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Observational Study on User Experience of In-Patient and Domiciliary Palliative Care Facilities Provided at Hospices

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Abstract: Palliative care in medical care is intended to provide comfort to patients with chronic or terminal disease from diagnosis and throughout the illness. MOH (Ministry of Health) has aimed to establish palliative care units for in-patient and out-patient facilities. However, there are no design guidelines for hospice centre because palliative care is still considered a new field in Malaysia. This study reviews the patients' perception of hospices in Malaysia based on layout, nature, privacy and social support. As a participatory hospice volunteer, this case study is carried out with qualitative observations and interviews on two chosen hospices as a case study based on their typology, namely Pure Lotus Hospice, an in-patient facility in Penang Assisi Palliative Care, a domiciliary facility in Petaling Jaya. The finding shows a strong correlation of user perception to the privacy provided in the hospice. This study infers planning for privacy should be a priority when planning for future hospices and policies.

Keywords: Patient perception, palliative care, hospice, interview, observations

1. Introduction

Hospice seeks to empower the dying patient with the ability to decide their care plan. However, services currently operate in conditions that make it difficult, even impossible, to provide the necessary medical treatment or ensure a safe and comfortable death (Hospis Malaysia, 2016). Malaysia's hospice continuum is constantly increasing. Palliative care was traditionally only given to late-stage cancer patients. Now, however, patients with non-cancerous life-limiting conditions receive palliative care. The Ministry of Health considers palliative care an important component of treatment that should be made available in all Ministry of Health Hospitals and at the community health services level (MOH, 2010). The Ministry of Health considers palliative care an important component of treatment that should be made available in all Ministry of Health Hospitals and at the community health services level (MOH, 2010). This thesis intends to explore the place and environment that the hospice is as important to the stages of death and dying as they are to our means of grieving and bereavement, and examine the patients' user satisfaction and experience with the palliative care services provided in hospices in Malaysia.

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2. Theories of Hospice

2.1 Hospice's Role as a Care Philosophy

The theory of palliative care has evolved since the hospice movement to include various services around the world. In Malaysia, more hospital and home-based services began to solidify around the early 1990s. One of the ways to define the philosophy of the hospice is outlined as follows: (a) providing the best medical care possible for the patient's medical discomfort; (b) providing an adequate understanding of the nature of the patient's condition and mental support in coping with the sickness as well as the impending death; (c) providing adequate spiritual assistance to the patient and family in dealing with the disease (Zimmerman, 1981).

2.2 Hospice's Role as a Care Facility

The hospice care service contains five basic typologies: the in-hospital hospice or palliative care units; the home; the nursing institute equipped with dedicated beds for hospice care; the medical centre affiliated free-standing hospice; and the non-hospital affiliated autonomous hospice. Hospice care service has three basic types based on its inhabitants: children, AIDS patients, and the elderly (Van den Berg, 2005). It is commonly considered a nurturing environment that leads to patients' safety and well-being (Ulrich, 2008): They contribute to a client's well-being, rehabilitation, and therapeutic, reducing patient tension and enhancing the patient's self-recovery potential.

2.3 Hospice's Role as a Healing Space

Table 1.1 - Physical Aspects of Hospice and the respective authors

Physical Aspects	Authors
Spatial Layout: single patient rooms, private bathroom and windows	Devlin and Arneill (2003); Van de Glind et al. (2007); Van den Berg and Van Winsum-Westra (2006); Ulrich et al. (2008); Mobach (2009); Herweijer-van Gelder (2016)
Nature: view of nature, presence of plants in the room and presence of images of nature in the room	Van den Berg (2005) Smith (2007); Ulrich et al. (2008); Park and Mattson (2009); Herweijer-van Gelder (2016); Rusdi and Omar (2019)

Table 1.2 - Social Aspects of Hospice and the respective authors

Social Aspects	Authors
Social Support: the extent to which the room facilitates this interaction.	Barlas et al. (2001); Devlin and Arneill (2003); Ulrich et al. (2008); Sadler et al. (2009); Herweijer-van Gelder (2016)
Privacy	Ulrich et al. (2008); Herweijer-van Gelder (2016)

Patients' perception is defined as an emotional response to an individual's place of residence (Devlin and Arneill, 2003). Van de Glind (2007) highlights that patients' satisfaction involves the occupant's spatial layout that encompasses the single patient room, bathrooms, and window placements. A key component of healing environments has always been nature as it reduces stress and enhances positive emotions (Van den Berg, 2005). Social support is the emotional, informational and tangible support that a patient receives and normally received from family and people in the social network (Ulrich, 2008). Privacy has the opportunity and choice to be alone or with other people, the possibility to withdraw from an unwanted situation visually and audibly and the possibility to not share information (Herweijer-van Gelder, 2016).

