Moving Towards Wellness:
Designing for the Chronically Ill 'Emerging Adult'

by

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of the Requirements for the Degree
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ABSTRACT

Overview: Transition from the pediatric to adult care setting for 'emerging adults' (ages 18-26) continues to develop as a growing concern in health care. The Adolescent Transition Program teaches chronically ill 'emerging adults' disease self-management skills while promoting a healthy lifestyle. Transferring this knowledge is vital for successful health care outcomes. Unfortunately, patients who have been transferred to the adult care setting, report that they felt lost in the system due to lack of communication between care teams, inadequate support systems, and insufficient disease management knowledge. To address these gaps, the design of the physical environment must adapt to these challenges while also meeting the needs of various chronic illnesses.

Methodology: Design thinking or human-centered design was utilized as the vehicle to discover unmet 'emerging adult' and adolescent health clinician needs. Ethnographic research methods involved observations at adolescent health clinics and in learning environments outside of the healthcare setting as well as interviews with 5 outpatient adolescent clinicians. A survey was also conducted with 16 'emerging adults' to understand how they learn. Lastly, a literature review explored the history of the adolescent, adolescent development, adolescence and chronic illness, and The Adolescent Transition Program.
Results: Findings revealed that physical environment must be conducive to meet a variety of clinical and education activities such as chronic disease management, support adolescent development, and should be more human-centered. The space should transform to the patient education or clinical activity rather than the activity transforming to the space. Five design recommendations were suggested to ensure that the outpatient clinic supported both clinician and 'emerging adults' needs.
DEDICATION

For my brother, Daniel, who inspired my research. I am extremely proud of you.
ACKNOWLEDGMENTS

I would like to thank my thesis committee; Professor Jose Bernardi, Professor Anni Damgaard, and Professor John Takamura for their continuous support and patience as I moved through the thesis process.

Professor Jose Bernardi was instrumental in stimulating design insight through brainstorming sessions and helping me to take my research to the next level through exploring spaces outside healthcare that foster learning and knowledge sharing. This helped influence my analogous research and gave me ideas about transforming the physical space by borrowing from best practices in higher learning and within libraries.

Professor Anni Damgaard was an amazing resource as her expertise in adolescence development and healing environments challenged me to advance healthcare through taking a more systems thinking approach. She helped me understand how behavior is shaped not only by context, but is influenced by the physical environment itself. Her constant encouragement, feedback, and knowledge sharing helped me immensely.

Professor John Takamura's vast knowledge of various research methods helped shape my understanding of how to search and collect rich data. Design research was a new field to
me when I began my graduate journey several years back. His ongoing advice and research techniques encouraged me to continuously ask why and maintain an intellectual curiosity towards designing to enhance a stakeholders' experience.
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CHAPTER 1
INTRODUCTION

Section 1 - Overview

In the United States, 1 in 15 adolescents have at least one disabling chronic illness and this number is growing (Sawyer et al., 2007). Chronic disease and its effect on children and families has replaced acute illness as the most serious issue in pediatric medicine (Hobbs, Perrin, & Ireys, 1985). A chronic illness is defined as "one that interferes in daily life for longer than 3 months in a year or requires hospitalization for more than 1 month in a year" (Pless & Pinkerton, 1975). The most common chronic condition is asthma, followed by sensory disorders and nervous system disorders (World Health Organization, 2011; Boice, 1998). Examples of chronic illnesses include HIV and other sexually transmitted diseases, diabetes, cancer, cystic fibrosis, and anorexia nervosa, among others (Boice, 1998). Most chronic conditions of childhood, unlike those of adults, are not preventable by lifestyle changes.

In the past, children with many of these illnesses would never have lived long enough to become adolescents. Fortunately, in the past 25 years, the survival rate has increased due to advancements in medicine and technology and better health care delivery (Williams, et al., 2002). Patients are expected to lead meaningful and productive lives despite having a serious illness (Boice, 1998; Sawyer et al., 2007). Ultimately, once
the patient reaches 18 years old or when the pediatric care team deems she/he is ready, the patient will transition out of the pediatric care setting through a process called The Adolescent Transition Program.

Section 2- Problem Statement

Transition is “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum et al. 1993). The Adolescent Transition Program teaches chronically ill patients (ages 18-26) disease self-management skills while promoting a healthy lifestyle. Transferring this knowledge is vital to successful health care outcomes. However, the program lacks structure which causes the quality of care to suffer.

Nine years ago my younger brother was diagnosed with Acute Lymphoblastic Lymphoma. Although he is now 26 and healthy, I watched as he struggled through the disease and during his transition from the pediatric to adult care setting, he did not get the support he needed to successfully combat the aftermath of cancer. He said that during his sickness

"There was a general lack of self-directed support. I had little understanding of the impending physical and psychological influences the chemotherapy would have on my body. I was left with an appreciation for modern-medicine and health care professionals, but lacked any sort of direction for maintaining my health and having access to continued care" (Almon, 2012).

