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Hospice topophilia and topophobia as experienced by a local population: Implications for equity of access

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ABSTRACT

The examination of hospice settings from the position of space and place is an emerging area of academic interest. Engaging with this perspective, this paper explores how topophilia and topophobia of the physical hospice setting coincides with and informs a broader love and fear of hospice care and UK hospice organisations. We report the findings of a qualitative study of 53 participants in the catchment population of a hospice in England. The coexistence of topophilia and topophobia of hospice is argued to have potential implications for equitable access to hospice care and may both facilitate and hinder efforts towards patient education and service improvement.

1. Introduction

Globally there has been increased interest in the equity of palliative care and how future needs may be met, particularly considering trends towards higher demand for end of life care (Sleeman et al., 2019; Larkin, 2019). Hospices provide one option for this care, but the services offered are known to be variable with documented inequity of access (Stajdhuar, 2020; Nelson et al., 2021). Within the UK there has been growing pressure to adapt and change hospice provision to improve inclusivity and accessibility (Hospice, 2018). In focusing on topophobia or fear of the hospice setting, this paper looks at how perceptions of hospice care may affect equity of inclusion.

The geographer Yi-Fu Tuan originated the term topophilia to refer to a positive emotional bond between person and place which may be experienced as love or admiration (Tuan, 1974). Tuan examined perceptions of the environment in relation to individuals' attitudes and values, arguing that culture influenced the positive relationships between people and places, including the understanding of a place's history and the symbolism that was attached to it (Tuan, 1974). Tuan later combined the concepts of topophilia and topophobia – a fear of places where we feel insecure - in his discourse on space and place, where he acknowledged that a place can be both loved and hated by different people because of their cultural background, experiences or relationship with that place (Tuan, 1977).

We propose here that the idea of an individual, or indeed a population, loving and/or fearing a place may have deep significance for hospice care provision and people's understanding and (dis)attachment to hospices.

The hospice is increasingly being studied from the point of view of space and place, with a recent growth in publications on hospice architecture and design appearing alongside studies exploring the lived experiences and spatial practices related to the inhabitation of hospice settings (McGann, 2013a; Verderber and Refuerzo, 2020; Harries, 2020; Bellamy, 2022; Worpole, 2023). Into the context of this emerging field of interest, this paper presents the findings of a study of the perception of a hospice by the inhabitants of its catchment area, revealing how their impressions of hospice care frequently overlap with, and are informed by, their perception of the hospice's physical setting. Employing Tuan's terminology, we discuss topophilia and topophobia as emotional responses to hospice settings which coexist within communities and even single individuals. The coexistence of topophilia and topophobia has previously been identified as existing in relation to other settings, such as the home, natural landscapes, and leisure settings (Gonzalez, 2005; Shores et al., 2024; Grundlingh, 2024) and are here presented as fundamental phenomena within the public perception of hospice and hospice care.

Research in palliative care needs to examine regional and national differences in context, culture, care practices, and terminology due to potential variations across populations (Timm and Vittrup, 2013; Kozlov et al., 2018). This study therefore investigated the interpretation and

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understanding of UK-based hospice care through the lens of a population in a geographically defined region representing the catchment of one hospice. The study aimed to uncover how people within that population - including patients, professionals, and the public - perceive hospice, and how that perception shapes their beliefs around the care that is provided, who accesses it, and how they access it. The findings indicate a strong connection to place, with a dichotomy of both love and fear of hospice care and the physical hospice environment.

2. Materials and methods

A case study methodology adopting a place-based approach was used to enable a diverse range of data and to facilitate '*in-depth exploration from multiple perspectives of the complexity and uniqueness of a particular project, policy, institutions, programme, or system in a 'real life' context*' [(Simons, 2009) p.21].

The focused region of this study was a UK city of approximately 300,000. It is a city known to have contrasts of affluence and growing commerce, and pockets of severe deprivation. Employment is high, but there are health concerns around lifestyle factors such as smoking and obesity. The hospice is a registered charity with both in-patient and out-patient services, family and bereavement support, localised training, support for other palliative care providers such as nursing homes, and a successful trading and fundraising section. The region and hospice have been anonymised to help protect the confidentiality of the participants of this study.

