

The Palliative Care Unit: Does Room Design Matter?

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Abstract

Objectives: The primary purpose of this needs assessment study, which looked at the palliative care population of Bridgepoint Hospital, Toronto, was to describe what patients and their families perceive to be important elements in the design of a hospital palliative care unit (PCU) for end-of-life care.

Methods: Twelve semi-structured interviews were conducted (six patients and six family members), using a set of nine standard questions. The qualitative philosophy of phenomenology was used for data analysis. Themes identified were grouped into two categories: I) External Reality and II) Internal Experience.

Results: In the External Reality category, participants identified eight themes: room size, noise, light, storage, temperature, colour, washrooms, and social spaces. Families identified additional factors: ventilation, furniture and hallways as social spaces. In the Internal Experience category, both groups identified privacy and autonomy. Shared rooms were mentioned in reference to companionship, social interaction, patient compatibility, visitor experiences and observing the dying process. Family members felt that room type should be based on the stage of illness, and expressed a need for spaces that promote participation in care.

Conclusions: Patients and their family members defined key issues related to end-of-life care and the physical environment. The preferences of both patients and their families demonstrate the need for a sensitive design approach to an environment for the terminally ill – one that provides a variety of private and social spaces.

This study looks at the palliative care population of Bridgepoint Hospital in Toronto, and evaluates patient and family preferences for room design and layout, as well as preferences for private versus shared accommodations.

Background

Bridgepoint Health is Canada's largest integrated health care organization for specialized complex care services, including rehabilitation, long-term care and community-based care.⁴ The Bridgepoint Hospital PCU has 41 patient beds and offers the option for short- or long-term palliation. The majority of rooms are shared by four patients (ward-rooms), several are shared by two patients, and there are currently no single or private rooms in either unit.⁵ The World Health Organization (WHO) defines palliative care as, "the active, total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families."⁶

One of the health concerns facing the patient population at Bridgepoint Hospital is their physical environment, which is an important determinant of health.⁷ The existing hospital structure, built in 1963, is semi-circular in shape, making it a challenge for many patients to navigate the hospital (Figure 1). Wheelchairs are difficult to manoeuvre in a curved hallway and patients suffering from neurological diseases can often become disoriented without proper visual cues. Rooms are small and unable to accommodate wheelchairs, which are left in the hall.^{5,8} There are no washrooms in any of the rooms; they are instead located at the end of each unit. Bridgepoint Health is currently embarking on a major redevelopment project that will include a new hospital building and the design of a new and larger PCU.^{4,5,8}

Precedent Research

The literature presents us with precedent studies that have suggested single rooms have a number of benefits over shared rooms, including greater flexibility, increased privacy, ease of sleeping and less noise. However, single rooms have also been said to have disadvantages when compared with shared rooms, including mood disturbance due to isolation, and poor nursing observation.⁹ A 2002 qualitative study conducted in the UK showed that while patients in a palliative setting may often prefer shared accommodations for the purposes of company and also for the constant reminder that another person may be experiencing similar events, family members often prefer private accommodations so that they may grieve and show emotion without others around.¹⁰ This study attempts to document whether the research precedents apply to a Canadian hospital, and extends the literature beyond the preference for private ver-

INTRODUCTION

Healthcare design is a growing field in research and clinical practice, with numerous studies demonstrating the impact of the built environment on health and health outcomes.^{1,2} The notion of evidence-based design "borrows from work done in evidence-based medicine to carefully observe, quantify and analyze the way people use buildings," and is increasingly sought-after, since a lack of published data exists, especially in Canada.³

The primary purpose of this qualitative study is to describe what palliative care patients and their families perceive to be important elements in the design of a palliative care unit (PCU) for end-of-life care. Secondary objectives include exploring whether differences in preferences and perceptions exist between patients and family members.

