THE ADOLESCENT'S HOSPITAL EXPERIENCE: PREFERENCES FOR ENVIRONMENTAL DESIGN

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"This world demands the qualities of youth; not a time of life but a state of mind, a temper of the will, a quality of the imagination, a predominance of courage over timidity, of the appetite for adventure over the life of ease."

Robert F. Kennedy

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Declaration

I certify that this thesis is a record of original work and contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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* Norton-Westwood, D. "The health-care environment through the eyes of a child—does it soothe or provoke anxiety?" Int J Nurs Pract.2012; 18(1): 7-11.

* Norton-Westwood, D, Pearson, A, Robertson-Malt, S. The ability of healthcare design strategies to reduce event related anxiety in paediatric patients: A systematic review. JBI Library of Syst Rev. 2011; 9(31):1298-1351.

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Deborah Norton-Westwood Date

Dedication

For Suzi,

"Understanding is perhaps one of the most important gifts one human can give to another. If we learn not only with our minds but with our spirits, the meanings of experience, we might better be able to say, 'I understand"

Munhall 1994

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Embarking on such a journey – the conducting of primary research and the writing of a thesis although a solitary and albeit often lonely pursuit is possible only in light of the guidance, wisdom, patience and unfaltering support of mentors, fellow students, colleagues, friends and family both near and far. To all, I wish to extend my sincere gratitude and appreciation.

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Abstract

Aim

The principle aim of this study is to examine what key aspects of the hospital built environment contribute to either a positive or negative hospital experience for the adolescent population.

Background

Research to date has demonstrated that adolescents in respect to Healthcare are an underserved population. In recent years with new construction and the renovation of existing healthcare facilities, attention is now being directed to the healthcare environment as a result of its' ability to impact patient care outcomes and patient and family satisfaction. However, adolescents pose a unique demographic due to: 1) Transition of Care 2) rapidly evolving stages of development and life changes and 3) the cost vs. benefit ratio in that adolescents represent a small demographic in comparison to the overall paediatric and adult population. Appreciating, understanding and highlighting the needs of adolescents in respect to the physical environmental will assist in the design of age appropriate healthcare environments that generate healthcare benefits for this dynamic age group.

Method

Utilising a qualitative interpretive approach informed by Heidegger's Hermeneutic Phenomenology,[1] a convenience sample of twelve adolescents aged 12-19 years of age living in Doha, Qatar were interviewed via open ended questions following a minimum of three days in hospital. Field notes were taken immediately after each interview with interview transcripts transcribed verbatim into narrative text via the Joanna Briggs Institute Thematic Analysis Programme (JBI-TAP). Aided by van Manen's six steps of thematic analysis common themes were identified.

Results

Four main themes were identified:

- The importance of physically engaging and stimulating environments that are age appropriate;
- The desire for privacy and personalisation of space;
- The importance of sustaining opportunities for family engagement within the hospital environment; and
- The world of connectivity- the sense of normality amidst chaos.

Conclusions

The findings are congruent with previous research that support the overall benefits of dedicated adolescent units and age appropriate environments. The adolescent perspective rarely acknowledged in unit design needs to foster a culture of community and openness where adolescents can feel safe to articulate their physical, cognitive and psychosocial needs.

Prologue:

In commencing the programme of research for the award of Doctor of Philosophy I had many questions ranging from: who will read it and where and how do I begin? Yet, the most poignant question is not the question that would be answered that day or even the next, but rather it is the question that drives the need for the research itself. Determining a topic of inquiry that upon completion is intended to contribute to an existing body of knowledge, resting in originality of approach and/or interpretation of findings, can present a formidable challenge. An orientation of inquiry commences with a thoughtful reflection on the knowledge, experience, and interest of the researcher and more importantly, determining an area of inquiry that is of importance and urgency to both the participants of the inquiry and also the audience (in this case, healthcare professionals, architects, and designers).

This study consists of two distinct phases: Phase 1 is a comprehensive systematic review of the international evidence (Chapter Four). In conducting a comprehensive systematic review I sought to answer the question '*Do design strategies reduce anxiety in paediatric patients?*' The results of that inquiry identified a gap in adolescent care which formed the proposition for the 2nd Phase of this inquiry – '*The Adolescent's experience of hospitalisation and as a result their preferences for hospital design'*.