Unfortunately, my brother’s experience isn't exclusive.
Patients, who have been transferred to the adult care setting, report that they felt lost in the system due to lack of communication between care teams, inadequate support systems, and insufficient disease self-management. "There [is] notable and demonstrable deficiency of services provided to patients to ensure a smooth transition. Data suggests that the health care transition can be traumatic and is related to adverse morbidity and even mortality outcomes" (Huang et al., 2011). Often, either care is delayed or the transfer of care is conducted when the patient isn't ready to transition. Both lead to financial and emotional stress on the patients, their families, and the health care system overall (Sable, et al., 2011).

Interventions to improve outcomes, determining the fundamentals of successful transitions, and the qualities of medical practices that promote successful transitions have yet to be fully identified (Huang et al., 2011). As a result, transition from the pediatric to adult care setting for patients ages 18-26 is fragmented and continues to develop as a growing concern in health care. To address these gaps, it is essential to examine the current state of health care within the United States of America.

Section 3 - Justification/Significance

Over the last 4 years, health care has been in the spotlight. On March 23, 2010, President Obama addressed the need for better and more accessible health care for all
United States citizens by signing and passing a comprehensive health reform, the Patient Protection and Affordable Health Care Act (aka PPACA) (Henry J. Kaiser Family Foundation, 2013). This Reform is also known as Obama care. The Patient Protection and Affordable Care Act contain 9 titles, each addressing an essential component of the Reform. These titles are "quality and affordable health care for all Americans, the role of public programs, improving the quality and efficiency of health care, chronic disease prevention and improving public health, health care workforce, transparency and program integrity, improving access to innovative medical therapies, community living assistance services and supports, and revenue provisions" (Democratic Policy and Communications Committee, n.d.). The phased implementation plan rolls-out various stages over the course of the next 8-10 years.

In 2011, as a response to the Affordable Care Act, the National Strategy for Quality Improvement in Health Care was established. The National Strategy for Quality Improvement in Health Care was the first "policy to set national goals to improve the quality of health care through setting standards and regulations to measure the quality of health care and its impacts on public health" (Robert Wood Johnson Foundation, 2012). To do this, the policy proposes a strategic plan for how to achieve better health outcomes for Americans through the creation of 3 aims and 6 priorities” (U.S. Department of Health and Human Services, 2013). These aims and priorities strive to improve the delivery of health care services, patient health outcomes, and population health. The
third priority, in particular, “promoting effective communication and coordination of care” is the specific topic I am directing my focus as it tackles The Adolescent Transition Program gaps as well as revitalizes the health care industry through a more human-centered model.

"Promoting effective communication and coordination of care [encompasses] human-centered coordination of care [which will] improve the patient's experience [and] lead to better long-term health outcomes (fewer unnecessary trips to the hospital, fewer repeated tests, fewer conflicting prescriptions, and clearer advice about the best course of treatment)” (U.S. Department of Health and Human Services, 2013). Effective communication includes "quality language assistance services and the adoption of electronic health records to make it easier for clinicians to effectively communicate with patients across settings, and new models of care delivery and payment” (U.S. Department of Health and Human Services, 2013). Additionally, this priority focuses on improving care coordination across health care settings.

Care coordination is planned patient care activities between 2 or more people involved in a patient’s care, which helps facilitate the appropriate delivery of health care services (McDonald, K. et al., 2007). Care coordination directly impacts the quality of life for chronically ill patients and it "establishes shared accountability and integration of communities and health care systems to improve quality of care and reduce health
disparities” (U.S. Department of Health and Human Services, 2013). This priority, along with the others, is imperative to implementing quality improvement efforts.

"Implementation of the National Quality Strategy involves identifying and prioritizing quality improvement efforts, sharing lessons learned, and measuring the collective success of Federal, State, and private sector health care stakeholders across the country” (AHRQ, 2013). The National Quality Strategy policy each year since its launch has undergone revisions to make it stronger and more applicable based on the achievements of the Affordable Care Act.

"The National Quality Strategy's first annual progress report to Congress, published in April 2012, elaborated on these 6 priorities and established long-term goals and national tracking measures to monitor quality improvement progress. The 2012 report also identified 3 strategic opportunities for improvement, which cut across all 6 priority areas. [This year the] second annual report provides updates on public and private payers' collaborative efforts to align quality measures, progress against national tracking measures (where possible) and establishment of aspirational targets (as needed), private-sector successes in each of the 6 priority areas, and progress on each of the 3 strategic opportunities" (AHRQ, 2013).

The future plan entails yearly revisions each focused on tackling another aspect of quality improvement.

This policy, I believe, has the potential to enhance the way care is delivered and improve health outcomes. It does, however, need consistent reevaluation and innovation to be successful and truly impact a patient in a positive manner. There also needs to be
agreement among political parties in determining the Health Care Reform's future as this decision will impact the National Strategy for Quality Improvement in Health Care policy's value, direction, and strategic roadmap. Financial consideration will also impact the direction of health care and best ways to combat chronic illnesses.

Treating chronic conditions is a very costly venture. Seventy-five percent of US health care costs are allocated to treating chronic diseases (Center for Disease Control, 2009; Hoffman et al., 1996). To supplement some of these costs as well as to decrease overall operating costs within the acute setting, many chronic illness health care services have moved to the ambulatory space. "In response to decreasing costs and national policy, shrinking reimbursement and new aims and standards, the practice of health care in ambulatory and outpatient settings has changed" (Sweetland, et al., 2012).