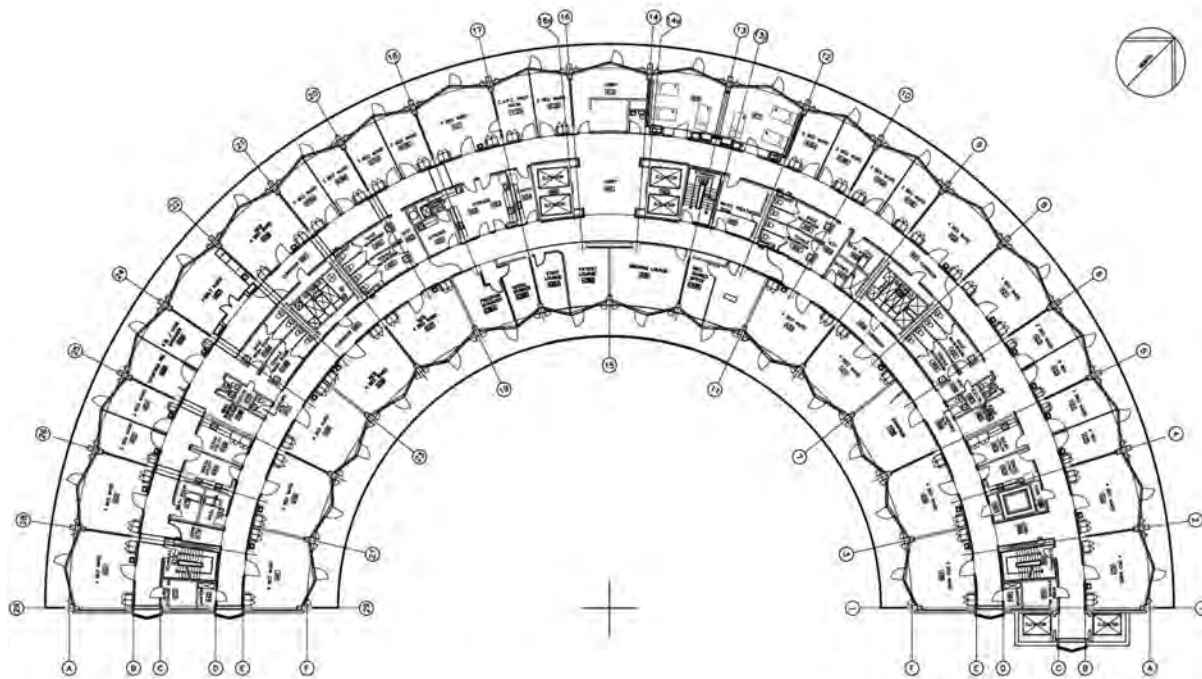


Figure 1. “Half Round” Bridgepoint Hospital Building (built 1963). Plan Courtesy of Perkins Eastman Black Architects, Toronto

sus shared rooms to include physical factors that promote comfort, layout and distribution of patient rooms.

MATERIALS & METHODS

Data collection was carried out during the months of February and March 2006 at the Palliative Care Unit of Bridgepoint Hospital. Both the University of Toronto Research Ethics Board and the Bridgepoint Research Ethics Board approved the study. Patients were eligible for the study if they were deemed healthy enough to participate by the medical and nursing staff on the unit. Informed written consent was obtained from all participants. Data was collected through semi-structured interviews using a set of nine open-ended questions (Table 1). Six patients and six family members were interviewed, each individually. Handwritten notes were taken during each of the sessions and were later converted into typed notes. Demographic characteristics of the participants are outlined in Table 2.

Data analysis involved five steps adapted from Nancy Diekmann, who developed a seven-step method for analysis of qualitative research based on phenomenological methodology.¹¹ The first step involved careful reading of interview notes, with the aim of distilling essential patterns and themes from the data. Common themes were then identified in order to develop a coding frame. Themes appeared to fit within two overall thematic categories: External Reality, defined as the relationship between people and their physical environment, and Internal Experience, defined as the way the environment mediates meanings, individual feelings and the relationships between people. The categories and their themes were then compared to

issues highlighted in the published literature. The third step involved the creation of a codebook and transcripts were thoroughly coded using the coding frame developed. The final step involved grouping interview statements with similar codes together, keeping patient and family comments separate. This allowed for a thorough analysis of each theme and a way to systematically compare and contrast the two participant groups.