In keeping with the methodological grounding of Phase 2 of the study (Heideggerian Phenomenology) I commence this report of my research with a gesture of 'transparency' in the form of a description of myself as a paediatric nurse who has a lifelong interest in design, and current employment on a project building a Women's and Children's hospital in Doha, Qatar. However, despite my education and experiential grounding in healthcare where the objective assessment of patients and positivism is the dominating paradigm, I was concerned that my chosen research question was too esoteric. Interestingly, such doubts were soon set aside as I had the opportunity to meet a young man.

His name is Ahmed* and accompanied by his mother he came to our project offices in the autumn of 2011 seeking assistance with his high school science project. Now two years later, Ahmed has completed his project and I was curious to hear about his experience. The following Case Study is a description of the conversation I had with Ahmed, in his home with his mother present, December 2013.

Ahmed's Story – A Case Study

Ahmed's story began in 1997 in Montreal, Quebec, Canada. The first and only child, Ahmed was born to a culturally diverse family; his mother French and his father Lebanese both had immigrated to Canada many years prior. It was during his mother's pregnancy that the antenatal diagnosis of a severe and complex cardiac anomaly - Atrioventricular Canal defect commonly referred to as AV Canal, was first discovered. For Ahmed's expectant parents, the news was devastating. Experiencing joyful anticipation of their first healthy newborn, such feelings were suddenly and unexpectedly replaced with anxiety and fear as they faced uncertainty at what lay ahead for their child and for themselves as parents.

Complex cardiac malformations frequently require 'staged' repairs and thus multiple 'palliative' surgeries. Regular visits to the Cardiologist and/or Cardiac Surgeon become a regular part of life. At the time of interview, Ahmed had undergone a total of eight surgeries and numerous minor invasive procedures. The surgeries all performed at Sainte-Justine's Children's Hospital (CHU), Montreal began with most significant surgery, the primary repair performed at five months of age, necessitating a hospital stay of 30 days.

Today at 17 years of age Ahmed's memory of past events related to hospitalisation,

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**To protect anonymity and confidentiality of the participant(s) the names have been changed.*

remain strong. Although details of early hospitalisations are lost or dulled a result of his very young age at the time, Ahmed's preferences for hospital design, particularly in the outpatient setting due to his many follow up visits, are clear. In fact, helping architects and interior designers create comfortable and engaging spaces for the paediatric/adolescent patient has become a passion of Ahmed's.

This passion became evident to all those around him when for a high school science assignment Ahmed chose to interview 50 patients visiting a cardiac outpatient clinic and based on what he learnt from these interviews Ahmed created a computer 3D design model of the 'ideal' clinic waiting room.

Below are excerpts of the interview with Ahmed:

"Ahmed can you describe some of your experiences as an adolescent inpatient?"

"In one of my surgeries I think it was for my gums, I was sent into a room after the surgery what is it called?" (Interviewer) "Recovery Room?" Ahmed continues, "Yes that is it. In that room there was a person next to me and I don't know the issue ….but he was very noisy- he would cry and complain. I don't know what happened but it was very disturbing as a patient. I can't blame him because you never know what has happened however you know in such an environment the situation is very stressful to the other party. It is not like the person who is in pain or is feeling sad can do much about it because that is how they feel, however with the environment being a very cramped room it has an effect on certain patients, especially due to the fact that you are nervous and you don't really know what is happening all these factors come into play- it is very stressful."

"You mention it is stressful can you describe that further?"

"Stressful in that you are thinking about what is going to happen to yourself and having that distraction coming into your thoughts. It is basically a negative – the unknowing-

things are happening and there are stages where you are completely alone other than the nurse, people you know and trust are not always with you. As adults they probably experience similar but being younger these thoughts come into play and you start to create these images in your mind. When faced with situations such as a person crying, pleading, or moaning it can lead you to thinking of the worst scenario. You may be perfectly fine, but it gets you thinking of the negative…. of what is going to happen."

"In your opinion what do you think would help to alleviate such stress?"