Outpatient facilities are now expected to deliver more quality care, but at a lower cost. The Health Care Reform targets the need for services that reach across a continuum of care for a patient.

"Providers should aim to improve population health and reduce the cost of care, while also creating an improved patient experience. With a growing understanding that health care costs are unsustainable, that physicians are increasingly in short supply, and that reimbursement is changing, the industry is beginning to change the way health care is defined, who delivers it and how" (Sweetland, et al., 2012).
"As health consciousness grows, it is shifting the focus of health care from illness to wellness. Health care providers are rethinking their treatment models and facilities, both to reflect the more holistic view of health that wellness implies and to remain competitive in a fast-changing marketplace. Wellness speaks to the human dimensions of health care and broadens its range of settings. It opens the door to innovation" (Gensler, 2013, p. 15).

This quote identifies the shift to not only treat a chronic illness, but also the need to maintain a healthy lifestyle through focusing on healing the mind, body, and soul. "The provider is realizing the benefits of a therapeutic environment, focusing on health versus sickness. These concepts of wellness and preventative health are becoming major ideas behind facilities design (Kobus et al., 2008, p. 247). Dr. Patch Adams said, "You treat, a disease you win, you lose. You treat a person, I guarantee you'll win" (1998). In order to accommodate this new way of care delivery, the overall design of the physical environment has to change.

The physical environment has to house a wider range of services, activities, and staff. In order to achieve this, outpatient clinics must utilize the space efficiently. Most outpatient clinics are moving towards an integrated model that supports multi-specialties in one space and activities. Education has also moved out of the acute setting and into the outpatient space, particularly in primary and community settings and in larger clinics. An outpatient environment must change to meet the new needs for multi-use of spatial configuration to accommodate a higher volume of clinicians and patients, increase
efficiency, and increase room utilization. Rooms that are tailored too tightly to a specific function will limit flexibility. "Designs", rather, "should provide for the flexible use of some spaces from day to day; and for the inevitable changes in the demand for services and the pattern of delivery during the life of the building" (HermanMiller, 2011).

Section 4 - Objectives/Intentions

Based on the market trends, rising numbers of chronic conditions, the shift to the outpatient setting, and the need for a more flexible space that adheres to a multitude of activities, this thesis proposes an alternate approach to chronic care structure and delivery in an outpatient adolescent health clinic by targeting the space itself in which the care and health education are delivered. Recent studies "show that a well-designed space, in all its forms, has the power to improve the quality of life" (Richardson, 2012, p. 24). To improve health outcomes, reduce costs, and make space more efficient for learning and chronic disease management, I am proposing a shift from teaching disease self-management skills in an exam room to facilitating this knowledge in another environment. As a final point, 5 design recommendations will guide a designer to create a healing environment that specifically meets 'emerging adults' and adolescent clinician needs.

Through careful design and involving my sample population, 'emerging adults' ages 18- 26 and adolescent medicine clinicians, I believe that the physical environment will transform care delivery, improve communication and retention, foster learning, and
build relationships between all stakeholders; pediatric and adult care teams and patients. After all, "collaboration and creation aren't bound to designated areas; they evolve throughout a space, absorbing different people, places, and perspectives" (Doorley, S. & Witthoft, S., 2012, pg. 5). I think this is an innovative and sustainable solution that will meet both short term as well as long term health care initiatives. Lastly, customizing the outpatient setting to meet the needs of the clinicians and patients, will aid in retention.

Retention is an issue in all health care specialties, but it is particularly challenging in adolescent medicine because adolescence is generally one of the healthiest periods of life. When a patient does have a chronic illness, it is important that they maintain regular appointments to ensure that their health is on track. Actually, "there is a need for better integration between health care and community-based youth health services, as well as the provision of education services that support the continuum of learning between school, hospital/outpatient, and home" (The Royal Children's Hospital, Melbourne, 2009). Understanding that young adults benefit from being involved in extracurricular activities such as hiking, biking, and other outdoor activities, helps to maintain a healthy retention rate in the outpatient setting. This can be accomplished through not only designing the built environment to include the clinician and patients' needs, but through incorporating the design recommendations to fully maximize the environment.
The design recommendations will enhance the space by creating feedback loops through engaging the appropriate stakeholders and to support disease self-management and lifestyle decision making. The space would also provide consistent and meaningful information that supports clinician to patient communication thus ultimately leading to long term improved health outcomes. Lastly, a healing environment that is "customized to a patient's preferences through control lighting, entertainment, and personal control over communication such as Internet access while receiving treatment or recovering, can increase patient comfort and bestow a sense of empowerment" (Fouts, 2008; Malkin, 2007).

Section 5 - Definitions/Nomenclature
Adaptive Design

Environmental design elements that can flex to activities need.

Adolescence

Comes from the Latin word “adolescere,” meaning growing into adulthood. Adolescents include a cohort of youngsters ranging from ages 12-25 (Steinberg, 2011).

Adolescent Transition Program

“the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centered to adult-oriented health care systems” (Blum et al., 1993).

