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

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

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

1. Introduction

Hospice seeks to empower the dying patient with the ability to decide their own care plan, but services are currently operating in conditions that make it difficult, even impossible, to provide the necessary medical treatment or to ensure the safe and comfortable death of a person. (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 to be an important component of treatment that should be made available in all Ministry of Health Hospitals and also at community health services level. (MOH, 2010). The Ministry of Health considers palliative care to be an important component of treatment that should be made available in all Ministry of Health Hospitals and also at community health services level. (MOH, 2010). This thesis intends to explore the place and environment that is the hospice are 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 a variety of 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 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 center 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 the safety and well-being of patients. (Ulrich, 2008): They contributes 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 emotional response to an individual’s place of residence (Devlin and Arneill, 2003). Van de Glind (2007) highlights that patients’ satisfaction involves 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 enhance positive emotions (Van den Berg, 2005). Social support is the emotional, informational and tangible support that a patient receives and which is normally received from family and people in the social network (Ulrich, 2008). Privacy is having 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).
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 3 main components, which are 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 and tabulated for comparison. A sample of 20 patients was selected from 2 case studies for interview with open ended questions. Section 1 contains demographic and social background of patients. Section 2 examines the thoughts of patients’ thoughts towards hospices and its role as a healing philosophy. Section 2 focuses on their views of the environmental influence as their personal healing space via 3 main attribute categories — part 1: satisfaction with layout; part 2: satisfaction with the provision of bathroom typology; part 3: satisfaction with the window placement of the hospice/bedroom. Section 3 focuses on patients’ comment on the social aspects of the hospice via 2 main attributes — part 1: social interaction in relation to the space taken place and part 2: significance of privacy in hospice. Case studies area focuses on 2 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 in terms in-patient care and out-patient care.

3. Findings

3.1 Space and Contexts

Pure Lotus Hospice provides a in-patient facility care for its patients. Dedicated spaces are provided to cater for the patients be it social spaces or functional spaces. The layout of the building has been designed by an architect during a recent built and renovation overhaul. There are shared 5 bedrooms for admitted patients with shared toilet for every 4 patients. The isolation of each spaces is pronounce for the ease of attention from the caretaker. Assisi Palliative Care is an outpatient facility thus the similarity present from patients’ home. Houses visited displays a similarity where minor changes done to the existing living space to accommodate patients. Although the spaces are familiar and friendly to the patients, from observation, the makeshift space from a patients’ residential proves to be inconvenient and often time a hindrance to the palliative care service needed to provide care for the patients.

3.2 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 are healthcare-architecture influenced with adhering to basic design guidelines of a specialized small in-patient hospital. The built environment is dominated by quality of balance and unity of with emphasis on symmetry through the use of different material finish as well as colour to achieve visual harmony for the patients. Spaces from daylighting to artificial lighting suitable for different spatial needs.

Assisi Palliative Care’s outpatients’ homes exhibit a typical residential house with emphasis on the care space namely the existing living room or the guestroom. Conditions of each houses varies with observation data showing little to minimal consideration to a proper healthcare healing environment attributes.
3.3 Patients’ Behaviour in the Physical Environment

In both case studies, observation data shows that the patients’ strong preference to the outdoor spaces to carry out palliative treatments. There is a strong correlation seen between the spaces used as well as 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. For patients from Assisi Palliative Care, most patients are situated at the living room for ease of interaction and view to the outdoor.

3.4 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 perception of the interviewees, hospice a place where they come to rest and seek company and care while being able to worship. It also provide ease of getting consultation and social support. |
| 2. Do you think the palliative care facility of the hospice are succeeding in achieving their objectives? | From the perception of the interviewees, most of them prefer the service of an in-patient facility as it is more frequented by the doctor. They also in favour of activities that can fill up their time as it becomes a social facility instead of a medical facility. |
| 3. Do you think the built environment plays a role in the healing process? Why? | From the perception of the interviewees, most of them think that built environment affects one’s health. Some have rearrange the spatial layout for better healing environment. [built environment] |
| 4. Do you prefer your current bedroom layout (shared) or do you prefer a single bedroom layout. Why? | From the perception of the interviewees, most of them prefer the single bedroom that has more privacy and free of judgement. On the other hand, some prefer to shift their bedroom to better suit their need. [single bedroom][private][judgement][shifting] |
| 5. What are your thoughts on the bathroom provision (shared). Do you prefer your private bathroom? Why? | Majority of the users preferred private bathroom mainly due to hygiene and also privacy reasons because it is where one is most vulnerable. On the other hand, most are also satisfied If bathroom strikes a familiarity to the user while requiring some changes to better serve patients [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 perception of the interviewees, most of them think bigger window will have better effect as it allow 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 outdoor to you? | All of them think outdoor is crucial as it connect them with the neighborhood. 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? | Majority prefer to have interaction at the living area for its ability to hold dialogue. 2 patients also highlighted that 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
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 different function when palliative care takes over.
10: What are your thoughts about being able to control and change the ambience | 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 a having control of personalised space is their utmost importance.

4. Discussions

With reference to the data collected through observation at the case study provided. These two case studies did not meet the single-bedded requirement however it can be observed that the in-patient facility of Pure Lotus Hospice is a better institution mainly due to it has a building that specializes 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 which enables the patient to look down allowing them to alleviate depression. (Herweijer-van Gelder, 2016).

However there is still a lack of single bed room design as well as private bathroom. Both case studies are with shared room and bathroom layout. Pure Lotus Hospice have a 2 bedded bedroom to 5 bedded bedroom which fall short on Ulrich’s spatial layout criteria. With shared bedroom more people in the room (more patients, family and staff present) which increases the risk of spread of infections and single patient rooms are easier to clean which also reduces the risk on infections. Because there are less patients in the room there is also less equipment in the room; therefore, there is less noise and patient sleep improves (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 coding from the semi-structured, 4 main themes have been identified: Privacy, Room Layout, Nature as well as Social. Privacy remain the most prominent discussed in the interview. To the patients’ privacy is having 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).

5. 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 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

6. Conclusions
This research paper has studied the theory of healing environment and its criteria to be considered a successful in a hospice design. Based on theories, it has been identified that there are main 6 criteria that define the healing environment in hospice as well as success of a hospice, namely, Bedroom layout, bathroom provision, windows, social support as well as privacy. From case study, we have learned that case study 1 in-patient hospice is better suited to care for palliative care patient even though it did not meet all the requirement namely the spatial layout of single bedroom and private bathroom.

From here on we understand that there is a need for a single bedroom layout and a private bathroom in order to meet all the healing environment criteria. This research paper also found the relationship of the user perception to the space and how they respond to each other. Through semi-structured interview, 4 themes were identified being privacy, room layout, nature as well as social support. Elements identified in the literature review correspond with these 4 themes that dictate how the user feel about the hospice architecture as a medium for healing.

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