi.org/10.1016/j.tmp.2019.100568>
- Kapferer, J. N. & Bastien, V. (2009). The specificity of luxury management: Turning marketing upside down. *Journal of Brand Management*, 16(5-6), 311-322. DOI:10.1057/bm.2008.51
- Kapferer, J. N. & Laurent, G. (2016). Where do consumers think luxury begins? A study of perceived minimum price for 21 luxury goods in 7 countries. *Journal of Business Research*, 69(1), 332-340. <https://doi.org/10.1016/j.jbusres.2015.08.005>

Kauppinen-Räsänen, H., Koskull, v. C., Gummerus, J., & Cristini, H. (2019). The new wave of luxury. *International Journal of Qualitative Market Research*, 22(3), 229-249.

<https://doi.org/10.1108/QMR-03-2016-0025>

Kellehear, A. (2013). Compassionate communities: end-of-life care as everyone's responsibility. *QJM: An International Journal of Medicine*, 106(12), 1071-1075.

<https://doi.org/10.1093/qjmed/hct200>

Ko, E., Costello, J. P., & Taylor, C. R. (2017). What is a luxury brand? A new definition and review of the literature. *Journal of Business Research*, 99, 405-413.

<https://doi.org/10.1016/j.jbusres.2017.08.023>

Lendon, J. P., Ahluwalia, S. C., Walling, A. M., Lorenz, K. A., Oluwatola, O. A., Price, R. A., Quigley, D., & Teno, J. M. (2015). Measuring experience with end-of-life care: A systematic literature review. *Journal of Pain and Symptom Management*, 49(5), 904-915.

<https://dx.doi.org/10.1016%2Fj.jpainsymman.2014.10.018>

Llamas, R. & Thomsen, T. U. (2016). The luxury of igniting change by giving: Transforming yourself while transforming others' lives. *Journal of Business Research*, 69(1), 166-176.

<https://doi.org/10.1016/j.jbusres.2015.07.030>

Mansvelt, J., Breheny, M., & Hay, I. (2016). 'Life's Little Luxuries?' The Social and Spatial Construction of Luxury. In J. Armitage & J. Roberts (Eds.), *Critical Luxury Studies* (pp. 88-107). Edinburgh: Edinburgh University Press.

Meier, D. E. (2011). Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Quarterly*, 89(3), 343-380.

<https://dx.doi.org/10.1111%2Fj.1468-0009.2011.00632.x>

Moore, A., Carter, B., Hunt, A., & Sheikh, K. (2013). 'I am closer to this place' - Space, place and notions of home in lived experiences of hospice day care. *Health & Place*, 19, 151-158. doi:10.1016/j.healthplace.2012.11.002

- Morris, J. N., Suissa, S., Sherwood, S., Wright, S. M., & Greer, D. (1986). Last days: a study of the quality of life of terminally ill cancer patients. *Journal of Chronic Diseases*, 39(1), 47–62. [https://doi.org/10.1016/0021-9681\(86\)90106-2](https://doi.org/10.1016/0021-9681(86)90106-2)
- Picardie, R. (1998). *Before I say goodbye*. UK: Penguin.
- Pine, B. J. & Gilmore, J. H. (1999). *The Experience Economy*. Boston, MA: Harvard Business School Press.
- Ruvio, A. & Belk, R. (2018). Strategies of the extended self: The role of possessions in transpeople's conflicted selves. *Journal of Business Research*, 88, 102-110. <https://doi.org/10.1016/j.jbusres.2018.03.014>
- Sandsdalen, T., Grøndahl, V. A., Hov, R., Høyve, S., Rystedt, I., & Wilde-Larsson, B. (2016). Patients' perceptions of palliative care quality in hospice inpatient care, hospice day care, palliative units in nursing homes, and home care. *BMC Palliative Care*, 15(1), 79. doi: 10.1186/s12904-016-0152-1.
- Stiehler B. & Lee L.W. (2016) *Luxury Branding in Emerging Markets*. Proceedings of the Academy of Marketing Science. Cham: Springer.
- The Choice in End of Life Care Program Board. (2015). *What's important to me. A review of choice in end of life care*. UK: The Choice in EOLC Program Board.
- Thomas C. (2005). The place of death of cancer patients: Can qualitative data add to known factors? *Social Science and Medicine*, 60, 2597–2607. <https://doi.org/10.1016/j.socscimed.2004.10.020>
- Thomsen, T. U. & Sorensen, E. B. (2006). The first four-wheeled status symbol: Pram consumption as a vehicle for the construction of motherhood identity. *Journal of Marketing Management*, 22, 907-927. <https://doi.org/10.1362/026725706778935619>

Tonner, A. (2016). Liminal mothers' negotiation of conflicting service consumption. *Journal of Marketing Management*, 32(1-2), 100-120.