Affordable Care Act

A comprehensive health reform passed on March 23, 2010 by
President Obama in the United States of America (Henry J. Kaiser Family Foundation, 2013).

**Ambulatory/Outpatient**
Receiving medical treatment without being admitted to the hospital.

**Best Practice**
“activities, disciplines and methods that are available to identify, implement and monitor the available evidence in health care” (Perleth, Jakubowski, & Busse, 2001).

**Collaboration**
"Action-oriented partnering in which various stakeholders create an
interdependent system as a means to achieve the larger goal; collaborators have clearly defined roles and responsibilities, complement and support one another's efforts, and share a sense of community" (Sobo, Kurtin, & Perrin, 2003).

Care Coordination

Planned patient care activities between 2 or more people involved in a patient’s care, which helps facilitate the appropriate delivery of health care services (McDonald, et al., 2007). It helps to ensure a patient’s needs/care preference are understood/shared between providers, patients, and family as a patient moves from one health care setting to another.

Care plan

Strategies designed to guide health care professionals involved with
Care plans are patient specific and are meant to address the total status of the patient. Care plans are intended to ensure optimal outcomes for patients during the course of their care” (The Free Dictionary, 2012).

<table>
<thead>
<tr>
<th>Care Team</th>
<th>A group of health care clinicians who care for a patient as they undergo health-related issues.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Care Model</td>
<td>Promotes “effective team care and planned interactions, self management support through use of community resources, integrated decision support, patient registries, and other supportive IT” (Coleman et al., 2009).</td>
</tr>
<tr>
<td>Chronic Condition/Chronic Illness</td>
<td>&quot;One that interferes in daily life for longer than three months in a year or...&quot;</td>
</tr>
</tbody>
</table>
requires hospitalization for more than one month in a year” (Pless & Pinkerton, 1975).

| Co-design | “Collective creativity as it is applied across the whole span of a design process” (Sanders & Stappers, 2008).  
"In co-design, diverse experts come together, such as researchers, designers or developers, and (potential) customers and stakeholders- who are also experts, that is, “experts of their experiences to cooperate creatively” (Sleeswijk Visser, Stappers, Van der Lugt, & Sanders, 2005). |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-Morbidities</td>
<td>Diseases that stem or coincide with the original diagnoses.</td>
</tr>
<tr>
<td>Design Thinking/Human-Centered Design</td>
<td>Is a collaborative and iterative process through which we unearth</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Deeper emotions, needs, and motivations of people</td>
<td>(IDEO &amp; +Acumen, 2013).</td>
</tr>
<tr>
<td>Developmental Change</td>
<td>Growth and change over time; for children, this occurs at a rapid rate, and their development in numerous areas (cognitive, emotional, social, physical) affects their ultimate health status (Sobo, Kurtin, &amp; Perrin, 2003).</td>
</tr>
<tr>
<td>Disease</td>
<td>A biomedical measureable lesion or irregularity in a person's physiology or anatomy (Sobo, Kurtin, &amp; Perrin, 2003).</td>
</tr>
<tr>
<td>Disease Management (DM)</td>
<td>An innovative approach to patient management for a specific disease using a comprehensive education and</td>
</tr>
</tbody>
</table>
treatment program that targets a single disease and is intended to reduce symptoms, increase quality of life, and decrease admissions and emergency visits (Sobo, Kurtin, & Perrin, 2003).

'Emerging Adulthood'
The time between adolescence and young adulthood describes a new stage in an individual's life course, one that involves multiple transitions such as high school graduation, a job, leaving home, getting married, or having children (Arnett, 2004).

Externalizing disorders
Develop when a young person's troubles are turned outward and are revealed in behavioral problems such
as aggression, delinquency, and truancy (Steinberg, 2011).

| Healing | "Is a multidimensional process with physical, emotional, and spiritual dimensions" (Hsu et al., 2008). |
| Health | "A state of complete physical, mental, and social well-being, not merely the absence of disease infirmity" (WHO, 2013). |
| Health Status | The overall health of an individual, as characterized by the extent of physical disability and overall well-being (Sobo, Kurtin, & Perrin, 2003). |
| Holistic Health | Focus on the whole person rather than just the disease itself and it is |
the balance between the body, the spirit, and the mind.

**Human-Centered**

"Marked by humanistic values and devotion to human welfare" (The Free Dictionary, 2014).

**Illness**

The lived experience of being unwell or suffering (Sobo, Kurtin, & Perrin, 2003).

**Integrated Care Approach**

Care coordination with the whole care team. The emphasis is on collaboration opposed to silos.

**Internalizing Disorders**

Occur when a young person's issues are turned inward and are exhibited in both cognitive and emotional distress like in anxiety or depression (Steinberg, 2011).
<table>
<thead>
<tr>
<th>Medical Home Model</th>
<th>&quot;A team-based approach to patient care through the continuum of care. The primary care physician leads the care with the patient at the center (AcademyHealth, 2009).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outcomes</td>
<td>The health results of the interaction between providers and patients within the health care system; a change, either positive or negative, in the health status of an individual, group, or population as a result of previous or concurrent care. There are 3 types of health outcomes; clinical, patient-based, and financial (Sobo, Kurtin, &amp; Perrin, 2003).</td>
</tr>
<tr>
<td>Patient-Centered Care</td>
<td>&quot;Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all</td>
</tr>
</tbody>
</table>
clinical decisions” (Institute of Medicine, 2001).