It was important that this study included the perspectives of people who were dying, people working within the local communities who had the potential to refer people into hospice care, and the wider population who arguably may be hospice users in the future. This resulted in three groupings of participants: patients, professionals, and the wider general population, which resulted in a total of 53 participants. To our knowledge, no other study on hospice care provision has examined the views of patients who do not access hospice care and the public, including people experiencing homelessness, as well as hospice patients and practitioners from the same population.

Different methods of data collection were selected which were considered most appropriate to each participant group, as summarised in Table 1. Identical questions exploring the topics on the meaning of hospice care, types of care, eligibility and access were posed to all participants, to enable analysis both within, and across the different participant groups. Pseudonyms were assigned to participants using an alphabetised system based on when they engaged in the study.

The study adopted a social constructionist perspective and acknowledged there are multiple knowledges, realities, or truths, which are dependent on conditions such as people's knowledge and experiences, as well as time and cultural location (Stainton-Rogers and Potter, 2006). This theoretical standpoint concurs with the thoughts of Berger and Luckmann who posited that objects could undergo *'objectivation'* whereby the object takes on a meaning based on the perceived purpose of that object in a particular context and time [(Berger and Luckmann, 2011), p.83]. For this study the object was the hospice building, and more abstractly, the care provided by the hospice.

This study applied a thematic analysis approach which has been used widely in palliative care research, including investigating perspectives within palliative care (Chapple et al., 2005; Froggat and Hockley, 2011; Powell, 2013; Sampson et al., 2014). The analysis required a reflective attitude to the data and findings, incorporating a familiarisation with the data, followed by creating initial codes which were grouped into larger themes for discussion (Sampson et al., 2014). Analysis occurred sequentially, focusing on the various sources of data first, and then a collective analysis of the whole data set. Generating the themes involved considerable reflection and analysis; using the case approach enabled that in-depth analysis to produce the most appropriate themes which reflected the content of the data. This paper focuses on the emergent themes of topophobia and topophilia. Ethical approval was gained from the Open University, and the UK National Health Service Research Ethics Committee (NHS-REC).

3. Results

This paper addresses two of the key themes identified within the results of this study: the significance of place within people's perceptions of hospice care, and how a duality of emotions was expressed relating to both a love and a fear, topophilia and topophobia, connected to the physical location of the hospice and the care provided. The findings are presented holistically, i.e. the collective responses from participants, as we did not find any significant differences between the study groups of patients, practitioners, and general public. The perspectives shared by the people experiencing homelessness also concurred with the overall findings in this study and are therefore not discussed separately.

3.1. Topophilia of hospice and love of hospice care

Individuals from each participant group expressed affection for the local hospice care provider, as well as for its physical setting. Even when participants were posed questions that related to hospice care, not the hospice environment, the setting was nonetheless referred to within several responses on the survey:

Table 1
Participant information.

Type of Participant		No.	Data Collection Method	Ethnicity and Gender		Age
Patients within last year of expected life	Accessing hospice care	3	Semi-structured face-2-face interviews	3 Male 5 Female	6 White British 1 White European 1 Black Caribbean	2 40-49 1 50-59 3 70-79 2 80-89
	Not accessing hospice care	5				
General public	Group 1 (random selection)	5	Face-2-face focus groups	7 Male 8 Female	11 White British 2 White European 3 Black British	2 18-25 3 25-34 4 35-44 2 45-54 2 55-64 2 65-74
	Group 2 (random selection)	5				
	Group 3 (people experiencing homelessness)	5				
Professionals working with people who may be at end of life	GP surgery clinicians	5	Qualitative postal survey	5 Male 25 Female	24 White British 2 White European 3 Black African 1 Asian	12 26-40 10 41-55 8 56+
	Hospice staff	5				
	Hospital staff	5				
	Homeless charities staff	5				
	Learning disability charities staff	4				
	Care home staff	3				
	Adult social care staff	3				

> *'it's positioned in a lovely place […] very calm and peaceful for patients'* (survey respondent from GP practice)

> *'when I visited the atmosphere was good and the setting lovely*' (survey respondent from homeless charity)

This suggests participants viewed hospice care and its physical setting as synonymous with their interpretation of the hospice environment being a pleasant therapeutic landscape, positively impacting their understanding of hospice care.