- 1) What are your thoughts about the patient rooms here on the 4th floor?
- 2) What would be your preference for a room if you had a choice? Why?
- 3) How does this room environment make you feel?
- 4) What control do you have over this environment? What would make a difference?
- 5) What do you do for privacy in a 4-bedroom room?
- 6) Do you like to share a room? Why or why not?
- 7) What are your preferences for washrooms on this floor?
- 8) How do you feel about other parts of this hospital?
- 9) If you had a chance to design this unit over again, what would it look like?

Table 1. Interview Questions

	Patients (n=6)	Family Members** (n=6)
Gender		
Male	2	3
Female	4	3
Age Bracket		
40-60	2	4
60-80	2	2
80 and over	2	
Room Type		
Shared room (2)	3	3
Ward room (4)	3	3
Palliative Care Unit Type		
Long-term unit (up to 1 year or more)	1	2
Short-term unit (0-3 months)	5	4

*Ethics approval was granted under the condition that participants remain anonymous, with no personal information obtained regarding type of illness. Ages have been estimated in order to provide some detail with respect to participants. No information was obtained regarding exact length of stay (only long-term vs. short-term), cultural and ethnic backgrounds, or religious beliefs. More female patients interviewed reflects the higher number of female inpatients in the Bridgepoint PCU.

**Family members included 1 wife, 2 husbands, 1 mother, 1 son and 1 daughter-in-law.

Table 2. Demographic Characteristics of Participants*

RESULTS & DISCUSSION

1. External Reality

In the category of External Reality, eight overall themes were determined to be important aspects of the physical environment for patients and families: room size, noise, light, storage, temperature, colour, washrooms, and social spaces (Table 3).

Room Size

Although all of the family members interviewed mentioned room size, only one patient did. Families felt that the rooms at Bridgepoint, approximately 90 square feet per patient, are too small (newer palliative care units allot about 200 square feet per patient): "There is not enough room for families to stand around the dying patient's bed." There is also a lack of storage space, both for personal items and for hospital equipment. One patient suggested incorporating regular service modules into the design of the halls, so that equipment can be stored in these alcoves without obstructing movement through the halls.

Light

Natural light was recognized by both participant groups, but more by the families as being "important in the feeling of well-being." Due to the current room configuration, if the patient by the windows keeps the curtain closed, natural light is blocked for the other bed located near the door.

Some patients said that they had not seen daylight from their beds for weeks because of this layout. Artificial light was also mentioned, as there currently exists only a fluorescent fixture over each bed. Participants acknowledged the need for softer light sources.

Noise

Patients and families discussed noise as being disturbing, including noise from roommates and other families, as well as staff and hallway noise. However, one patient felt that the noise in the halls from staff was a positive factor as a constant reminder of activity and life. Families prefer not to close the doors to the rooms in order to block the noise, for fear of nobody monitoring their loved ones.

Washrooms

The feelings surrounding washroom preferences in a PCU were unanimous amongst all participants. Each patient room, whether shared or private, needs a connecting washroom, with or without bathing and shower facilities. Washrooms located down the hall are not acceptable to patients and families. The PCU currently has one sink per room, but it is not centrally located and tends to be used by only one patient and their family. Suggestions by participants were to have one sink per bed or a central sink for each room, in addition to connected washrooms.

Social Spaces

Under the theme of social spaces, it was felt that choice is needed. One patient said, "There should be several options for lounge spaces: some larger ones and a few smaller ones to sit in with a visitor or by oneself." It was generally felt that current lounge spaces on the ward have little privacy and no choice over the television channel selection. Patients and families preferred the smaller "quiet room" on the ward as a more private space that they could reserve for family events, in comparison to the more public lounge spaces.

Additional Features

Additional design recommendations included a central nursing station so that nurses can access rooms and observe patients easily, colourful spaces and a more home-like setting for the ward, as palliative care does not require the same amount of medical equipment as other wards and thus the environment can be made less institutional in appearance.