Patient-Centered Design

"Supports patient-centered care by creating environmental conditions that facilitate healing. Principles include privacy, facilitate communication, collaboration and trust, encourage patient and family participation, empower patients, promote safety and security, provide accessible accommodations, create a comfortable environment, facilitate healing support staff’s goals through design and respond to unmet needs” (Institute for Patient-Centered Design, Inc., 2011).

Quality of Care

Is a universal measurement system that is designed with the goal of promoting wellness through predetermined outcomes.
Self-management “Set of medical constructs about what constitutes good disease management” (Sawyer & Aroni, 2005).

Stakeholder A person who has a vested interest in something.

Substance Abuse Is the "maladaptive use of drugs" which includes alcohol and legal/illicit drugs (Steinberg, 2011).

The Adolescent Transition Program “The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum et al. 1993).
Teach-back Method

Away to confirm that the patient understands the information by explaining it back to you.

Well-being

Refers to good health and welfare (Webster, 2013).

Wellness

Is the optimal state of health for individuals and organizations (World Health Organization, 2013).

Section 6 - Assumptions/Limitations

I hypothesize that the physical environment design recommendations will meet the needs of chronically ill 'emerging adults'. 'Emerging adult'-centered design
considerations will aid in resolving the current transition challenges by creating an environment that fosters peer support, increases the line of communication between care teams and other resources, creates a space that targets 18-26 year olds, and will empower the patient to take ownership of her/his health.

As far as limitations, the study sample size is a factor as qualitative research was done by looking at only one health care organization. Although research was conducted both within an adolescent clinic and several school clinics, the sample size was limited due to a small demographic of adolescent health practitioners and 'emerging adult' participation. In addition, the study could have included chronically ill patients going through transition to get their perspective about their needs as they move from one care setting to the next. Patient input would have also aided in validating the design considerations.
Figure 1: Study Limitations

Section 7 - Organization

The project approach used both quantitative plus qualitative data. Quantitative data provides useful information, but it’s unable to uncover human behavior identifying on its own. Whereas, qualitative doesn’t reveal the broader picture. However, weaving nuance with numbers allows us to truly understand the landscape that we want to work in.

Qualitative research was conducted at libraries in Roanoke, VA and in the Phoenix Metro area in AZ, Arizona State University, and at 3 adolescent health outpatient clinics in Roanoke, VA.

Figure 2: Project Approach
CHAPTER 2
LITERATURE REVIEW

Section 1 - Conceptual Framework

The 3 key components of the conceptual framework are The Adolescent Transition Program, adolescent development, and chronic illness. Each are these are important to framing the larger issue at hand. The Adolescent Transition Program isn't streamlined and patients feel lost as it doesn’t prepare them. Next, adolescent development is complex time of life with many normal changes occurring psychologically, emotionally, and developmentally. Then another level of stress is added to an adolescent's life if they have a chronic illness. The sample population encompasses ‘emerging adults’ ages 18-26 who are transitioning to the adult care setting. The focus of the thesis is the exam room in which each component overlapps as the exam room is where the care is delivered and the education facilitated.
Section 2- Introduction

"Healthy adolescence is a critical transitional period that includes the biological changes of puberty and the need to negotiate key developmental tasks such as increasing independence and normative experimentation" (HealthyPeople.gov, 2014; Mulye et al., 2009; McNeely & Blanchard, 2009; Halfon & Hochstein, 2002). Adolescents' health practices can influence their overall well-being. For example, by incorporating the right amount of nutritious foods like fruits and vegetables into their daily routine as an adolescent, this will enhance their ability to ward off heart disease or a stroke later in life. As a result, adolescence is an opportunity to promote healthy behavior and lifestyle choices that can be carried through to adulthood.
Adolescence comes from the Latin word “adolescere,” meaning growing into adulthood (Steinberg, 2011). It was G. Stanley Hall, father of adolescence psychology, who coined the term "Adolescence" in 1904 (Steinberg, 2011). Adolescents, according to him, included a cohort of youngsters ranging from ages 12-25. Prior to this categorization, people were either children or adults. Children were dressed like adults and worked side by side with adults. In fact until the early 1900s, adolescents made up about 40% of the workforce. Some adolescents worked in factories, while others, mostly boys became farm workers, and girls were hired by elite families to do domestic work. However, the lives of adolescents were altered drastically through several transitions, such as the Industrialization age, the post World War II era, and the Information era.

Section 3 - Adolescent Development

In the late 1900’s, during the Industrialization era, changes in the workforce and the economy took place. Agriculture declined and people began moving into cities. The workforce started to change as machines were introduced and could produce more than twice as much as one worker. Soon machines started replacing workers, thus the availability for jobs declined. As jobs became scarce and more competitive, adolescents were removed from the labor force to allow for more skilled adults to work. Adolescents were placed in full-time school with their peers to prepare for their future. By 1918, mandatory education laws were passed for the masses shortly followed by labor laws which were introduced in the early 20th century. These labor laws kept adolescents out
of the workforce. High school for the masses became common in the 1940-1950s keeping adolescents in school for longer periods of time, while their elders dominated the workforce. Adolescence became a preparation period for adulthood in which youngsters "remain economically dependent on their parents and are requiring guidance and supervision" (Steinberg, 2011, p. 91). Adolescence was redefined again after World War II.