Participants also focused on the physical hospice setting rather than the care being delivered, a commonality across responses. When describing their high regard for the hospice care provider. A number of participants described the setting in positive terms such as feeling welcoming, comfortable, or cosy. This linked this to a perceived similarity to a domestic setting or care home:

> *'Nursing care but more like home than a hospital'* (Survey respondent from learning disability charity)

> *'I'd see it as a bit like an old folk's care home, sort of similar, with some similar issues. It's not the same thing, but I would expect a certain number of lounges, comfortable seats, you know, nice beds, areas where families can go'* (Focus group 2 general public participant)

The perceived pleasantness of the setting was linked to a positive interpretation of the hospice organisation. The high regard for the organisation was expressed in positive language such as 'wonderful,' 'lovely' and 'amazing' by both hospice users and those not accessing the hospice. Daisy, a hospice user, expressed her high regard for the hospice as a comforting feeling about hospice care, stating that the community's admiration for the hospice could put her friends and family at ease:

> *'It's a place where everybody knows … If you say you are going to [name] Hospice, you don't have to explain where you are going. I think it's a comfort thing? For them? And somewhere that's going to look after me when I really need it … I think people have got a love for places like [name] Hospice, I really do … It's lovely and comfortable, and they're nice and warm, and there's all things going on'* (Daisy, hospice patient)

The high regard for the hospice created the perception among participants that it was better than other hospice care providers, and there was nothing about the hospice that could be improved:

> *'From my aspect what they do is probably a higher standard than probably a lot of hospices currently, probably across the UK. It would be interesting to see where it ranks'* (Focus group 2 general public participant)

> *'It is very well regarded within the local community. It has an excellent reputation for high standards of care and supportive staff'* (Survey respondent from adult social care team)

This positivity impacted on people's willingness to discuss changes or improvements to the services currently provided, with some emphasising their lack of ability or willingness to provide any constructive or negative feedback:

> *'I've only got positives; I have not experienced any negatives and I'm not going to say something to exaggerate a negative'* (Clive, hospice patient)

The love of the hospice was also expressed in the sense of community ownership of the hospice, which manifested in involvement with fundraising and volunteering. These activities created a perceived connection to the site and appeared to enhance participants' positive affection of the hospice:

> *'I've worked in different companies and the hospice is always one of the fundraisers, one of the first names that comes out there, and in, I went to school here, and in school, we did fundraisers, and that was one where everyone had gone, everyone's got a story about it, a connection, I think it is really well regarded, erm, in terms of the work they do, like the impact they have on people'* (Focus Group 1 general public participant)

> *'Because it's not funded by the government, basically it's done by donation, we got the hospice café up here, gives them so many thousand pound a year, well, without people such as that, I don't think it would survive'* (Alan, non-hospice patient)

A common perception across the responses was a mistaken belief that hospices do not receive any government or NHS funding, demonstrating a lack of knowledge about hospice care providers. The local population may support the hospice through a connection with a geographical form of social identity (Carvalho et al., 2019) which can create a sense of social value, benefitting the local community for their involvement with the hospice (Ordille, 2016). Significant local fundraising had supported the establishment of the hospice in the 1970's and its subsequent development and service provision over recent decades, a history of fundraising and local connection our participants may have been aware of. However, the lack of knowledge of the hospice's services was noticeable, as referenced by Emma when reflecting on the local community:

> *'They'll know about [name] Hospice, but they won't know* ***about*** *[name] Hospice'* (Emma, non-hospice patient – participant emphasis)

This suggests that while topophilia of hospice settings and the love of hospice providers were connected for participants, they exist separately from an understanding of hospice care and are not necessarily underpinned by accurate knowledge of either the hospice site or the care provided.