"At that point you just have to have separate rooms I know it is not always the ideal case for a hospital but that is how it should be. When you are put in these recovery rooms you should feel that only the people that you know and trust are going to be inside the room with you. You are at a point where you are getting better however you are not there yet. Having two families worry about someone in the same room sure it saves space, and sure it does save money, however it is definitely not the way to go. It doesn't make the journey for the patient comfortable. For patients in a critical state, having space for your family is a must so you need to have single rooms I think that is an obligation- you just have to."

Inpatient Paediatric Units:

"I was pretty young when I was an inpatient but my experience was good at Sainte-Justine and being in a paediatric hospital they definitely made sure the children were taken care of. Areas within the unit if I remember were different sections- if you were a toddler you were with other toddlers and older kids with older kids. I was an open room but there weren't that many patients in the room."

Ambulatory or Outpatient Clinics:

"In more recent years apart from minor procedures, you mention that your main access to the healthcare system has been through follow up visits to the outpatient clinics. Can you describe some of your impressions of that experience?"

"In the hospital I was at in Canada, the waiting areas were sectioned off by specialities and because it was a paediatric hospital there was a lot of entertainment for the children to keep them busy such as toys and games, while arriving here in Qatar it was different. I was transitioned at the age 10 to Adult services- a decision that was more for my parents- they wanted to meet and have the same doctors as I got older. However for myself, although it definitely was a different experience, I think I matured or adapted to the environment pretty well. I was with older people. I was used to having entertainment you know or television to keep my mind off things or to keep me busy while waiting. Here, while they had television most of the time what was playing was the News. It was in Arabic and it was not like anything really happy, it was 'Breaking News'- things happening in the world- terrible things which personally I don't think is the best thing to show to someone waiting to have a check-up for a heart condition. You are already anxious and something could be happening in your home country and you are worried about your family and your blood pressure goes up. It is these factors that people have to think about as it really does have an effect on the patient themselves."

"Was it these issues that motivated you to do your own research for your science project?"

"Definitely, it was not only the fact of the environment it was also the state of the waiting rooms, the way they organised the patients, it was kind of uncontrollable at times. In Canada it is more controlled but here I have seen it where sometimes there are so many patients that at times you don't really know where to put them and they are just standing. When you are in a clinic room, patients would knock on the door

asking if you were finished or the Doctor was free. You wouldn't see that in Canada mainly because the waiting rooms and check-up rooms are in different sections. Here, you have seats for waiting right outside each check-up room. It's fine, but when you have a whole row of seats full it is a problem. I have told them and they (the hospital administrators) agree and have noticed themselves that it is an issue of concern. Like myself, those I interviewed also commented on the comfort of the seating, cleanliness of the area and the lack of colour in the areas. At the new Heart Hospital- that is what it is called, I have noticed they have improved on such issues- they have comfortable chairs, couches, indirect lighting, use of colours, plants, windows- it was really nice and you could see that the patients were more organized. Waiting rooms are still a bit claustrophobic but much better as the patients I interviewed agreed."

"Based on your experience as a patient, and having conducted your own research can you describe what the ideal inpatient room would look like if your friend had to go into hospital tomorrow?"

"You have to think not only of the patient but also the family and friends visiting."

- "Private room with space for family or whoever the patient wants to be there"
- "Comfortable seating- chairs and/or couches"
- "Windows, natural light and indirect lighting"
- "Access to Internet is a must."
- "Colours of the wall - I personally like beige, orange and yellows but it is difficult as each person has their own colour preferences."
- "Plants"
- "Since I was young I have always had a thing about bathrooms and using public bathrooms so that is a big issue from a cleanliness and privacy perspective."
- "Double room but only maximum of two patients and of similar age. This can have both pros and cons but if you have someone with the same disease you have this mutual experience can offer someone who is supportive and communicative."

"People don't consciously realise that such little things help, but when you have been in both environments like I have both when I was younger and now that I am a teenager, you actually feel different- you can see it – you can compare. That is why I had the thought and motivation to conduct such a project. I have been in such different hospitals and many different situations that I can create a comparison; together with my fellow cardiac patients we can try to provide the information and highlight our issues and hope that those who run the hospitals listen."