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Closed Panel : STS and the Design of Dying, Death and the Afterlife I

**A Place for Mortality: in-patient hospice architecture and its role in a dignified death.
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Abstract

This paper explores the role of design and architecture within palliative care environments to influence a positive experience of dying. As more demands are placed on in-patient hospices, many providers look to rejuvenate their facilities. Can multi-sensory, tactile approaches form rich comforting environments for those at the end of their life?

Formed of three qualitative case studies that unpick the subjective nature of the topic; local, regional and national scales develop narratives exploring the successes and failures to promote personal dignity. Beginning with an auto-ethnographic account of the authors time in a local hospice where the author’s Mother passed away; to primary data gathered through interviews with users from a regional hospice before a concluding analysis of a new build hospice.

The notion of ‘home’ is subjective reality experienced differently by all - however dignity within the but environment relies on a spatial hierarchy revolving around the needs of the dying person. This study highlights architectural strategies, from urban design to bespoke furniture, that mediate the details of domestic and hospital architecture by encouraging interactions of the dying person beyond the boundaries of their bedroom. Both socially and sensorially to promote a good life right to the very end - maintaining a connection between the dying person and the external world. The study draws attention to how rationalising medical environment and infrastructure offers a greater sense of trust to the dying person at the end of their life; markedly more personable than the environments of an acute hospital.

1. Preamble

“We have to put death into a space – to become something natural, and not a taboo...the hospice [gives] a signal in the public sphere that death is here – death becomes visible.”¹

Dying has for an extensive period of human civilisation been a process that occurred at ‘home’ - yet more of the population are dying in places of medical establishments as family units become dispersed in the face of the advancement of modern medicine. The over-medicalisation and institutionalisation is engendering anxieties and concerns for what “could be more properly regarded as a “natural” part of the life-cycle”² - illness taking precedent over person. Should there not be a focus on providing exemplary dignified environments for the those in the last moments of their life?

The consideration of sensory perception and atmosphere by many contemporary architect’s attempt to break away from homogenous generic spaces. They aspire to reconnect our bodily senses to what Bloomer and Moore describe as being architecture that is a “a sympathetic extension of our sense of ourselves”³ In the architectural profession the “front line” centre’s of palliative care are often overlooked for architecturally accessible day hospices where more lax medical regulations allow for imaginative and tactile environments that can invigorate our experience of place. What methods of inhabitation do patients and families respond to most positively in hospice environments and what lessons can be learnt in relation to dignity and dwelling in future hospices?

2. Methodology

2.1. Primary account – first-hand knowledge

My narrative is ‘the story [that] enables the reader to enter the subjective world of the teller...’⁴ by placing ‘emphasis on the ways in which I have interacted and been immersed with the

¹ SIGNAL Architects, *Programme For The Good Hospice In Denmark: An Outline For The Hospice As Part Of Palliative Care*, 2006, p. 23 <<http://www.hospiceforum.dk/media/TheGoodHospiceInDenmark.pdf>> [Accessed 7 June 2017].

² Brenda Neale, "Informal Care And Community Care", in *The Future For palliative Care: Issues Of Policy And Practice* (Birmingham: Open University Press, 1993), pp. 52-67 (55).

³ Kent C Bloomer, Charles Willard Moore and Robert J Yudell, *Body, Memory, And Architecture* (New Haven: Yale University Press, 1979), p. 78.

⁴ Ken Plummer, "The Call Of Life Stories In Ethnographic Research", in *Handbook Of Ethnography* (London: SAGE, 2001), p. 401.

culture being researched'⁵ and a critical self-awareness, it is intended that my uncommon positionality allows a visceral understanding of the research topic. My position as having borne witness to the subtleties and realities of a space in which individuals spend their last living moments develops the subjective rigour that a purely academic desktop evaluation cannot provide. The narrative of the inquiry takes the form of a multi-sensory account drawn from my memories of the senses of that experience - sounds, smells, textures, lighting is explored to provide insight into elements of the atmosphere that become key triggers of either comfort or discomfort.