Post World War II, the serious mature adolescents who existed in the past became what are now referred to as teenagers. Teenager suggests a more frivolous and carefree age, one in which the individual spends a lot of time in leisure and consuming goods. A significant social change that influenced the teenager concept was the increased prosperity and economic independence enjoyed by American adolescents. The term 'youth' also was reintroduced, but this time rather than referring to someone who was 12-24 years old, it now referred to individuals within the growing college population and rise in student activism. 'Youth' are now referred to as individuals in between adolescence and young adulthood (18-22 years old). Adolescence was not only transformed by the growing interest in pursuing college or more education post formal schooling, but by the Information age.

During the Post-Industrial era or Information age, automation, globalization, downsizing, and outsourcing blue and white collar jobs left young adults in a position
where they were no longer needed in the workforce. This cohort of young adults are experiencing an unprecedented long "transition period" in waiting to obtain financial stability, marry, and start a family thus further postponing the shift to adulthood. The transition to adulthood has become so delayed in many industrialized societies that some have suggested that there is a new stage in life called 'emerging adulthood'.

2.3.1 - 'Emerging Adulthood'

'Emerging adulthood' is a term coined by psychologist Jeffery Arnett. It refers to young people ages 18-25. This age demographic plus 26 year old individuals are the focus of the thesis as these ages signify a period where much change occurs. In fact, the term 'emerging adulthood', the time between adolescence and young adulthood, describes a new stage in the individual's life course, one that involves multiple transitions such as high school graduation, a job, leaving home, getting married, or having children (Arnett, 2004). 'Emerging adults' are seen as "educated singles" as they decide to take a period of time before undertaking full adult responsibilities. These individuals who are in their late teens and early twenties feel that they are neither teenagers nor adults (Gorter, et al., 2011), which is very important in understanding why this age demographic is underrepresented in healthcare. Care delivery and health outcomes are impacted by developmental changes and other uncertainties during 'emerging adulthood'.
Feelings of anxiety and ambiguity are increasing, because young people's lives are so undecided. Often young adults "struggle with uncertainty even as they revel in being freer than they were in childhood or will be once they take on the full weight of adult responsibilities” (Weissberg-Benchell, et al., 2007). Adapting to new social roles during 'emerging adulthood' affects the quality and salience of relationships with others. Relationships with parents may change as young people become more independent as 'emerging adults' are taking on roles similar to their parents. As part of this transition from family, friendships become increasingly essential to well-being (Sherman et al., 2006). In fact, these social transitions impact risk behavior for 'emerging adults'.

Social transitions affect an adolescent's views on social status as well as their beliefs regarding age-appropriate behavior (Arnett, 1994 & Nurmi, 1993). 'Emerging adults' may not experience their chronological age evenly, while others feel younger. Depending upon how old the 'emerging adult' feels will impact his or her behavior. "Those who feel older might spend more time with opposite sex, feeling more autonomous, and engaging in more problem behavior" (Galambos, et al., 1999).
'Emerging adults' put less emphasis on the achievement of explicit roles such as parent, spouse, and worker as essential characteristics of adulthood. 'Emerging adults' as well as their parents, deem self-reliant character traits such as responsibility and independence as more important predictors of adulthood.
'Accepting responsibility for one's self' and placing an emphasis on psychosocial maturity is seen as a defining feature of reaching adulthood among parents (Nelson et al., 2007). This can entail moving into a separate household or being able to support oneself financially. Family roles such as marriage and parenthood no longer mean that an adolescent has become an adult. "Only 17% of respondents in one study indicated that being married was necessary and only 14% indicated that it was necessary to become a parent in order to reach adulthood" (Arnett, 1998). The defining criterion of adulthood in contemporary society has become the same for both females and males in that adult status is either evenly important or unimportant (Arnett, 1998). In any event 'emerging adulthood' is a period of many transitions. 'Emerging adulthood' is also a period of developmental transitions.

2.3.2 Developmental Changes

Developmental features during 'emerging adulthood' are very important to understand for healthcare workers who help coordinate care for this age demographic as they transition from the pediatric to adult care setting. These include "1) the exploration of possible identities before making enduring choices, 2) instability in work, romantic relationships, and living arrangements, 3) a focus on oneself and, in particular on functioning as an independent person, 4) the subjective feeling of being between
adolescence and adulthood, and 5) the subjective sense that life holds many possibilities" (Steinberg, 2011, p. 92).

"In developmental transition, adolescents and young adults are particular sensitive to the contextual or surrounding environmental influences such as family, peer groups, neighborhood, etc. that may challenge health and well-being. Addressing the positive development of young people facilitates their adoption of healthy behaviors and helps to ensure a healthy and productive future adult population (HealthyPeople.gov, 2014; McNeely & Blanchard, 2009; Mulye, 2009).

In addition to developmental changes impacting well-being, psychological changes can impact it as well.