3.2. Topophobia of hospice and fear of hospice care

The fear of hospice was expressed in discussions about the finality of hospice care and manifested in diverse ways between participants. Some directly associated the hospice with death and dying:

> *'I think of death, that's what I think of about the hospice'* (Focus group 1 general public participant)

> *'I thought it was a place to die'* (Focus group 1 general public participant)

For other participants, the perceived connection between hospice care and death meant that the hospice setting was imagined as a location to which people would go but never return:

> *'You go there you are not coming back. I've seen the hospice. That's how I understood it. No coming back out'* (Focus group 3 participant experiencing homelessness)

> *'You don't really think of people coming back out, do you?'* (Focus group 2 general public participant)

> *'I think that people, like you said, you know at end of life go in and they are there to die so, like once you are in a hospice I thought you don't normally come out'* (Focus group 2 general public participant)

For these participants, the hospice setting was perceived as an ominous or frightening location which embodied the finality of death. Participants also linked the connection to death with the idea of hospice care being only for the final weeks or days of life:

> *Frances: Hospice … that's somewhere I go to die, like elephants go off somewhere to die. If someone said hospice care, I would think of my experience of it, with my aunt, and my friend's mum, they went in, literally, and then died a couple of days later.*
>
> *Interviewer: So you see it as right at the end of that time then*
>
> *Frances: Yeah like when you can't be looked after in your home anymore, then you would go into a hospice to die …* (Frances, non-hospice patient)

A commonality across all participants including professionals, was a belief that the time when patients were accepted into hospice care was at the point of being very close to death:

> [Hospice care is for] *'people who are identified as dying and are likely in their last days or hours of life* (Survey respondent from nursing home)

> *'It's helping people to live out their last moments of life'* (Focus group 3 participant experiencing homeslessness)

Such perceptions are strongly indicative of a lack of awareness of hospice care being available for longer periods of time, or that it can be delivered in the community, again demonstrating the poor understanding of hospice care among participants.

Fear of hospice care was expressed differently between patient age groups. Frances, who was 47, believed using any services from the hospice was accepting the label of 'dying'. In her view this was a common perception, and created a fear of being associated with or entering the hospice for any reason:

> *'I think most people are scared of [name] Hospice, and to be associated with anything to do with there, like, be it counselling, or lymphoedema clinic, because automatically if something has anything to do with [name] Hospice it's because they are dying'* (Frances, non-hospice patient)

This shows how fear of the hospice and its perception as a place of death and dying created a reluctance among patients to accept hospice care referrals. Barbara, who was 57, also agreed there was a stigma of hospice care and an association with death. She acknowledged an irrational fear of shortening her own life if she were to agree to inpatient hospice care:

> *'When I was asked if I'd like to come here I sort of thought, "Oh I don't know if I want to go to the hospice" and I didn't know if I was jinxing myself. It's really silly, you have this, these thoughts and you know, like "I hope I never have to come here because I'm really, really ill"'* (Barbara, hospice patient)

Barbara appeared to be distancing herself from the identity of a hospice patient, despite being one, as she related being a hospice patient with the inpatients who were in a different part of the hospice building to the day centre she used. Barbara and Frances' comments show how their decision making about accepting hospice care was influenced by their (mis)perceptions of the 'correct' time to access hospice care and their fear surrounding what acceptance of this care would mean.

The older patients, such as Daisy, 81, perceived that fear was only a temporary feeling, connected more to their diagnosis rather than the hospice itself. She perceived hospice care to be a preferred option for older people, because of its association to comfort and care:

> *'I honestly do think, when you mention the word 'hospice,' erm, I think, it's probably seen as a relief to some people that they are going there, and they know they are going to be looked after … I don't think anybody, once they've got over the initial scary bit of being told its terminal, I think they would rather be in there than anywhere else'* (Daisy, hospice patient)

Even with this connection to dying, Daisy clearly stated that the prospect of being looked after at the end was a positive aspect and an attraction of hospice care. George, 73, similarly expressed his belief that the acceptance of hospice care, and of death, is related to age, and that as he has got older, he was less fearful:

> *'Things that used to frighten people years ago, maybe don't frighten them anymore. It's just I think they realise they think of things, and they process it, and it's not as frightening as what it was many years ago. Like … Hospice isn't as frightening to me now as it was many years ago'* (George, non-hospice patient)

This suggests that the extent to which decision making about accepting hospice care is impacted by the fear surrounding the hospice's association with death and the label of being a dying patient may differ between age groups and would not impact all patients uniformly.