2.2. Secondary account – convenience sampling

The selection criteria for this case study was defined to echo the limited choice that a dying person may have when planning or choosing to move to a hospice at the end of their life. Persons with terminal illnesses are not likely to want or be able to travel long distances, yet options are limited to the single hospice operating in the specific county. The critical case sample then was provided by participants who have had 'specific experiences' and took the role of the key informant.⁶ A short survey of no more than 5 questions posed to a small group of volunteers, that specifically asked for single word answers meant to evoke concepts and opinions was developed. Due to the limitation of the ability to build a rapport with the participants due to time constraints, this method provides a very simple way of initiating conversations.

2.3. Tertiary account – desktop analysis

The final case study is an example of a new build hospice that has gained critical acclaim as being a landmark project. The selection criteria for this account was driven by the project's recognition - a judgement sample stemming from a desire to analyse a building that was pushing the boundaries of both concept and quality of build. Due to the complicated nature of developing a brief for an intensive programme and securing necessary funding, the number of new builds are few in number dramatically narrowing the choice of hospices. Comprising

⁵ Nicholas L. Holt, "Representation, Legitimation, And Autoethnography: An Autoethnographic Writing Story", *International Journal Of Qualitative Methods*, 2.1 (2003), 18-28 (18)
<<https://doi.org/10.1177/160940690300200102>>.

⁶ Martin N Marshall, "Sampling For Qualitative Research", *Family Practice*, 13.6 (1996), 522-526 (523).

of a desktop study, which provides an overview of not only the site history and location, but development history, concept design and project aims and outcomes. The research will be carried out via primary and secondary source information inspired by the aims and outcomes of post occupancy evaluations.

3. The city hospice

Standing in the immense void between the furniture and my Mum's bed, I could feel my body desperately reaching out to touch and contort into shapes that felt familiar, yet nothing fit. I was too far away. How could we be close if the chair stops me; if it's too low to be level with her bed and too restricting to stretch out and hold her hand. I wanted to fit into this room just how we fit into the spaces at home.

The building was rectangular in plan with a small courtyard space in the middle. Offset from the central courtyard was the main corridor, with the bedrooms on the other side. It seemed to me sad that the garden was cordoned off; I noted that the windowsills were so high in the corridor that if you passed in a wheelchair or bed you wouldn't be able to see outside. All the bedrooms looked out to the external surroundings of the hospice wedged in its enclosed urban setting overlooked by roads.

It was silent, so blissfully silent compared to the unrelenting cacophony of the hospital. My ears tuned into the individual noises, birds outside, the soothing sound of people's voices, the occasional trickle of water. Buffered by a row of houses I could hear in the distance the joyous cheers of the children playing in the local park, the delightful tones echoing gently through the corridor as I turned into the room where my Mum lay. There was a view out of the windows to the left; pockets of greenery just visible over the windowsill before the other hospital buildings started. It made me think of her mobility, or lack thereof and her limitations. She lay confined to the scene in front of her.

As Maggie Keswick Jencks, the pioneer behind Maggie's Centre's wrote in her essay 'A View from the Front Line' - '...interior spaces with no views out and miserable seating against the walls all contribute to extreme mental and physical enervation. Patients who arrive relatively hopeful soon start to wilt'⁷ To dwell wasn't merely inhabiting the room, it wasn't enough. In a

⁷ Maggie Keswick-Jencks (London: Maggie's Cancer Caring Centre, 1995), p. 21.

transient place as the hospice, personal possessions were hard to display or find place for. There are textures and actions that can feel familiar but are not exclusive to individual people. The philosopher Maurice Merleau-Ponty proposes that as participants in environments, we take on the role of actors contributing to building our own worlds, not that of being a static audience member confined by the parameters of the stage, “I am not a spectator beholding a visual panorama, but an actor staging an ever-changing scenic drama.”⁸ She had not given up on living, yet it felt that the space had.

4. The suburb hospice

Providing a limited amount of beds on a first come first serve basis for the entire region of the city of Bristol, every effort is made to accommodate those who wish to move to the hospice, yet the abrupt nature of terminal illness means choice of facilities is not a luxury a dying person may have.