**Figure 4: Adolescent Development**
2.3.3 - Psychological Well-being

Psychological well-being during 'emerging adulthood' is generally one of positive and improving mental health. In one study, 4 groups of 'emerging adults' between the ages of 18-20 were evaluated; 1) those who reported positive well-being across the entire interval, 2) those who reported negative well-being across the entire interval, 3) those whose well-being started low but increased, and 4) those whose well-being started high but decreased" (Schulenberg, et al., 2004). Foremost findings confirmed that over 80% of the sample population confirmed great steadiness in their feelings concerning increased well-being over the time period. This is a constant indication found in many other studies which indicates that psychological functioning in childhood and adolescence is foretelling of future success (Shanahan, M. & Bauer, D., 2004). This means that if an individual does well in one stage of her/his life like high school, she/he will most likely do well later on in life. Psychological well-being correlates with the emotional development of an 'emerging adult'.

2.3.4 - Emotional Health

Emotional health is always part of our lifecycle; however individuals in late adolescence to young adulthood often struggle to adjust to the new social roles and responsibilities of adult life (Schulenberg, J., et al., 2004). Depressive syndromes accompany stress caused by this adaptation process and often cause developmental
delays in emotional competence as well as decreased physical activity in early adulthood (Cullen, K. et al. 1999). Reasons for this include low self-efficacy and low levels of community engagement (Myers, R. & Roth, D., 1997). In addition, psychosocial problems can lead to internalizing disorders, externalizing disorders, and substance abuse causing risky behavior (Achenbach & Edelbrock, 1987).

*Internalizing disorders* occur when a young person's issues are turned inward and are exhibited in both cognitive and emotional distress like in anxiety or depression (Steinberg, 2011). *Externalizing disorders* develop when a young person's troubles are turned outward and are revealed in behavioral problems such as aggression, delinquency, and truancy (Steinberg, 2011). Substance abuse is the "maladaptive use of drugs" which includes alcohol and legal/illegal drugs (Steinberg, 2011). Repeated exposure to drugs can harm the brain's development through less natural dopamine circulation, which is one of the neurotransmitters that affect a person's experience of pleasure. Too many drugs can make the brain require drugs to experience normal amounts of pleasure. "Exposure to drugs in adolescence is more likely to lead to an addiction than exposure to drugs in adulthood" (Steinberg, 2011).

Substance abuse during adolescence is often linked to an earlier psychological disorder. It can stem from hostile or conflicted family relationships. Furthermore, peers who use or tolerate drugs, and become substance abusers are more likely to have parents
or significant others in their home that make drugs easier to access (Steinberg, 2011). Protective factors that decrease the likelihood of an adolescent becoming a substance abuser are positive mental health, a healthy relationship with family, good academic standing and success, and religious activity involvement (Steinberg, 2011). These risky behaviors among other normal developmental stages for an 'emerging adult' may be compromised when they develop a chronic illness.

Section 4 - Chronic Illness

Generally adolescence is one of the healthiest periods in the human lifecycle. There is a low occurrence of chronic illness, less short-term hospital stays, and fewer days in which an individual stays home sick (Steinberg, 2011). Conversely, 1 in 15 adolescents in the United States have at least one impeding chronic illness and this number is growing (Steinberg, 2011; Sawyer et al., 2007).
Chronic illnesses are caused by pathological changes in the body that are nonreversible, permanent, or leave residual disability (Kerson & Kerson, 1985). They may be characterized by periods of recurrence and remission and they generally require extended periods of supervision, observation, care, and rehabilitation (Kerson & Kerson, 1985). At one time, children with chronic illnesses would not have lived long enough to become adolescents.

"Increased life expectancy in both developed and developing countries due to nutrition, hygiene and control of infectious diseases among other reasons are leading to an epidemiologic transition. Noncommunicable diseases which include chronic diseases and disability are emerging as major health problems" (Michaud et al., 2007). In fact, the
increased rates of chronic illness among children and adolescents will constitute the main cause of death by 2020 (Epping-Jordon et al., 2001; Michaud et al., 2007; WHO, 2001). The most common chronic condition is asthma, followed by sensory disorders and nervous system disorders such as hearing loss, blindness, multiple sclerosis (WHO, 2011; Boice, 1998). Other examples of chronic illnesses include HIV and other sexually transmitted diseases like herpes and gonorrhea, diabetes, cancer, cystic fibrosis, and anorexia nervosa, among others (Boice, 1998). Thus, chronic disease and its effect on children and families has replaced acute illness as the most serious issue in pediatric medicine (Hobbs, Perrin, & Ireys, 1985).