In summary, expressions such as 'no coming back out' and 'place to die' reveal a stark contrast with the love of hospice care described by participants. Perceiving hospice care as synonymous with a hospice which is a 'place to die' could undoubtably impact people's willingness to consider hospice care as an option for themselves, their families, or their patients, and it is notable that the idea of the hospice as a physical place of death was evident in all participant groups. This perceived connection to death could work to contradict any awareness of the support and care that hospices provide for patients in the final years and months of life.

4. Discussion

The findings demonstrate a collective love and fear of hospice and hospice care, with both views often occurring simultaneously. Variance due to participants' age and circumstances such as prognosis were evident, highlighting that these emotive responses to hospices are complex and multi-layered. This may be due to people's perspectives on time, space, and the material world changing as they age (Bray and Goodyear-Smith, 2013). It was noticeable across participant responses that individuals frequently defaulted to discussing the physical space of the hospice, despite the questions posed being about the hospice organisation or care. This suggests the physical hospice site was connected, or even synonymous, in participants' minds with hospice care itself, meaning that both topophilia and topophobia of the hospice setting have significant potential to impact the perception of hospice care and its providers. This has important implications for the delivery of care and for hospice organisations, as we explore here.

4.1. The importance of hospice space

Milligan and Wiles suggested that care as a concept should not be limited to specific places and spaces (Milligan and Wiles, 2010); however, this research found that care was very clearly associated with the hospice building. The important of hospice space is asserted by McGann, who argues that 'the denial of the importance of quality space is contrary, not only to the inceptions of the hospice movement, but also to the findings of evidence-based healthcare design research' (McGann, 2013b). Indeed, the association between place and specific care practices is found regularly within healthcare, both in the evidence for the impact healthcare design can have upon patient experience and health outcomes, and the affective influence of healthcare spaces (Ulrich et al., 2008; Green and Lawson, 2011). Maggie's Centres, for example, have been described by Martin and others as having an 'emotional power' and as being 'emotionally charged buildings' which provide not only material, but social and affective resources due to their designs (Martin et al., 2019; Martin and Roe, 2022). Hospice care providers can reinforce the association between space and care themselves, for as Worpole argues, philosophies of care can be reflected in the architectural design of hospices, with design playing 'a key role in shaping people's expectations of later and end of life care' [(Worpole, 2023), p.8].

Hospice design can also perpetuate misconceptions of hospice care. Hospices within the UK were originally designed for longer term inpatient care provision, and as an alternative to hospital or home as a preferred place of death (McGann, 2011). This is markedly different to their current purpose, with most care provided by UK hospices in people's homes (Hospice UK, 2024). It can be challenging for physical hospice care environments to create a new identity which reflects this change in service model, leading to a misrepresentation locally of their role and function (Thornham and Parry, 2014). Research focusing on the symbolic understanding of mental asylum buildings provides findings which are relevant for the stigma which can be attached to hospice settings:

> *'The longevity in a stigma persisting results from that stigma becoming a myth or urban legend which continues to be written and rewritten in the history of a site until it becomes part of the identity of that place'* ((Gibbeson, 2020), p.3)

Brown posited that 'hospice' has three aspects – the philosophy of hospice care, the welfare policy, and the place (Brown, 2003), and it has been suggested that focusing on that ethos helps to define hospice care as an approach, rather than a building (Moore et al., 2013). Hospices themselves may believe that their ethos and philosophy are their most important aspects, but the community perceptions that we evidence in this research demonstrate that the physicality of place was the most notable aspect of hospice care provision for the community and therefore requires careful consideration in understanding public perceptions of hospice.