Amongst a pocket of tranquil greenery, the hospice sits in one corner of the park, facing a quiet residential road moments away from the A-road that leads back to the city; in-patients orientated back towards the park. A large car park surrounds the site, instigating a journey through the one-way system before arriving at the main entrance. Designed for day hospice users and loved ones, a lofty glazed atrium supported by large steel beams on timber plinths at skirting level intended to remove connotations of cramped hospital waiting rooms. By contrast the dying’s persons entrance⁹ sits to the rear of the site, amongst back of house facilities bypassing the layers of day hospice and communal areas.

A key finding of the data revealed that, without prompt, the participants defined the words ‘home’ and ‘homely’ as being inappropriate for describing hospices. In their place was suggested ‘safe’ and ‘secure’. As one commented “I wonder if it was too homely...there has to be a certain amount of efficiency, feeling like everybody is in control. like you're being looked after...”¹⁰ What this suggests, an astute observation on the balance between providing both medical and psychological care, is that designing an environment that is too domestic

⁸ Christopher Macann, *Four Phenomenological Philosophers* (London: Routledge, 2005), p. 188.

⁹ If arriving by ambulance as is the norm; it would only be on rare occasions that an in-patient would arrive by other means.

¹⁰ Interviewee Three, 2017.

may undermine the reassurance that the medical staff are able to perform their job of looking after the dying person to the best of their abilities. Participants were clear to mention that whilst aspects of domesticity had their place in the hospice "... at the end of the day it's a hospice, there has to be a hospital bed, everything that has to go with nursing a very disabled, very ill person..."¹¹. One comment highlights the need for "...space for something personal..."¹² whereby the bedroom can be flexible to adapt to the various situations of the dying persons who inhabit it, a scale of furniture and space that works in harmony with the equipment, without forcing a family orientated atmosphere which may be distressing for those without loved ones to support them.

It was particularly noted that "...people's privacy is...paramount, I think it's having the choice to be private and have that, but to integrate and talk to other people as well, I think that's to not feel isolated... you might feel in a hospital"¹³ This is not a question of the provision of single rooms over shared wards but instead the level of interaction that the room may offer the dying person. For those entering a hospice on their own the ability to connect and engage with the everyday of life is crucial, "I think that people still want to feel that kind of connection..."¹⁴, in essence to not feel forgotten about or that you do not matter. The current relationship to the outside world, via the landscaped garden is similar to that of the city hospice - the windowsills being at such a height that makes it difficult for the dying person to comfortably see out from their bed.

It is reasonable to expect that given the complexity of the hospice typology design guides provide key information on the operation of its day to day running; elemental to the provision of high standard of care. Yet, two out of 52 pages in the 'Design Guidelines for Specialist Palliative Care Settings', one out of 44 pages in the 'Design & Dignity Style Book' and none within the reports from the Kings' Trust turn their focus to the intimate environment of the dying persons, the bedroom. Given the intense nature of the way in which the dying person will dwell within the room, this does not appear to be proportional to the reports design ethos.

¹¹ Interviewee One, 2017.

¹² Ibid.

¹³ Interviewee Three, 2017.

¹⁴ Ibid.

A similar feature of all reports is the lack of precedent images, diagrams or sketches to help communicate the concepts within the written text.

5. The hamlet hospice

The hamlet hospice was described by the client as being a “...a landmark new vision for future Healthcare environments.”¹⁵ which they hoped the sustainable approach of the architect and design team towards the concept [and resulting design] would set it apart from any other new dedicated in-patient hospice in the United Kingdom. The key aim for the hospice was to ensure that a new building ‘is fit for purpose with scope for growth and development to respond to the changing needs of the community.’¹⁶

Discussions with the project architect revealed the extent of the community consultation, what they described as a perpetual back and forth conversation was upheld from the beginning of the feasibility study through to detail design. The architects would consult at the beginning and end of each stage to ensure that the concerns of the stakeholders were being recorded and resolved before moving on. By working from the anti-brief in layperson’s terms the stakeholders found description of architectural problems easier. Basing concept and spatial planning around the parameters of the stakeholder’s connotations of spaces the resulting environment creates the impression of a building scaled to human interactions. One that Eileen Gray described as embodying the “the minute situations of daily life”¹⁷ The synergistic nature of the brief development between architect and user affirms that belief mentioned earlier that successful hospice care is beyond the ‘bricks and mortar’¹⁸ but extends to the fundamental approach to the philosophy of care and respect of the dying persons.