Family Concerns

In the category of External Reality, family members raised additional themes to the ones identified by patients: halls as social spaces, ventilation, furniture and PCU location within the hospital. Two family members felt that hallways were a potential space for social interaction, noting that most communication takes place in these circulation spaces versus the specified lounge areas. Four family members discussed ventilation as a fundamental component of a PCU. Toileting at the bedside leads to odours that invade the space of other patients, making it unpleasant for visitors and families. Thus, an efficient air exchange system should

1. External Reality	2. Internal Experience
1) Room size	1) Room type a) preference: single, shared, wardroom b) feeling/mood when in room
2) Storage a) personal b) equipment	2) Autonomy a) privacy b) control
3) Light a) natural b) artificial	3) Shared space a) supportive companionship and social interaction b) patient compatibility c) observable death and dying process d) visitor experiences e) feeling secure as patient is not alone*
4) Noise	4) Stage of care and room type* a) STP vs. LTP b) privacy need as disease progresses
5) Temperature of rooms	5) Patient being moved as indication of death being near*
6) Colour of spaces	6) Spaces creating independence*
7) Washrooms and sinks in patient rooms	
8) Social spaces a) family room, lounges, quiet room b) cafeteria c) main entrance & lobby d) halls*	
9) Air/ventilation*	
10) Furniture*	
11) Kitchen and laundry facilities*	
12) Location of PCU in hospital*	

Note: Themes marked with an asterisk indicate family member preferences, which were not mentioned by patients (all other themes were mentioned by both patients and families). Themes are in no particular order.

Table 3. Categories and Themes Identified

be considered for shared inpatient wards. Families felt that at least one comfortable chair is needed next to each patient bed, as current chairs are institutional and uncomfortable for visitors: “I sit in my husband’s wheelchair to watch television with him. I can’t even watch television on the chair that is in the room, it is too uncomfortable.” Two family members felt that the PCU should be located on the main floor of the hospital, so that patients can easily access the outdoors if they are ambulatory. (Architecturally, a terrace or roof garden could be an alternative for higher floors.)

2. Internal Experience

In the category of Internal Experience, three overall themes emerged from the data analysis: room type, shared space and autonomy (privacy & control) (Table 3).

Room Type

All participants discussed preferences for room type. Three patients said that they would prefer to be cared for in a single room; reasons provided including being a private individual and feeling upset because of noises from room-mates, such as laboured breathing and moaning. Two of the three remaining patients expressed a preference for a

shared room with two beds. Although they acknowledged that a single room yields more privacy, their desire for a shared room was based on companionship and being able to observe the surrounding activity: “I wouldn’t choose a private room – I would rather have a roommate. I would think it would be very lonely in a private room.” However, they acknowledged the need for private rooms to be made available for patients who might prefer this option. The remaining patient was also in favour of a shared space, but for financial reasons felt that a wardroom with four beds would be his first choice.

Similarly, three out of the six family members said that they would prefer a private room; reasons included wanting to visit with their loved ones in private, and their view of dying as a personal process: “A family should have their privacy and should not share the death with three other people. What you say in the heat of the moment – when you announce your love for someone, it is better not to be overheard.” In comparison, two of the three remaining family members said they would prefer shared accommodations, because of the possibility of social interaction and having others around to observe their loved ones in case of emergency. The sixth family member said that she had initially wanted a private room for her husband, but upon spending

time with him in a wardroom and interacting with other families, she now prefers a shared room.

Shared Space

Due to the frequency with which it was discussed, the theme of shared space was explored further with all participants. Reasons given for this preference were supportive companionship and social interaction, patient compatibility, and observing death and the dying process. Patients with a shared room preference felt that companionship outweighed the desire for the privacy that one could obtain from a single room: "Shared rooms in palliative care are an important part of the environment, with respect to the friendships and comfort that develops between patients." Barriers to communication between patients and families in a shared space included different languages spoken and patients who keep their curtain drawn.

Although several patients brought up the distressing feelings they experienced when watching and listening to their roommates, one patient felt comforted by observing the dying process: "It was good to see that (dying peacefully) because you often hear horror stories surrounding death and dying in a hospital." Families were concerned that noises and the suffering of roommates would distress their loved ones. One mother said that her daughter insisted on keeping the curtain open so that she could constantly check on her dying roommate, to make sure that she was not in distress. Family members brought up an additional benefit of a shared space: the notion of feeling secure, as their loved one is not alone when they cannot be there. In case of a medical emergency, families were eased knowing that roommates could notify medical personnel, as there is limited visibility into the rooms by staff.