4.2. *Topophilia: community origins and the 'culture of niceness'*

While a love of hospice may simply be assumed as a positive force within a community, its causes and ramifications are arguably complex. The love of the hospice was frequently expressed by participants as a sense of belonging and ownership. The funding model for UK hospices usually necessitates some degree of community fundraising, and participants' references to fundraising activities demonstrated a sense of collective responsibility for supporting the hospice. Even without direct experience of hospice care, participants nonetheless perceived an affinity and collective involvement, for example small gestures such as buying a hospice lottery ticket creating a sense of '*doing my bit*.' Similarly, the involvement of volunteers was perceived as crucial and influenced the perception of the connection between the hospice and the local communities. This connection has been evidenced since the creation of the Modern Hospice Movement, with Cicely Saunders recognising the importance of volunteers within hospices (Saunders, 1990).

Indeed, all participants demonstrated a strong affection for the local hospice, finding it challenging to consider negative opinions or suggest improvements. This affection towards hospice care has been referred to as a *'culture of niceness'* [29 p.212]. Personal experience of the hospice did not appear to be necessary to perceive it as a positive place and therapeutic landscape, as participants' positive attachments to the hospice were expressed independently of direct involvement or experience with the organisation.

The culture of hospice care is intrinsically linked to that of the communities and population it serves. The language used within those communities are therefore influential in shaping people's perceptions. Participants struggled to define hospice care but reiterated their positive views in generic terms such as *'wonderful'* and *'lovely*.' Their high regard also related to hospice staff - being described as *'fantastic'* and *'angels*' - the hospice organisation, and the hospice building. The love of the physical setting resonates with Tuan's theory of topophilia (Tuan, 1974), which describes how people and cultures relate positively to their environment, physically, spiritually, and emotionally. This topophilia demonstrates what Kearns and Gesler noted when they discussed how places achieve reputations (Milligan and Wiles, 2010), and an understood truth, described as a *'cultural construction that arises from experiences, perceptions, ideologies, attitudes, and feelings'* [(Kearns and Gesler, 1998) p.17]. Such an understood truth about the hospice was evident in participants responses, which reflected a shared belief in the '*niceness*' of the hospice and the care it provides within this geographical region.

A focus on the physical location was evidenced in participants' responses on the aesthetics of the hospice. Participants noted how 'peaceful' and 'calming' hospice care was, demonstrating affinity to the landscape and environment as Tuan first described (Tuan, 1974). Davidson and Milligan advocated prioritising emotions when trying to understand how people perceive social spaces (Davidson and Milligan, 2004), linking back to original concepts of therapeutic landscapes (Gesler, 1992). The positive emotions expressed by participants in relation to the hospice space included it being described as comfortable, warm, or welcoming, with the hospice setting likened to non-institutional spaces such as domestic or care home settings. It was interesting to note that participants only linked positive attributes to the notion of home-like settings in these comparisons, describing the hospice space as positive because it differed from institutional settings such as the hospital, and not engaging with negative connotations of the home as a space of fear, alienation or domestic violence (Blunt and Varley, 2004; Blunt and Dowling, 2006).

4.3. *Topophilia: implications and potential mitigation*

The positive associations of hospice have potential implications for both public education on hospice care and the improvement of hospice buildings and services. High regard for a hospice organisation may facilitate local efforts towards awareness raising as audiences positively predisposed to hospice organisations could be more receptive to public engagement programmes. It could, however, also create difficulties for hospice organisations attempting to ascertain which improvements may be needed locally if individuals are unwilling to critique an organisation due to personal or professional relationships, or their affection. As noted in this research, there was a discomfort in critiquing the hospice by patients receiving hospice care, which may have been due to the relationship they had developed with staff. There may also have been a perception that criticism could impact their care, or bias towards giving responses that they considered were socially expected (Kamudoni et al., 2018). Worpole has furthermore identified how hospice staff can be reluctant to voice criticism of their sites or organisations "for fear of upsetting generous donors and fund-raisers," thus perpetuating the universally positive image of the hospice (Worpole, 2023).