¹⁵ "Architype / St. Michael's Hospice / The UK's Leading Passivhaus, Sustainable Architects", *Architype.Co.Uk*, 2020 <<https://architype.co.uk/project/st-michaels-hospice/>> [Accessed 13 September 2015].

¹⁶ Architype, *St Michaels Hospice Design And Access Statement*, 2010, p. 6 <<https://www.herefordshire.gov.uk/planning-and-building-control/development-control/planning-applications/details?id=102265&search-term=HR1%204HA&search-service=postcode&search-source=Postcode&search-item=HR1%204HA>> [Accessed 13 September 2015].

¹⁷ Juhani Pallasmaa, *The Eyes Of The Skin* (Wiley, 2012), p. 62.

¹⁸ G Young, "Hospice And Healthcare", in *Hospice: The Living Idea* (London: Edward Arnold, 1981), pp. 1-10.

Any person arriving is welcomed straight into the core of the spaces; emblematic of a focus on the 'person' opposed to the 'patient'. The transitional nature of crossing a threshold or boundary is highly symbolic; stepping as it were into the hands of the staff and into the acceptance that this will be the last building you enter. The act of entering into the centre, fully surrounded by the care spaces and the opportunity to look out to the landscape beyond embodies a sense of protection, almost womb-like. The clear definition of entrance and exit strategies away from ambulances or hearses lessens potential for distressing dying person, and or grieving persons. The material strategy to the new in-patient wing is successful in helping identify and emphasise a scale of domesticity to the dying person's future bedrooms; cedar shingles to the main administration block as you approach warms and will embrace the passing of time, settling the building into its place. Douglas fir timber cladding to each individual bedroom in each cluster creates a richness and calmness to the views from the dying person's bedrooms and a continuation of tactility from inside to outside.

The single storey in-patient wing to the hospice is shielded from any ambient noise pollution from the rest of the village by a dense two-storey administration block which allows the in-patient wing to exist in the landscape beyond. The junction of the new and old provides a clear 'heart' to the building, the old building and day centre to the left and in-patient to the right. Circulation to the in-patient wing is achieved through a central spine. Generous in both height and width, the corridor is flooded with natural light by roof-lights creating diversity between the intimate contemplation spaces rhythmically placed between the clusters and the larger animated communal living room spaces situated at the heart of each. The natural light here not only provides spatial distinction but the passing of time to visually manifest, refracting off the timber soffit making present the world outside – a dis-connection often felt in deep plan hospitals. Small intimate sitting spaces punctuate the communal and private spaces to encourage places of contemplation and reflection as opposed to the impression of clinical 'waiting' areas. A sense of rhythm through change of scale maintains a sense of domesticity between all the different zones of the building.

Re-configuring the traditional domestic 'airing cupboard' or 'ante-room' results in a visceral sense of inhabitation, rather than existence. The concept of clusters of bedrooms came about from the 'anti-brief' approach to the definition of what was not wanted. The bedrooms of the

dying persons at the hamlet hospice are scaled continuations of the larger material and phenomenological strategies of the hospice as a whole. The downpipes from the bedroom roofs have been designed to divert down the terrace structure to discharge into galvanised steel ‘pond’ tubs. Trickling and cascading, they create a visual and audio stimulus; drawing the natural landscape closer to a soothing bodily interaction that talks of the familiarity of the sensory everyday life. As Pallasmaa writes “...the flatness of today’s standard constructions is strengthened by a weakened sense of materiality.”¹⁹ The hoists installed in every room, instead of folding in a cumbersome manner into a corner or left visible as a permanent reminder of the dying persons loss of mobility are recessed flush to the ceiling and integrated as a piece of bespoke joinery. This piece of furniture serves the purpose of moving the hoist out of sight but provides a space for personalisation by the dying person.