3.0 Methodology

Multiple case study method is chosen as a method for this research with 2 case studies. The data collection for this research comes from physical observation on case studies and conducting semi-structured interviews with the patients from 2 of the case studies. Physical observation focuses on three main components: physical attributes (space and context, architectural aesthetics and patients' behaviour in the physical environment), social needs (safety, security and community component), and facilities and services. Findings from each case study are documented tabulated for comparison. A sample of 20 patients was selected from 2 case studies for an interview with open-ended questions. Section 1 contains the demographic and social background of patients. Section 2 examines the thoughts of patients' thoughts towards hospices and their role as a healing philosophy. Section 2 focuses on their views of the environmental influence as their personal healing space via three main attribute categories — part 1: satisfaction with the layout; part 2: satisfaction with the provision of bathroom typology; part 3: satisfaction with the window placement the hospice/bedroom. Section 3 focuses on patients' comment on the social aspects of the hospice via two main attributes – part 1: social interaction about the space taken place and part 2: significance of privacy in hospice. The case studies area focuses on two palliative care service hospice located in Malaysia, namely Assisi Palliative Care, Petaling Jaya, and Pure Lotus Hospice, Georgetown Penang. The primary criteria for choosing the case studies are their typology regarding in-patient care and out-patient care.

Fig. 1 - (left) Case study 1 (Assisi Palliative Care); **(right) Case Study 2 (Pure Lotus Hospice)**

2.0 Findings

4.1 Space and Contexts

Pure Lotus Hospice provides in-patient facility care for its patients. Dedicated spaces are provided to cater for the patients, be it social spaces or functional spaces. An architect has designed the layout of the building during a recent built and renovation overhaul. There are shared five bedrooms for admitted patients with a shared toilet for every four patients. The isolation of each space is pronounced for the ease of attention from the caretaker. Assisi Palliative Care is an out-patient facility; thus, the similarity present from patients' home. Houses visited displays a similarity where minor changes were done to the existing living space to accommodate patients. Although the spaces are familiar and friendly to the patients, the makeshift space from a patients' residential proves to be inconvenient and often a hindrance to the palliative care service needed to provide care for the patients.

4.2 Architectural Aesthetic

Pure Lotus Hospice adopts a modern architectural style identical to most healthcare services in Malaysia. The detached building consists of 6 storeys, surrounded by green landscape. The material used is healthcare architecture influenced by adhering to a specialised small in-patient hospital's basic design guidelines. The built environment is dominated by the quality of balance and unity, emphasising symmetry through different material finish and colour to achieve visual harmony for the patients—spaces from daylighting to artificial lighting suitable for different spatial needs.

Assisi Palliative Care's out-patients homes exhibit a typical residential house emphasising the care space, namely the existing living room or the guestroom. Each house's conditions vary, with observation data showing little to minimal consideration of a good healthcare healing environments.

4.3 Patients' Behaviour in the Physical Environment

In both case studies, observation data shows the patient strongly prefers a strong correlation between the spaces used and a visual link to the outdoor spaces. Pure Lotus Hospice provision of dedicated outdoor spaces such as the activity roof and garden yard that is part of the palliative treatment schedule proves to be favoured by the patients. Most patients from Assisi Palliative Care are situated in the living room for ease of interaction and view to the outdoor.

4.4 Open-Ended Questionnaire

Table 1.3 - Tabulation of interview data

Question	Keyword and Primary Coding from Case Study 1 & 2
1. In your opinion, what do you think hospices are for?	From the interviewees' perception, hospice is a place where they come to rest and seek company and care while worshipping. It also provides ease of getting a consultation and social support. [Rest][Company][Worship][Ease][Social]
2. Do you think the palliative care facility of the hospice is succeeding in achieving its objectives?	From the interviewees' perception, most of them prefer the service of an in-patient facility as the doctor more frequents it. They also in favour of activities that can fill up their time as it becomes a social facility instead of a medical facility. [In-patient][Doctor][Homelike][Activities][Social]
3. Do you think the built environment plays a role in the healing process? Why?	From the interviewees' perception, most of them think that a built environment affects one's health. Some have rearrange the spatial layout for a better healing environment. [built environment] [serene][rearrange][ease][navigate]
4. Do you prefer your current bedroom layout (shared) or prefer a single bedroom layout? Why?	From the interviewees' perception, most of them prefer a single bedroom that has more privacy and free of judgement. On the other hand, some prefer to shift their bedroom to suit their need better. [single bedroom][private][judgement][shifting]
5. What are your thoughts on the bathroom provision (shared). Do you prefer your private bathroom? Why?	The majority of the users preferred private bathroom mainly due to hygiene and privacy reasons because it is where one is most vulnerable. On the other hand, most are also satisfied If the bathroom strikes a familiarity to the user while requiring some changes to serve patients better [private][hygiene][privacy][vulnerable][familiarity]
6. What do you think about the window height in the room? Would you have preferred to have it bigger?	From the interviewees' perception, most of them think a bigger window will have a better effect as it allows them to connect to the external world. Similarly, they prefer to be in closer proximity with the window, such as sliding windows [glare][view][balcony][connect][sliding door]
7. How would you describe the importance of the outdoor to you?	All of them think outdoor is crucial as it connects them with the neighbourhood. The ability to view out satisfies his needs to go out. Similarly, interviewees prefer to have activities outdoor. [connect][view][artificial light][brighter]