Overall, half of the participants interviewed would prefer to have private rooms in a hospital PCU. Individual preferences for room type are shaped by both personality (e.g. being a private person) and events (e.g. seeing a family member, who is a patient, enjoy a shared room). It became clear throughout the data collection that towards the end of life, people still appear to be very adaptable to the environment. Firm beliefs about room type were expected at the outset of the research, but views appear to change for both patients and families, depending on various factors, such as the stage of illness, roommates and witnessing events.

Patient Compatibility

Patient compatibility was a greater issue than anticipated at the outset of the research. One patient felt that preferences for room type are dependent upon compatibility with roommates: "I would most likely welcome a single room if I was with someone I couldn't get along with." The majority of patients and families said that there should be more attention given to ensuring that patients who are placed together in the same room are similar in terms of health status. They explained that being placed with a roommate who is not compatible would enhance the difficulty of the experience: "The physical environment is always the same, but the feeling shifts according to the roommate." This particular patient felt that a PCU design should focus on separating the ambulatory patients by giving them smaller private

rooms to sleep in, but provide more community spaces where patients can gather and spend the majority of their day.

Privacy & Control

When asked about privacy and how it is achieved in a shared space, patients said they use the curtain when medical or nursing care is administered, or for personal hygiene reasons. However, even with the curtain fully drawn, patients reported feeling uncomfortable. One patient preferred to keep the curtain fully drawn at all times, while the others expressed a preference for not wanting to feel separated from the activity around them: "I don't like to be shut in, I don't draw the curtain. I like to be aware of things going on around me." All six family members said that there is a complete lack of privacy in the rooms and that a curtain is not sufficient. A curtain does not provide a sound barrier and one family member suggested the use of moveable screens or soundproof partitions as an alternative. Generally, patients appeared to adjust to the space around them and have learned to create a sense of privacy, while families felt that privacy is totally lacking for their loved ones and for them as visitors.

Family Concerns

Family members again brought up additional themes in the category of Internal Experience (Table 3). In terms of stage of care and room type, one family member felt that patients in a short-term ward could benefit from shared spaces, but in a long-term ward there is more time to observe suffering and death, and so a private room is preferred. Four family members felt that privacy is needed as diseases progress: "If someone is obviously dying, maybe they should be wheeled into a private room where the family can congregate." However, another family member expressed fear in seeing a patient moved to a new space, as this could indicate that death was near. Thus, there is a need for flexibility in room assignments throughout a patient's stay, taking into account patient and family desires. Finally, two family members mentioned the need for spaces that recognize their role as family and promote a feeling of independence, such as laundry and kitchen facilities. These spaces allow families to participate in the care of their loved ones, which is part of the overall philosophy of the palliative care environment.

Study Limitations

There were certain limitations in this study. Perhaps the most significant limitation is the small sample size and the fact that the researcher was the only individual to collect and code the data. In addition, audio-recording of interview sessions was not possible and no transcripts were produced. In order to address this issue, the data was kept consistent by taking the best notes possible, in addition to strategic listening during the interviews in order to record text to use as quotes in the final research report. Finally, this small sample of participants drawn solely from one hospital setting may limit the ability to generalize results. However, the qualitative literature also argues that a small participant group is not necessarily chosen to represent some part of the larger

1. External Reality

Adequate room size, approximately 150-200 square feet per patient.

Alcoves in hall for storing equipment and shelving in rooms for belongings.

Natural light accessible for each patient bed and provision of a reading lamp.

Moveable partitions that create privacy and block noise, as an alternative to curtains.

Colourful spaces and a home-like setting.

Washrooms connected to each room and a sink for each bed or a central sink.

A variety of social spaces, with an allowance for several smaller community areas. Architecturally, the design of halls as possible interaction areas for patients, families and staff has much potential.

Adequate air exchange system, as odours can disturb patients and families.

