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# Author's Accepted Manuscript

Title: 'I am closer to this place' – Space, place and notions of home in lived experiences of hospice day care

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**TITLE: 'I AM CLOSER TO THIS PLACE' – SPACE, PLACE AND NOTIONS OF HOME IN LIVED EXPERIENCES OF HOSPICE DAY CARE**

**Abstract**

In the United Kingdom hospice day care services are the fastest growing yet least researched of the palliative care services. Using photo-elicitation interviews with 11 day care patients attending a specialist hospice day care setting we explored their experiences of the hospice as a place and how these changed over time.

Informed by concepts from existential and humanistic geography we propose three existential modes of being – Drifting, Sheltering and Venturing - which characterize the patients' lived experiences of the hospice. Our phenomenological analysis shows that the hospice is (re)constructed purposefully to achieve a sense of 'home' and 'homelikeness', creating an important therapeutic landscape for patients.

**Keywords:** UK; space/place; hospice; home; homelikeness; therapeutic landscapes

**Introduction**

In the UK, the 282 palliative day care facilities are diverse, broad and complex in scope and philosophy (Stevens, et al, 2011). Typically, hospice day care provides a facilitative environment for people with terminal or life limiting illnesses and their families. Whilst most patients have cancer, patients with other conditions including Motor Neurone Disease, Parkinson's disease and AIDS are increasingly seen as eligible. The hospice day centre commonly provides a combination of medical, social and respite care alongside arts and crafts, baths, cooked meals, massage and relaxation therapies during weekdays (Goodwin, et al, 2002, Myers and Hearn, 2001). The centres stand alone, or are attached to the inpatient

unit of a palliative hospital ward or a residential care hospice in the community. Although day care services are the fastest growing of a wide range of palliative care services, they are also the least researched (Myers and Hearn, 2001, Spencer and Daniels, 1998) and still remain somewhat confusing entities to many patients and health professionals (Myers and Hearn, 2001, Littlewood and Johnson, 2006). A more complete understanding of what they provide and how they contribute to the holistic care of patients is needed (Stevens, et al, 2011).

### **Hospice, Home and Place**

The principles of the modern hospice movement now inform services which have developed in different settings including hospitals, hospices, day care units and individuals' homes. The terms 'hospice' and 'hospice care' are frequently taken as a philosophy of care, omitting the importance of the physical place (Howarth, 2007, Salisbury, 1999, Spencer and Daniels, 1998). Raudonis and Acton suggest that:

*“Hospice is a concept of care, not a place. Hospice is based on a holistic philosophy of living and dying.” (ibid 1997, p, 140)*

The tendency to focus on the philosophy of care may encourage a disengagement from, and diminish the importance of, an understanding of hospice as a place and the experience of place in illness. Indeed, if it is based on a holistic philosophy, hospice *must* incorporate place. Brown (2003) describes the hospice as having a three-fold ontology, existing as a philosophy, a welfare policy, and a place. We contend that all action has meaning only in the context of

its surroundings, and thus hospice will always be co-constructed between philosophy and place.

The importance of creating a 'homelike' setting and notions of home in hospice environments is arguably a central tenet of hospice care yet few studies have engaged with this notion (Thompson, 1990, Rasmussen and Edvardsson, 2007, Kellehear, et al, 2009). Hospice day care has been described as a safe "retreat" or "haven" (Lawton, 2000), a "home" setting (Gates, 1991) or a "space to live" (Cannaerts, et al, 2004) whilst hospice in-patient wards have been described as a "no-place" (Lawton 2000). Brown (2003) considers hospice at home, but not home at hospice. Roush and Cox (2000) consider the meaning of home and its importance to reshaping how hospice nurses care for individuals at home. So far, only the work of Rasmussen and Edvardsson (2007) in a Swedish in-patient hospice and Godkin (1980) in an American hospital-affiliated palliative care unit seem to have engaged with the hospice environment from a truly place-centred perspective. This is surprising since it seems almost taken for granted that the values and the premise (and promise) of hospice care are that it should create a homely, rather than a clinical/medical, hierarchical and alien environment. This premise – albeit under-researched - is one of continuity between the patient's home and ideal notions of home (Cooper-Marcus, 1999, Verderber and Refuerzo, 2006). From a geographical perspective 'homely' places have been studied in a number of healthcare settings such as hospital isolation rooms (McKeever, et al, 2002) and residential care homes, where the replication of a homely environment was depicted against a tensile relationship between institutional and domestic attributes leading residents to feel they were "in a home" rather than "at home" (Peace and Holland, 2001).