Hospices therefore need to be mindful of the love of hospice and the unwillingness to constructively critique it, in particular in relation to how it may impact upon people's uptake and use of hospice care, and how hospices can improve service access and delivery to make it equitable. While UK government and charitable organisations endeavour to raise awareness of death and dying and the argued preference for care at home at end of life, there is an assumption that people understand hospice care due to the high regard in which hospices are held both locally and nationally. This research demonstrates, however, that while the topophilia of hospice may create the perception of knowledge and an understanding of hospice care among individuals, their level of knowledge about what care is offered, who it is for, and how it is accessed can in fact be varied.

Furthermore, people may not wish to 'bother' hospice staff, either because they are seen in such high regard, or, as in the case of patients such as Alan or Emma in this study, they may not feel 'deserving enough' or 'ill enough' to receive hospice care. Hospices need to be prepared to address such perceptions in patients, their wider communities, and healthcare professionals who may be required to refer clients for care.

4.4. *Topophobia: intersecting fear and stigma of hospice settings and hospice care*

Despite the considerable love for the local hospice evident in participant responses in this study, it was interesting to note how commonly discussion of hospice care and it's setting also evoked negative responses, which were often voiced alongside that positivity. As with the topophilia of hospice, the fear and stigma of hospice can be seen as complex in both their causes and their implications for hospice care providers.

4.4.1. *Topophobia of hospice buildings*

Fear of hospice was frequently directly associated with the hospice setting and building, therefore best understood as a form of topophobia. Exploring the concept of stigmatisation of place, Crang concluded it was often due to unequal relationships between the people connected to that place (Crang, 1998). With the hospice, the divergence between the status of those with a terminal illness, compared to those considered healthy or potentially curable, could be a driving force behind the stigma associated with the setting. In this study, the younger patients did not perceive themselves as dying, despite having a life-limiting condition, disassociating themselves from eligibility or even a desire for hospice care.

The patients interviewed described hospice care as related to their local hospice building, primarily as day provision and inpatient services, and most had known someone who had died in the hospice. This may have influenced their view that the hospice and its care were to be associated with the very end of life. This is a common view evidenced in other research where palliative care is perceived as a diminished possibility (Cheng et al., 2019; Van Klinken et al., 2019) in that hospice can be seen as *'a place to wait for death'* and *'an end to perceived hope'* (Collins et al., 2017).

The topophobia of hospice was not only related to the hospice building in a general sense but extended to the perception of stigma associated with specific parts of the building. Patients perceived the inpatient ward in particular to be a place of death, where one enters and never leaves. Patients using the outpatient clinic demonstrated a fear of this other section of the hospice, and distanced themselves from it, seeing those patients as different to themselves. This identity, which was established from the beginning of the Modern Hospice Movement, is still prevalent despite changes to care provision since the 1960s. Modern hospices were originally created as places for people to die comfortably, where care and support could be delivered that was, at that time, unavailable elsewhere. This research suggests that people still perceive this earlier form of hospice provision when considering hospice care today.

4.5. Stigma and topophobia: implications and potential mitigations

The stigma and topophobia of hospice identified in this study can have a range of negative implications for the delivery of hospice care. Indeed, there has been a known stigma worldwide related to the terminology 'palliative' and 'hospice' (McPhee, 1979; Giesbrecht et al., 2018). Therefore, this is not a new challenge for hospice care, however it is one that has not previously be explored in depth in relation to the hospice place and space.

The fear of the hospice setting and the perception of it as a place in which to die, or to not return from, could undoubtably impact the acceptance rates of hospice care referrals among the patients and family members holding these views. Half of the patients interviewed were reluctant to associate themselves with hospice care because of their fear that this association would cause them to become stigmatised with the negative identity of dying, and that they would be accepting they were nearing the end of their own life. These included patients receiving support from the local hospice, who either wanted to disassociate from the hospice, or certain elements of hospice care such as the inpatient unit. This concept has been noted in spatial stigma studies, where people from stigmatised geographical locations try to symbolically distance themselves from their location (Keene and Padilla, 2014). Hospice care providers need to explore ways to combat this stigma and the fear of the hospice space, potentially be raising awareness among their local communities about the reality of the hospice environment, which may be unknown to many people, or by allowing public visitors into the hospice to reduce the fear of the unknown.