Question	Keyword and Primary Coding from Case Study 1 & 2
8. Where do you prefer to interact with other people/patients?	The majority prefer to interact in the living area to hold dialogue. 2 patients also highlighted that the outdoor provides a more relaxed setting. Similarly, domiciliary patients have the same preference as they prefer not to be seen too attached to their home [interact][bigger][relaxed][attached]
9: Where do you prefer to interact with your family?	All of the patients prefer a separate living area for interaction with their family. Preferably spaces that is semi private and should be open and easily accessible. Spaces take on the different function when palliative care takes over. [interact][semi private][indoor][transform]
10: What are your thoughts about being able to control and change the ambience	The majority agree the control is prominent to liberate patients to create a sense of independence. 4 patients pointed out that they prefer minimal assistance, and having control of personalised space is their utmost importance. [independant][personalized][smart home][privacy] [serene][rearrange][ease][navigate]

5. Discussions

Concerning the data collected through observation at the case study provided. These two case studies did not meet the single-bedded requirement; however, Pure Lotus Hospice's in-patient facility is a better institution because it has a building specialising in taking care of the patients. Based on the Ulrich theory of supportive design for a healing environment. According to Ulrich et al. (2008), windows should be large so that bedridden persons can look outside onto sunny nature spaces. The renewed building of Pure Lotus Hospice has a modern facade low parapet. The window becomes larger and lower, enabling the patient to look down, allowing them to alleviate depression (Herweijer-van Gelder, 2016).

However, there is still a lack of single bedroom design as well as a private bathroom. Both cases studies are with shared room and bathroom layout. Pure Lotus Hospice has a two-bedded bedroom to 5 bedded bedrooms that fall short of Ulrich's spatial layout criteria. With a shared bedroom, more people in the room (more patients, family and staff present), which increases the risk of spread infections and single-patient rooms, are easier to clean, reducing infections. Because there are fewer patients in the room, there is also less equipment in the room; therefore, there is less noise and improved patient sleep (Devlin and Arneill, 2003).

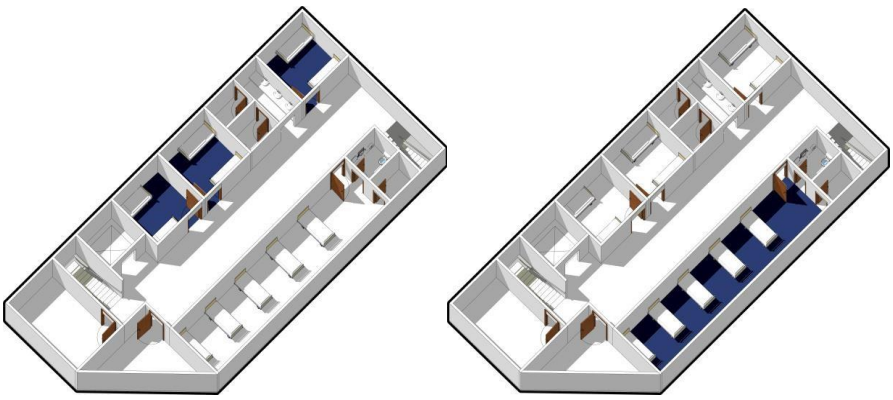

Fig. 2 - (left) Typical 2 bedded room; **(right) 3-5 bedded intensive care room**

A relationship was found between healing environment aspects and the level of well-being of patients. However, this relationship was not highly significant, and only 4 out of 6 factors showed a significant relationship. Based on the semi-structured coding, four main themes have been identified: Privacy, Room Layout, nature, and social. Privacy remains the most prominently discussed in the interview. To the patients' privacy is having the opportunity and choice to be alone or

with other people, withdraw from an unwanted situation visually and audibly, and the possibility to not share information (Herweijer-van Gelder, 2016).

6. Recommendations

This research study recommends that the key components which acquired low satisfaction level from patients to be reassessed and improved for future serviced hospice developments. Improvements on the following variable components are fundamental in the future development of hospice care facility to enhance patients' satisfaction levels

- Single bedroom rather than multi-bed rooms
- Effective ventilation systems
- A good acoustic environment
- Improved floor layouts and work settings
- Appropriate lighting
- Better ergonomic design
- Acuity-adaptable rooms
- Nature Distraction
- Daylighting

7. Conclusions

This research paper has studied the healing environment theory and its criteria to be considered successful in a hospice design. Based on theories, it has been identified that there are main six criteria that define the healing environment in hospice and the success of a hospice, namely, Bedroom layout, bathroom provision, windows, social support, and privacy. From the case study, we have learned that case study 1 in-patient hospice is better suited to care for palliative care patients even though it did not meet all the requirements, namely the spatial layout of a single bedroom and private bathroom.

We understand that there is a need for a single bedroom layout and a private bathroom to meet all the healing environment criteria. This research paper also found the relationship between user perception and how they respond to each other. Through semi-structured interviews, four themes were identified: privacy, room layout, nature, and social support. The literature review elements correspond with these four themes that dictate how the user feels about the hospice architecture as a medium for healing.

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