Kellehear and Pugh (2009) note that studies by Bury (1982) and Exley and Letherby (2001) show the hospice environment as playing an important role in the social and spiritual wellbeing and the biographical continuity of those whose life course has been disrupted by the onset of chronic illness. However, while the intention of hospice is to provide some sense of biographical continuity to the life of the patient and their family, work by Broom and Cavenagh (2011) shows transitions into the hospice in-patient environment can also be disruptive, presenting the hospice as a semi-liminal place in which dialectical tensions may exist for some patients. This dislocation is experienced in both spatial and social domains. While Broom and Cavenagh (2011) address in-patient hospice transitions, these themes have been explored less in day care facilities, which differ in that patients are often in the earlier stages of illness, attending perhaps only one day a week.

Clearly, 'home' is not simply a residence but a way of being-in-the-world, a spatial metaphor for our relationship to places (Manzo, 2003), and an embodied experience of existence within the world (Svenaeus, 2001). Notions of home are central to Heidegger's understanding of the lived experience of human existence and the nature of our 'being-in-the-world' (Heidegger, 1971, Malpas, 2006). Svenaeus draws on this Heideggarian typology to explicate his phenomenology of health and illness: Heidegger contends that (cited by Svenaeus 2001, p, 94) the familiarity of the world in which we live is always pervaded by a homelessness: "This is my world but it is also at the same time not entirely mine, I do not fully know it or control it." We share the world with other people, and though the world is *my* world and I am at home in *my* world, this 'mineness' also incorporates *otherness* in the sense that the world has meaning for other people as well, thus we are never fully at home in the world. This basic underlying not-at-homeness, is kept at bay during health as we are engaged in routine activities that matter to us and have meaning for us, and health is then to be understood as a

*homelikeness*: “a being at home that keeps the not being at home in the world from becoming apparent” (Svenaeus, 2001, p, 94). When this everyday unselfconsciousness is disrupted by illness, it is experienced as a form of anxiety, which Heidegger referred to as the ‘uncanny’ or *unheimlich*, literally ‘unhomelike’ (Svenaeus 2001). Our basic not-being-at-home in the world is brought forth into a pervading unhomelikeness, characterised by feelings related to the disease, “experienced as a breakdown of understanding, which manifests itself concretely as pain, fatigue, nausea, anxiety, and so on” (Svenaeus 2009, p, 417). Svenaeus’ unhomelikeness focuses on an alienation from a sense of self and his phenomenology of health and illness furthers an understanding of how our experiences of illness affect our lived experiences of place.

### **Therapeutic landscapes and re-engaging with existential geographies**

The concept of therapeutic landscapes (Gesler, 1992) usefully provides a metaphor to explore the relationship between health and place (Gesler, 2005). According to Williams, “therapeutic landscapes are those changing places, settings, situation, locales, and milieus that encompass the physical, psychological and social environments associated with treatment or healing” (1999, p, 2). The therapeutic landscape concept has so far been used to explore a variety of healthcare settings including the hospital (Gesler, et al, 2004, Kearns and Barnett, 2000, Kearns, et al, 2003), birthing room (Fannin, 2003) and family planning clinic (Gillespie, 2002). However, Williams notes a shift in health service delivery in the transfer of care towards more informal settings such as the home, suggesting the notion of therapeutic landscapes provides a more holistic, socio-ecological perspective through which to view this shift in geographies of care (Williams 2002). Implicit within the therapeutic landscape notion is the concept of a positive sense of place (Relph, 1976, Tuan, 1977), and maintaining this creates possibilities for health promotion and a healing environment. Williams (2002) quotes



Jackson (1989 p.13) stating that a positive sense of place is “deeply relevant to the basic need for internal cohesion, mental health, a sense of security and direction, and a feeling of relationship with the world around one” (Williams 2002, p, 149). This is never more so in the case of terminally ill patients in whom these needs are often compromised. Whilst the idea of home is often presented as positive, it can also be a site of struggle. Exploring the home as an informal care setting, Donovan and Williams (2007) suggest that the meaning of home may change during illness, from therapeutic to non-therapeutic, particularly for informal caregivers. The physical and emotional labour involved in continuous care work is often straining physically, mentally, spiritually and intellectually. The hospice, potentially offers an ideal of home away from home, offering respite to patient and any informal carers, yet this ideal of home in hospice has not yet been explored through the notion of therapeutic landscapes. We acknowledge Milligan and Bingley’s (2007) warning against taking an uncritical view of what constitutes therapeutic landscapes, and recognize that environments may be experienced differently by individuals who experience non-therapeutic qualities such as fear and anxiety, in what others may intend as a therapeutic landscape.