The issue of the timing of hospice care was also shown to be a key area of misunderstanding for participants. Hospice care was viewed as being primarily delivered in the time just before death, with the hospice setting perceived as a place to go to die, rather than to go to for longer-term care. This misinterpretation of the reality of hospice care provision may impact both referral frequency and referral timings. This is concerning because late referral into hospice care has been shown to affect the type of care provided and the effectiveness of that care (Murray et al., 2017). Allsop et al. identified that UK hospices still are delivering what they define as a 'last weeks of life' service with 40% of referrals occurring within 30 days of death, particularly for older patients and those with non-cancer diagnoses (Allsop et al., 2018). What is unclear from Allsop et al.'s research is whether the patients were offered hospice care earlier, and refused, or whether the referrers did not offer the option of hospice care until the patients were nearer to the end of expected life. The extent to which fear and stigma surrounding the hospice setting may have played into this dynamic is also unclear and requires further investigation considering the prevalence of this fear evidenced in this study.

The correlation between hospice (care) and death which creates such stigma can be difficult to remove (Goffman, 1963). Certainly, the perception has persisted for decades that hospice care is only related to the very end of life, indicating it will be a challenge for hospices to alter this perception among the public. One direct approach to combat these issues would be education for healthcare providers and the public. The definition of hospice care and a particular focus on when it can be appropriately delivered needs emphasising to healthcare professionals and within local communities to reduce the risks to patients of not receiving timely and appropriate palliative care. It is crucial that hospice care providers are aware of the stigma surrounding their care, and the misconception that it is only available in the period immediately receding death, so that they can take steps to educate their wider communities to begin to redress this.

5. Conclusion

The findings of this paper demonstrate the importance of centralising hospice space and place in the discourse surrounding individuals' experiences and perceptions of hospice care. While the love of hospice organisations, and the fear of hospice care, are themes that have been separately identified in the public perception of care at end of life (Bray and Goodyear-Smith, 2013; Gill, 2020), this paper shows that they are often intrinsically linked to the idea of the hospice as a physical place, with topophilia and topophobia of hospice informing individuals' beliefs and decision-making regarding hospice care.

Future research in this field needs to embrace conceptual discussions about end of life space and explore individuals' emotional connections to these spaces. Research into the importance of hospice space and space and the community model of palliative care may help to redefine what we mean by a hospice care space, not only to understand how people perceive their care space, but also how we can change perceptions about hospice and palliative care more broadly. More attention is also needed in research to understand how perceptions of physical hospice settings impact broader public perceptions of hospice care, and the extent to which these perceptions impact healthcare professionals' decision-making regarding hospice care referrals, and patients' and relatives' decision-making on referral seeking and acceptance.

Our research furthermore points to several recommendations for policy and practice. Public education on when, where and by whom hospice care can be received is a key issue that needs addressing within wider populations to overcome inaccurate perceptions of hospice care. Hospice organisations will, however, need to be mindful of the potentially dominant focus among their audiences on the physicality of place when raising awareness in the community about their ethos and service provision. Understanding that fear and stigma coexist with love and affinity for hospice settings and organisations is an important strategic first step for hospices when building relationships with healthcare professionals, patients, and wider communities. We suggest that opening hospice grounds and providing imagery of the environment to the public, and offering familiarisation visits for patients and families in the period preceding the need for acute care, could be ways to reduce the fear and anxiety associated with hospice spaces and the subsequent impact on referral acceptance. Some hospices have taken more creative measures to reduce the stigma of place for example by venturing into educational visits and links with schools (Paul et al., 2019).

Positive misperceptions of hospice care providers could furthermore hinder attempts to engage with patients and the public on service improvements and the diversification of hospice care if providers are perceived as already offering an unfaultable service. Hospice organisations may therefore wish to engage in education alongside consultation on service improvement to facilitate constructive feedback from communities.

CRediT authorship contribution statement

Zana Bayley: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Lucia Crowther:** Writing – review & editing, Dr.

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Data availability

The data that has been used is confidential.

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