6. Foundations of design

6.1. Community compassion

The hamlet hospice’s Head of Fundraising said “Building a new hospice is not a vision in itself. What is visionary is what our new premises will mean for patient care and support.”²⁰ Resulting in an attitude and approach to palliative care that extends beyond the physical structure of the building, reaching out to address the specific needs of the staff and volunteer team of that specific hospice and their demographics. It encompasses insights and visions of the day to day people [and as far as possible the dying person] - who understand the minutiae of palliative care. A participatory design process may result in a longer consultation and design period - but by doing so allows the nature of the care given to flourish and focus truly on the experience of the dying person.

6.2. Urban privacy

As McGann describes the deep plan internalised environments of hospitals ‘disconnect the occupier from the world outside...unconnected to his or her own world, dis-identified.’²¹ The architect’s deliberate situation of the hospice at the ‘cusp’ between the silence and

¹⁹ Pallasmaa, p. 31

²⁰ Housing LIN, *A Fresh Approach To Palliative Care – Sustainable Design*, 2015, p. 1
<http://www.housinglin.org.uk/_library/Resources/Housing/Practice_examples/Housing_LIN_case_studies/HLIN_CaseStudy_109_SustainableHospice.pdf> [Accessed 13 September 2015].

²¹ Sarah McGann, *The Production Of Hospice Space* (United Kingdom: Taylor and Francis Ltd, 2013), p. 59.

ambience of the everyday life of the hamlet allows the dying person to not be condemned to existing outside the world or overlooked by mundane infrastructure, but connected to the outside realm in a controlled and selective manner. In locations, such as the suburb and city hospice that are not surrounded by landscape creating captivating ‘micro’ gardens or courtyards that provide stimulus other than visual will inspire the dying person.

6.3. Arrival rituals

The decision to move from your home, hospital or other location in a large part is a part medical but is also psychological and an ability to willingly accept your course. It should follow that the journey made to arrive at the hospice reflects this. As Pallasmaa muses, ‘the door handle is the handshake of a building’²² - the crossing of the threshold is the occasion of the place within – ‘handshake’ implying a physical connection between the person and the act. The hamlet hospice provides an excellent example of the attention to the act of arrival to ensure a dignified approach from the viewpoint of the dying person; cedar shingles breaking up the form as you approach and the sweeping drive of cobbled brick sets welcoming you into the centre informing an architectural language that lies between hotel, home and hospital.²³

6.4. Domestic ecologies

A successful amalgamation of these typologies embraces a delicate balance making sure to create an appropriate hierarchy for each ecology of room; one that embraces the social role of loved ones in the dying person’s life. Simple provision of space for loved ones to sleep in the bedroom easily without need to organise a separate family room maintains the social unit and feelings of security of being near loved ones. The hamlet hospice encourages a ‘physical insideness’ through the re-invention of familiar intimate domestic moments; the mantelpiece, the airing cupboard and the living room. Given that the length of time a dying person may spend in a hospice can vary dramatically, the personalisation of a room is not always feasible or appropriate, highlighting the bedrooms need to be able to adapt to all the distinct situations of people who may live there.

²² Pallasmaa, p. 65

²³ McGann, p. 57.

7. Conclusion

Hospices are destined to be the mediation between the anonymous hospital room and intimate home. It is the balance of these roles that enable hospices to offer a dignified environment in which to live the last days of their life bringing together the most appropriate concepts to an architecture that is defined by ‘the experience of the occupier looking out, rather than the outsider looking in.’²⁴ As one stakeholder described “...it’s about living...allowing [dying] people just to be normal and have a life, have a social face, and not feeling anyone is feeling sorry for them or feeling depressed...”²⁵ This outlook and attitude is given strength by the actions of the architecture, supporting the community care framework.

At the conclusion of this study, the act of dwelling with dignity is not a question of generic ‘cosiness’, an over-romanticism of the nostalgic aesthetics of ‘homeliness’ and perceived comfort but a summation of efforts to construct an environment that is a physical reflection of palliative care, and one that encourages whole bodily interactions not only socially but sensorially. Dignity in the context of the in-patient hospice is the feeling of not being treated as a patient; but being allowed to feel yourself, a person. A place of death being the hospice puts the dying person’s identity above the treatments, the ward rounds, the clipboards.

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