While we draw on therapeutic landscapes as a way of exploring how patients perceived the various physical, symbolic, social and psychological landscapes of the hospice, our interpretations are also guided by the work of the existential geographers Seamon (1979, 1985), Buttimer (1980) Relph (1976) and Tuan (1977, 1979) whose work draws on Heideggerian phenomenology and Svenaeus’ phenomenology of health and illness which extends Heidegger’s account of being-in-the-world (Svenaeus 2001). Heidegger’s notion of being-in-the-world refers to the notion that we are always already *in* and *of* the world in which we find ourselves; we are indivisibly intertwined with it and all meaning and knowledge is therefore inescapably embedded or emplaced within it, and the structure

through which this lived reciprocity unfolds is called the lifeworld (Heidegger, 1971, Moran, 2000, Svenaeus, 2001, Seamon and Sowers, 2009). Our experiences within the lifeworld are always therefore experiences *in* and *of* spaces and places.

### **Methodology/Methods**

This phenomenological study focused on an exploration of the geography of care within a hospice day care environment. The study used semi-structured interviews and photo-elicitation interviews with patients, staff and therapists; however, in this paper we report findings which arise from the analysis of the patients' data.

### **Setting (context)**

Situated in northern England, the hospice provides specialist palliative care for terminally ill people and people with life-limiting conditions who require management of complex symptoms. The hospice comprises a 19 bedded in-patient unit on the ground floor, and the day care unit on the first floor. The unit provides for up to 20 day care patients per day, each attending one session per week. The hospice is well known in the community with more than 65 percent of financial support coming from fundraising activities and voluntary donations.

### **Sampling**

Purposive sampling was used to target recently admitted day care patients (aged over 18 years) at the hospice. The sample consisted of 11 day care patients. There were no restrictions on race or gender.

## **Recruitment**

Patients who met the inclusion criteria were informed about the study and given an information pack by a senior day care nurse (SDCN). The following week the SDCN would ask the patient if they agreed to meeting with the researcher [AJM] so that he could introduce himself and talk about the research. If the person agreed to take part, written consent was requested. The interview was undertaken at the hospice by AJM at a time convenient to the informant. As a means of reducing any pressure on informants AJM checked with the SDCN beforehand to determine whether the informant still wanted to be interviewed that day. Sometimes the patient would decline if they were feeling unwell. Twelve patients consented to take part, however, one died before commencing the research. While the hospice cares for individuals with a range of chronic or terminal conditions all patients recruited to this study had cancer. Of the 11 patients who participated there were 9 men and 2 women.

## **Access and Ethical Considerations**

Before applying to the Local Research Ethics Committee (LREC), AJM approached the hospice's Head of Care and spoke to a number of therapists and staff to seek their opinions on the proposed research. The proposal was approved by the hospice board of governors and official agreement to start the research was received December 2006. Ethical approval by an NHS ethics review committee was granted in July 2007.

## **Data collection**

To explore the lived experiences of patients, we used both face-to-face semi-structured interviews and photo-elicitation methods (Radley and Taylor, 2003a). In the past, the use of photo-elicitation in social and health care research has been rare (Harper, 2002), however, it

has an increasing evidence base in health-care research with the development of a coherent evidence base studying space and place (Oneha, 2001, Radley and Taylor, 2003a, Radley and Taylor, 2003b, Epstein, et al, 2006, Rapport, et al, 2007). Previous experience in the research team of using photo-elicitation and semi-structured interviews guided our decision to use this combined approach (Carter, 2005). The photo-elicitation method provides a way to study less accessible environments, as seen through the eyes of the informants, providing a bridge between psychological and physical landscapes (Bignante, 2010). The method offers a more nuanced and deeper understanding of how patients experienced the environment of hospice day care.