At least one comfortable, easily moveable chair next to each patient bed.

If the PCU is not on the ground floor, terraces and roof gardens can be designed.

2. Internal Experience

Provide a variety of room types: both private rooms and shared two-person rooms.

Allow control over personal space in terms of sound, temperature, lighting, etc.

Place patients with similar health statuses together in a shared space.

Provide ambulatory patients with smaller rooms and larger community spaces.

Consider room type related to stage of care, and consider spatial flexibility as the environment needs to be adaptable to the changing needs of patients.

Provide kitchen and laundry facilities for families, in order to create a sense of independence and allow them to help in the care of the patient.

Table 4. Design Recommendations for a PCU

world. According to McCracken (1988), the first principle when selecting respondents is that "less is more and for many research projects, eight respondents will be perfectly sufficient. It is more important to work longer, and with greater care, with a few people than more superficially with many of them."¹² Thus, the results of this research may not be applicable to all palliative care patients and their families, but it does provide a glimpse into the nature of palliative care at one Canadian hospital. These results may also vary across cultures and geographic locations, so this would have to be explored further in future studies. The conclusions and design recommendations made in the following sections are based on the research findings from this study's sample of twelve participants.

CONCLUSIONS

In this study, seriously ill patients and their family members defined key issues related to the design of the physical environment in palliative care. Patients' individual preferences may depend on their own symptoms and experiences, particularly their interactions with other patients. Therefore, it could be assumed that end-of-life care facilities require a range of room types and sizes to enable patients to select the type that they prefer.

The data obtained from this study supports two interesting conclusions. First, being able to decide what levels of

privacy and community patients and their families want appears to be extremely important to them. Second, being able to control the environment is also essential. Meeting these needs will likely lead to higher levels of comfort for patients and their families towards the end of life. These results demonstrate that matters of privacy versus community and personal control over the environment are fundamental in an inpatient setting and are of great significance to patients and their families.

The results of this study have significant clinical and design guideline implications. The findings suggest that a more tailored or patient-specific approach to palliative care design may be required, given the variability in preferences, both among patients and also between patients and family members. Ultimately, what is needed is a sensitive design approach to an environment for the terminally ill, which takes into account both patient and family preferences.

RECOMMENDATIONS

An important observation made throughout the interview process and later confirmed with data analysis was the notion of individual variation in the perception of physical environment design. This indicates the need for a variety of patient rooms and public places. More detailed individual assessments are recommended, in order to gain a more thorough understanding of what individual patients and

their families experience. In addition, patient and family preferences for room type may change as death approaches and thus more careful research into the stages of the dying process and how this relates to room preferences must be explored.

Design recommendations for a shared patient room include allowing for privacy through some form of partial walls or soundproof partitions that could then be opened should companionship and social interaction be desired. In addition, there is potential for incorporating the idea of halls as community spaces into a PCU design. The current research results suggest that this type of design concept may support patient and family preferences for rooms that provide privacy, with ample space provided just outside the rooms for social gathering. Patient room sizes could be reduced in order to allow for wider corridors, which would serve as both circulation space and community space. Table 4 outlines a summary of design recommendations for a PCU.

Future directions for this research include expanding the participant population to include hospital staff members and integrating their suggestions with those of patients and families.

The main recommendation arising from the results of this study is the provision of choice in terms of room type. When asked what they would do if they could redesign the unit themselves, all twelve study participants reinforced this design suggestion. One family member from Bridgepoint said, "I think at different stages [of care], you need different things. I think you'll always need the option of single and shared rooms."

Acknowledgements

Thank you to Dr. Donna Henrikson for reviewing the manuscript. This study was supported by the University of Toronto Faculty of Medicine's Determinants of Community Health II course and Bridgepoint Hospital. The author wishes to acknowledge Dr. Ian Johnson, Dr. Robert

Sargeant, Dr. Vincent Chien, Kathi Carroll, Lori Wilson, Lori Jimenez, and Brenda Stein, for their support and guidance. The author offers sincere appreciation to the study participants - the patients and family members who took the time to participate, despite all of their grave personal difficulties.

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