<https://doi.org/10.1080/0267257X.2015.1089306>

Turley, D., O'Donohoe, S. (2017). Mortality, morality and the marketplace. *Consumption Markets and Culture*, 20(5), 456-476. <http://dx.doi.org/10.1080/10253866.2017.1367679>

Turner, E. (2012). *Communitas: The Anthropology of Collective Joy*. New York: Palgrave Macmillan.

Tynan, C., McKechnie, S., & Chhuon, C. (2010). Co-creating value for luxury brands. *Journal of Business Research*, 63(11), 1156-1163.

<https://doi.org/10.1016/j.jbusres.2009.10.012>

Vargo, S. L. & Lusch, R. F. (2016). Institutions and Axioms: An Extension and Update of Service-Dominant Logic. *Journal of the Academy of Marketing Science*, 44, 5–23. DOI: 10.1007/s11747-015-0456-3

Veblen, T. (1994) [1899]. *The Theory of the Leisure Class*. London, UK: Penguin Books.

Walls, A., Okumus, F., Wang, Y., & Kwun, D. J. W. (2011). Understanding the consumer experience: An exploratory study of luxury hotels. *Journal of Hospitality Marketing & Management*, 20(2), 166-197. DOI: 10.1080/19368623.2011.536074

World Health Organization (2015). WHO Definition of Palliative Care.

<http://www.who.int/cancer/palliative/definition/en/> Accessed 3 January 2018

Wu, C. H. J., & Liang, R. D. (2009). Effect of experiential value on customer satisfaction with service encounters in luxury-hotel restaurants. *International Journal of Hospitality Management*, 28(4), 586-593. <https://doi.org/10.1016/j.ijhm.2009.03.008>

Zomerdijk, L. G., & Voss, C. A. (2010). Service Design for Experience-Centric Service. *Journal of Service Research*, 13(1), 67–82. <https://doi.org/10.1177%2F1094670509351960>

Table 1. Touchpoint Identification

Source	Details
Palliative care/Hospice policy documents	e.g., The Choice in End-of-Life Care Program Board, 2015; Department of Health, 2016; Hospice UK 2015
Academic palliative care literature	e.g., Churchman et al., 2014; Lendon et al., 2015; Meier, 2011; Sandsdalen et al., 2016
Hospice reports from CQC	The independent regulator of health and social care in England
Interviews with senior staff	CEO; Medical Director; Head of Clinical Services; Head of Fundraising.
Interviews: frontline & backroom staff	Ward nurses; Outpatient clinic nurses; Healthcare assistants; Reception staff; Volunteers.
Introspection	Two authors shared their first-hand experiences as loved ones had accessed hospice services
Unstructured interviews with 3 service users	No pre-determined questions: we simply asked users to tell us their most important memories and feelings from their recent experiences.
Customer experience literature	e.g., Helkkula et al., (2012); Zomerdijk and Voss (2010)
Observation	We visited a hospice several times, closely observing spaces and watching service users

Table 2. TTT Antecedents

Antecedent	Inspiration for TTT
Touchpoints	Any possible interaction (physical, symbolic, social) with any aspect of a service
Service Blueprinting	Mapping of tangible and intangible elements of the service: patient experiences must go beyond the clinical encounter.
Customer Journeys	Linear (and systematic) mapping of the customer experience. Journeys have a beginning, middle, and end-points and linkages between these stages are also important
Servicescapes	Place impacts experiences. Often overlooked, the environment in which healthcare is experiences can have a profound impact on people's experiences.
Rich Pictures	Pictures connect to sub-consciousness better than words & can uncover otherwise hidden emotions

Table 3. Participant Sociodemographic Profile (n=140)

Unit	N	Age								Gender		Ethnicity		SEG*		
		Under 14	15-24	25-34	35-44	45-54	55-64	65-74	75+	M	F	WB**	NWB***	AB	C	DE
A	38				1	7	4	15	11	10	28	37	1	17	17	4
B	31				2		3	14	12	15	16	31	0	14	14	3
C	28			1		6	4	5	12	12	16	27	1	12	12	4
D	21			1		7	5	5	3	5	16	21	0	9	9	3
E	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

*Socio-Economic Group

**White British

*** Non-White British

Figure 1. Example of the little extras touchpoint images



Figure 2: Conceptualizing Experiential Luxury in Palliative Care