Patients were interviewed as soon as possible after their initial entry to day care in order to explore their first impressions of entering into the hospice. Subsequently, to explore any changes in hospice experiences and meanings, patients were then asked to photograph the spaces and places around the hospice that they found in some way positive or therapeutic, and those which they felt were negative or non-therapeutic. Patients were given disposable cameras capable of 27 exposures, when they signed their consent form. Patients were asked to take as few or as many photographs as they wished. During the six weeks after their initial interview patients photographed spaces and places in and around the hospice. The minimum number of photographs taken by a patient was nine, the maximum was 27. Information sheets given to informants stated that informants should be “particularly considerate of other people, as they may not wish to be recorded in a photograph”. When AJM spoke to the informants, he asked them not to include other people within the photographs unless they had that person’s permission and in the knowledge that their image would be ‘blacked out’ and not used in any publications. Films were processed so that AJM could arrange the photo-elicitation interview for the following week. More often this second interview occurred more

than six weeks later due to the informants' fluctuating health status or other commitments. Only five of the 11 patients completed both interviews as some died and others became too ill to carry on.

Prior to each photo-elicitation interview, the researcher [AJM] coded the informant's photographs on the back with a 'P' to indicate 'patient', a number to indicate which patient, and each photograph was distinguished alphabetically e.g. 'P5A' would indicate 'Patient' informant number 5, photograph A. Within the interviews the photographs were handed to the informants. The informants had control of the photographs allowing them to determine how they proceeded. The researcher verbally mentioned each code during the conversation so that the photographs could be identified on the audio-recording and transcription. The patients were asked to describe the content of the photographs in response to guiding questions such as: "Can you describe to me how you feel when you look at this photo? ...How do you feel when you're in that place? ...What is it about that place that you find therapeutic / dislike?" The interviews were recorded with consent and anonymised at the point of transcription. Pseudonyms were assigned to each informant and then used for the remainder of the study.

### **Data-Analysis**

Initial coding of the transcripts helped to signpost themes which were then reflected upon in a hermeneutic phenomenological manner. Initial codes included, for example, "feeling safe to talk", "closer relationships", "intimate spaces", "trusting in staff", "going out of the way". These led to the formation of the sub-theme "patient-staff relationships", which eventually became a part of the overarching theme "Sheltering". Four fundamental 'existentials' guided

phenomenological reflection; lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relations (relationality or communality) (Van Manen, 1997). In the process of phenomenological questioning, reflecting and writing, these four themes focused on the patient's experiences of the physical, social and symbolic landscapes of the hospice. Analysis of the lifeworlds described by the informants resulted in insights in: how they spoke about spaces and places within and outside the hospice, their experiences of their own body in health and illness, how they spoke about the past, present and future, and their relationships with friends, family and hospice staff.

## Findings

In reflecting on the themes it became apparent that three overarching existential themes resounded across the narratives of the informants. These became the three existential modes of being of 'drifting', 'sheltering' and 'venturing' that characterise the patients' lived experiences of the hospice.

Each theme conveys a mode of being which reflects the way patients related to their particular lifeworld at particular times, from their reflections on how they felt before initially entering into hospice day care and during their time there as a day care patient. We now describe each of these themes using direct quotes from the informants. Pseudonyms are used throughout, followed by the abbreviations *DCP* (Day Care Patient), and either *Int1* (first interview) or *PEI* (photo-elicitation interview).

## Drifting

Essentially, drifting is characterised by feelings of uncertainty and lack of control. As Frank (1995, p, 1) suggests, “serious illness ‘is a loss of the destination and map’ that had previously guided the ill person’s life”. Patients’ narratives often illustrated how they had effectively lost the bearings with which they had previously navigated their life and faced the chaos of uncertainty, experiencing fear when initially entering the hospice.

### Fear of entering the hospice

When entering the hospice for the first time, patients often described feelings ranging from apprehension, to fear, anxiety and dread. Such anxiety could originate from the patient’s own imagination; from the perception that hospice was a place to die, media representations and/or previous visits to friends or relatives who were in-patients. Bill felt it was a “place of no return” where things always “ended badly”. Andrea described apprehension and feeling “dubious”, giving the impression of uncertainty and doubt: a sense of drifting in the unknown:

*“It’s just what people think of places like this. Everybody just assumes this is where you’re coming to die, and it’s not, it’s a brilliant place.”(Andrea:DCP,Int1)*

Jim was both more graphic and explicit in his description of his initial fears of hospice as a place:

*“What I feared most was ...it was one of those grab places, they get you, they take you in...and you never come out of these places [...] I suppose I’ve watched too many movies really like you know [...] Well I always expected long corridors and dark passages and...people in rooms where they were...they either couldn’t come out of you know, bedridden or...and I just found the whole thing you know, in my mind very disturbing” (Jim:DCP,Int1)*

### The chaos of uncertainty

Jim’s initial fear of the hospice coupled with a lack of knowledge and uncertainty surrounding his disease combined to create a sense of what Relph (1976) describes as existential outsidership: a sense of not belonging. This was perhaps compounded by the alienation that some patients experienced in their lives prior to entering the hospice, which arguably influenced their experiences and perceptions of the hospice as a place. The patients no longer inhabited the world as they had before the disease, but became alienated from their sense of self and their taken-for-granted lifeworld:

*“People are scared of me now. They don’t come near me because they don’t know what to talk about” (Jim:DCP,Int1)*

Arthur describes this same sense of alienation. On visiting his local public bar where talking with friends was part of his taken-for-granted lifeworld his friends behaved differently when they found out he was terminally ill:



*“You know they're all talking around me. [...] It's like the old poor lepers isn't it? [laughing] [...] You know, 'oh he's a leper, throw him on an island somewhere'” (Arthur:DCP,Int1)*

Rather than being ‘at home’ in the bar, he found himself cast out of his familiar world, drifting in a state of unhomelikeness.

The sense of drifting was also apparent in the way that people experienced uncertainty around their illness. Patients saw the hospice as a place to find out more about their cancer, to build up some idea of a negotiable landscape. This was not always successful as Jim described feelings of being “left up in the air”. The individuality of cancer and the uncertainty surrounding the course of the disease was something he had not previously considered, not realising that “everyone is taken differently”. Jim talked about never getting to know at “what stage” he was at or whether he was improving or deteriorating. The hospice provided an “opportunity to find out how I’m doing”. Essentially Jim wanted some sense of orientation. Relph (1976, p, 43) in proposing that places are the basic elements in the ordering of our experiences of the world, leans on Max Scheler’s assertion: “To find one’s place in the world, the world must be a cosmos. In a chaos there is no place.” Cosmos may be defined as that which has a known order and meaning and therefore represents a navigable place. Jim was essentially describing a chaos, drifting in a ‘meaningless’ space:

*“...I could never ever guarantee how I’m going to be from day to day. One day I could be fine [...] but, there’s days when I can cope and there’s days when I have absolutely no chance at all” (Jim:DCP,Int1)*

Jim essentially describes feelings of placelessness (Relph 1976), in the sense that he was trying to establish a bearing within the psychological space of his own illness.

Despite their initial fears over entering into the hospice, all patients in the study felt more positive as they spent more time at the hospice. There was no doubt that the hospice was “good place” to those who chose to keep visiting. Even though Jim would never be able to guarantee how he would feel day-to-day, his experiences of the care offered “dispelled the fear and the dread”.

### **Sheltering**

The informants’ initial drifting experiences gave way to a sense of sheltering as they became comfortable and at home within the hospice.

Hospice day care offered a place in which they could re-orient themselves towards a sense of homelikeness, through experiences of sheltering. Patients sheltered within a sense of certainty in the care which was provided, in supportive relationships with staff and other patients, and in a sense of community, while the notion of home was never far from the patient’s imagination or the staff’s intention.

A common feature of patients’ experiences was a certainty of care, fostered by a sense of trust and a perception of staff acting through vocation which created a sense of ontological security:

*“...If they’ve given you something and then you say ‘and when you get time can you do so and so...’ They’ll say ‘I’ll do it now’. Or if they can’t do that they’ll*

*give you a time it will happen. And it did happen. Often they would go outside and because there are more people around, they would say ‘Percy needs so and so’ and it wasn’t trivialised, nothing was trivialised. A glass of water wasn’t trivialised, it came” (Percy:DCP,Int1)*

Patients were made to feel valued as individual people. This value was felt in the ‘closeness’ and proximity of care available to patients at the hospice; having time for patients, attending to their needs in such a way that conveyed they ‘mattered’ to the staff, created a sense of proximal caring, reducing the sense of distance between patient and staff (Malone, 2003). Giving a patient a time when something will be done creates what Bachelard (1964, p, 8) describes as: “a fixation in the spaces of the being’s stability – a being who does not want to melt away...” providing something that is certain for the patient to hold onto.

#### Patient-Staff relationships

Whilst patients sheltered within a certainty of care, they also described their relationships with staff in ways that suggest security, warmth, familiarity and closeness:

*“I’m closer to this place [hospice day care] than I am with my GP, my own family doctor [...] I feel like I can talk about more things here. Polly’s (auxiliary nurse) very good at bringing stuff out of me you know, she cajoles me...but I find that pleasant and easy to deal with” (Jim:DCP,PEI)*

Jim’s explanation of the human-human relationships he experiences are not separate from the human-place relationship which he describes as “close”. When he thinks of place he thinks of people-in-place, thus the place is not perceived as separate from the people within it. This

highlights the notion that relationships are always *emplaced* contributing to a sense of place that is essentially a part of the illness experience. He was “closer to this place” than he was with other places associated with his care, because of the therapeutic environment. Patients’ also perceived that the staff enjoyed their job and, as Douglas explained, it was “innate, that they’ll help you without question”. Percy stated:

*“...I believe these people do mean it – that they enjoy coming to work. They all have an attitude that says they’re here because they actually like doing it, but I’m sure that a lot of them could be earning more money doing something else, somewhere else. But they choose to be here, and they’re bloody good at it.”*  
(Percy:DGP,Int1)

The recognition that staff chose to care for patients because they genuinely enjoyed their jobs added to the patient’s perception of being in a place where one would be helped ‘without question’, confirming a sense of sheltering.

#### A “home from home”

Patients who had experienced drifting came to shelter in various ways; through a certainty of care, a sense of rootedness and at-homeness (Seamon, 1979), and feelings of ontological security (Giddens, 1990), redolent of those found in ideal notions of home. Constructed in a physical sense as a “home from home” the hospice incorporated items and symbols which were familiar to patients, such as flowers on the balcony, comfortable furniture and a place to relax and regenerate. Carl’s experience of homelikeness was evident in his description:

*“As I say, I have a garden, a big garden at home, and it’s like anything else, weather permitting I’ll sit out in there you know [the balcony in day care]. [...] In a way it’s a bit like home from home when I’m on my own you know and just chill out and relax” (Carl:DCP,PEI)*

Other symbolic items included odd mismatched furniture, the “humble jumble of bits and bobs” as Douglas described them, which being elements in the symbolic environment of home extended a sense of the domestic, creating a less institutional, more informal homely space, valued by the patients:

*“The key thing is, is that most of us have got houses, or lived in houses, or know people who’ve got houses, in which their living room is identical [to this one]. That to me has a warmth. A comforting feel of home about it. And it’s clean, it’s tidy, it’s neat. It’s a place where you can go and sit and enjoy the atmosphere” (Douglas:DCP,PEI)*

Douglas’ comments on the living room were particularly poignant in terms of Seamon’s (1979) notion of at-homeness which includes warmth, a comforting feel of home, where one can relax and enjoy a positive atmosphere.

Encouraging patients to treat day care as an extension of their own home creates a continuity that is important to the ideals of the hospice itself: that death is a natural continuation of the life cycle, as natural as the cycles of growth and regeneration apparent within the gardens of the hospice which provided a place to relax and reflect for many patients and staff. The

freedom and at-easeness to be able to *act* and to *be* as if one were in one's own home, creates the feeling of a home from home and the possibility of shelter.

### Home and Safety

A sense of being safe also enabled the patients to feel relaxed and secure. The physical, symbolic and social environments combined to create a sense of safety essential to the ideal of home and shelter:

*“...I feel very relaxed and I enjoy coming here [...] it's pleasant it's relaxing and you feel safe. And that to me is the most important thing. [...] That...you do feel safe you know, you feel like you can talk about anything. You feel like you're amongst friends [...] But yes that's the main thing here, is that you're relaxed and it's friendly and you feel safe” (Jim:DCP,PEI)*

While hospice provides this homelike shelter, patients also took the opportunity to venture and explore what lay beyond.

### **Venturing**

Homelike places provide a “point of departure” from which we move out and venture into “and take possession of the world” (Relph 1976, p, 40). The hospice offered opportunities for the patients to orient themselves, to find their bearings and to move forward with their life. For some, that involved making new friends, learning new arts and crafts, learning about their own disease, and experiencing new ways of being cared for.

“A vastly more interesting way forward”

In venturing, patients found opportunities to reach beyond their sheltering to return to a world from which some of them had felt alienated. While sheltering implies pause, venturing implies movement through which there is a basic transcendence of the present condition (Tuan 1977) and a sense of directedness. The hospice represents a pause on the patients' illness journey, a pause for rest and nurturing, but it can also provide choices and opportunities to venture forward to transcend a state of unhomelikeness, by moving towards something meaningful. Simply attending day care can be seen as venturing, as Jim suggests it taught him to get out and about, essentially to 'live':

*"It's taught me I think since I started coming here, that I must make the effort to get out and about. And there's a lot more to life than just sitting at home watching the television and reading the odd book and that, and worrying about what might be." (Jim:DGP,PEI)*

The act of 'getting out and about' speaks of movement, a venturing into the wider world, and embracing a wider perspective. Jim's words lead us to the sense that in his discovery he could move beyond his anxieties about dying. Similarly, Douglas pointed out that the hospice enabled him to move beyond such anxieties, opportunities such as learning to paint, having complementary therapies, and forging new friendships helped him to see beyond his sphere of illness:

*"...if you can be drawn into a circle of people who are positive and encourage you to look out beyond your sphere of nine to five then you can make the experience a positive one. It's up to you. [...] But you know there are opportunities there that can make you a positive person...and that to me is a way*

*forward. Vastly more interesting way forward than sitting here moping day after day” (Douglas:DCP,Int1)*

Being drawn into a circle of people who were positive and encouraging is characteristic of a sheltering experience but is also seen here to support venturing outside of the normal “sphere of nine to five” and what might be interpreted as the taken-for-granted routines and spaces of everyday life. Douglas described opportunities that provided him with “a way forward” and a sense of really *living* despite the constraints of his illness; a sense of venturing in a new and more positive way beyond the static alternative.

#### The limits to venturing

The hospice day care unit was situated on the first floor of the hospice building and the in-patient wards were on the ground floor along with the treatment rooms, the hairdressers, the shop and the smoking shelter. As a result day care patients would often come into contact with in-patients. In the first interview Jim spoke of meeting one of the in-patients at the smoking shelter. It was a revelation to him that the man was not in a state of “terror” but “living his life like me”. Jim spoke of how, over the weeks, he had learned to manage and “live with” his cancer. However, during the second interview he spoke of the limits to his venturing; that he had a feeling there were places, corridors he could not go beyond. He stated that he had “just built my own story in my head”. Psychologically he had created places he feared to go for what they might reveal. When asked if he put limits on himself, Jim replied:

*“Yeah, yeah, if you will really. Well because...you're in a sensitive place Drew.*

*There's people here dying [...] Like I say I can make things off limits, and even*



*now I feel that way. I don't ask anybody what's down there, because I already know the answer up here [Jim points to his head]. I've already made the answer up" (Jim:DCP,PEI)*

Jim's refusal to ask about the nature of those places highlighted his fear of crossing the final threshold, in terms of his own dying. He already had a sense of those places though he had not seen them; he imagined what they would be like, creating a psychological landscape of fear. He therefore defined the limits of his venturing, based on his fears of confronting his own death. He firmly emplaced himself in day care, not wishing to venture "downstairs" to the in-patient wards, illustrating how place functions to define one's sense of self:

*"To me this place is sensitive. Even though I find it relaxing and I come here for the day, but I have the limit. I just come here for the day care, enjoy the company, see the doctor, bit of time for me and relaxation and everything. But I do not want to go downstairs and see these people who are [close to death] [...] So it's difficult for me to say but I find that terribly sensitive, I don't know how I'd cope with it [being an inpatient]" (Jim:DCP,PEI)*

Jim's use of the term "sensitive place" is appropriate, as sensitive suggests an appreciation of other's feelings, and something kept secret or undisclosed to avoid endangering security.

Douglas' need to only go to places that were "important" to him was illustrated in his photograph of the staircase (see figure 1) at the end of the day care unit that joined the upper floor (administrative offices) and the ground floor (the in-patient wards):

*“Until we took these photographs, I hadn’t been upstairs, or downstairs. Other than to come in [to day care]. Whereas here we are re-affirming that concept, that there are other areas. There’s only one photograph of that, and it’s simply showing that...it exists. Because I haven’t been there, I haven’t been downstairs to where all the hospital care cases lie [...] I think it was last week when I saw a patient being delivered by...actually on a bed...the whole basket case. [...] The whole point of this photograph was just that there is things going on upstairs and things going on downstairs, and there’s a lot more going on than I’m aware of. [...] I don’t think to be honest it’s going to do me much good to find out”*

*(Douglas:DGP,PEI)*

**[Insert figure 1 here]**

To Jim and Douglas, their former perceptions of hospice as an ‘end place’ resurfaced, regardless of what they already knew to the contrary. Downstairs remained a ‘place for the dying’ a place for ‘basket-cases’: the limit of their venturing. These self-acknowledged limits reveal the fears and anxieties about crossing the final threshold. They also highlight that not all places within the hospice were perceived as therapeutic.

### **Drifting, Sheltering, Venturing: Finding a sense of home**

The findings illustrate how drifting, sheltering and venturing provide a way to access the deeper meanings of home and place in terms of how the patients experienced these at the hospice.

We have shown that in drifting patients' experience a loss of a sense of being at home in the world evident in feelings of existential outsidership (Relph, 1976), alienation, and uncertainty about their disease, their future and day care, which for many represented a psychological landscape of fear (Tuan, 1979). Giddens' notion of existential anxiety has resonance here; as the confidence in a continuity of self-identity and surrounding social and material environments is disrupted, questions arise about the self, others and the object-world, leading to ontological insecurity (Giddens, 1990, Giddens, 1991). This corresponds with Svenaeus' (2001) notion of unhomelikeness. Yet within drifting there is also venturing in terms of a search for meaning – essential to finding homelikeness within the self, and a search for a sheltering environment or homelike place. Thus the three existential modes may occur simultaneously within one another.

In sheltering, the patients' search for meaning defined the hospice as a place of knowledge – a “centre of meaning, or focus of intention and purpose” (Relph 1976, p, 22), helping to reorient them within the chaotic space of their illness. Through the social, physical and symbolic landscapes of day care, patients experienced ontological security, rootedness and a sense of at-homeness (Seamon 1979). This alternate homelike place helped them to become re-attuned with a homelikeness within the self. If unhomelikeness is equated with illness (Svenaeus, 2001, Svenaeus, 2009) and a sense of drifting, then homelikeness is equated with a feeling of at-homeness (Seamon, 1979) and sheltering, whilst venturing further strengthens notions of home as a significant anchor or point of orientation with the world (Relph 1976). Finally, in venturing, day care was experienced as a place that offered various opportunities for patients to re-engage with their life in a more meaningful and positive way.

While the experiences of day care patients reflects an almost uniformly positive perception of the hospice as a therapeutic place, the three modes of being show that this was not unchanging throughout. Not all places were perceived as therapeutic. As Milligan and Bingley (2007) suggest, it is critically important to recognise the ‘scary’ places in what might otherwise be perceived as a uniformly therapeutic landscape. The notion of boundaries to the therapeutic is implicit in the example of the in-patient ward, and these boundaries eventually have to be crossed if a patient accepts admission to die at the hospice. The hospice is essentially a liminal place characterised by many transitions (Froggatt, 1997) and the three modes of being described here may provide a way to explore such transitions in greater depth.

## **Conclusion**

Our phenomenological approach and use of theoretical concepts from existential geography has allowed us to theoretically contribute to the area, by bringing attention to the meaning-structure of the lives of people receiving care within the particular locality of a hospice day care setting.

Ultimately, the modes of drifting, sheltering and venturing reveal how patients perceived the spaces and places of the hospice in the context of health and illness, and how the various physical, social and symbolic landscapes of the hospice helped to mediate the transitions between the unhomelike and homelike, helping patients to find a sense of home, within themselves and within the hospice. In doing so our research reveals some of the essential characteristics of the meaning-structure of the lives of day care patients within the context of

the hospice setting, adding to a more complex understanding of *how* terminally ill people experience hospice as a place, and *why* they experience it as they do.

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Caption for Figure 1

Figure 1. Douglas's photograph of the staircase at the end of the day-care unit.



**Research Highlights**

- Using concepts from existential geography we consider hospice as a homelike place
- Through qualitative methods we explore patients' lived experiences of hospice day care
- Hospice can be a therapeutic landscape which includes non-therapeutic places
- As a place hospice helps to mediate transitions between the unhomelike and homelike
- We propose three existential modes that illustrate becoming 'at-home' in hospice