Moreover, "patients with chronic illnesses use by far the greatest proportion of health care dollars. Three fourths of health care expenditures are to provide direct care to those who are chronically ill (Center for Disease Control, 2009; Hoffman et al., 1996). More than 7% of this is due to adolescent chronic illness (Center for Disease Control, 2009). The rising costs of health care have made it crucial to prevent the development of chronic illnesses more effectively and efficiently" (Funk & Tornquist, 2001, p. 3). Unfortunately, most chronic conditions of childhood, unlike those of adults, are not preventable by lifestyle changes (Sawyer et al., 2007). When a chronic illness cannot be prevented, the aim is to deal with it effectively by reducing its influence and development and boosting regular functioning (Funk, S. & Tornquist, 2001, p. 5).
2.4.1 - The Illness Experience

Chronically ill adolescents undergo the same experience and same developmental needs as healthy adolescents do. For example, they all go through puberty, which include physical and cognitive development. They attend school, need leisure time, and become involved with peer relationships (Flavo, 1991; Lubkin, 1990; Miauton, 2003, p.683; Erikson, 1960; Siegel, 1987). The social transition in adolescents' lifestyles is frequently very stressful for healthy adolescents. It is even more trying for chronic ill adolescents considering that they have to deal with treatment of a long-term or life-threatening disease (Zevon, Tebbi, & Stern, 1987; Woodgate, 1998).

Chronic illness stressors include activity limitations, hospitalization, pain, medications, school absences, extended diagnostic studies, and surgery (Woodgate, 1998). Stressors cause fear, anxiety, and grief reactions (Woodgate, 1998). "Fears associated with illness include the fear of loss of physical integrity, an inability to separate successfully from one's parents, loss of self-control, being different from peers, and dying" (O'Doughtery & Brown, 1990).

Stress may also heighten as some chronic illnesses result in impaired functioning, limitations in self-care and activities of daily living, loss of independence, pain and discomfort, emotional problems, and self-image changes (Lubkin, 1990: McBride, 1993). Although patients can lead productive lives despite serious illnesses (Boice, 1998), the
diagnosis of a chronic illness at any stage in life may affect an individual’s functioning on a developmental, psychological, psychosocial, spiritual, or emotional level (Miauton, Narring, & Michaud, 2003; Sawyer et al., 2007; Tansella-Zimmermann, 1995).

2.4.2 - Adolescent Development

Chronically ill adolescents experience discomfort caused by the illness itself and relating co-morbidities. These co-morbidities can include developmental issues such as "The exploration of possible identities, work instability, romantic relationships and living arrangements. A focus on oneself and, in particular on functioning as an independent person, the subjective feeling of being between adolescence and adulthood, and the sense that life holds many possibilities" (Steinberg, 2011, p. 92).

As one moves through late adolescence, establishment of identity, separation from family, and development of a capacity for intimacy are important tasks toward social maturity (Boice, 1998). In sum, having a chronic illness in childhood may hinder the achievement of important developmental tasks or personal goals of 'emerging adulthood' (Bauman, 2000; Schwartz & Drotor, 2006). Accordingly goal pursuit is a crucial element of establishing autonomy and an identity.
Goal pursuit is critical for adult identity development, life satisfaction, and it helps to elicit a sense of self-efficacy (Little & Chambers, 2004). Adolescents and young adults are increasingly autonomous in setting goals, such as academic and career achievement in addition to developing close relationships. These goals are directly related to well-being in young adulthood (Arnett, 2000; Schulenberg, Bryant, & O'Malley, 2004). Consequently, a better understanding of the impact that chronic disease has on goal setting can highlight interventions to increase resiliency and treatment adherence for young adults. Therefore, personal goals setting is essential for clinical interventions in illness management (Schwartz & Drotar, 2006). It is important to understand that during times of adversity, individuals often re-evaluate and reprioritize expectations to maintain realistic and meaningful goals (Kin & Fung, 2004). In particular, expectations related to social acceptance are prioritized.

An overarching concern relates to social acceptance. Social/peer acceptance is a part of normal adolescent development, however there is a greater emphasis on it when an individual has a chronic illness (Boice, 1998). Often chronically ill adolescents spend the majority of their time with adults, isolated from other teenagers (Boice, 1998; Siegel, 1987). Chronically ill adolescents may feel reliant on their support system, which includes parents, caregivers, their medical team, and friends to help them get through the challenges they experience. Peer acceptance is extremely important in adolescence as "may determine the extent to which [one] feels rejected and isolated. Peer acceptance or
lack of it may contribute to stress" (Seligman & Darling, 1989, p. 22). Krementz (1989) refers to a 16-year-old female with cancer, who said,

"When I first told my friends I had cancer, they were really shocked. Some of them started behaving differently toward me. Now I rarely see my friends. I mainly talk to them on the telephone" (p. 74).

Group and peer acceptance serves as an initial step toward establishing an identity (Siegel, 1987; Thompson et al., 2008). Efforts to take part in group activities (especially athletics) can be hindered or prohibited by physical handicaps, thus slowing down the group identity development and possibly restraining peer relationships. McAnarney et al. discovered that children with arthritis demonstrate considerably poorer adjustment when compared with a control group who didn't have arthritis (1974). When a chronic illness interferes with group involvement, forging an identity can become very difficult.

2.4.3 - Psychological Adjustment

The greatest challenge chronically ill adolescents will experience is the ability to psychologically adjust to their new situation (Boice, 1998; Wallander & Varni, 1995; Woodgate, 1998). Those with less noticeable chronic conditions may deny that they have a disease, which can lead to internal conflict and anxiety. Krementz (1989), for instance, quotes a 15-year-old female with lupus:
"I look like such a normal person that when I get sick inside, my friends think I'm faking it to get out of class .... One of the reasons lupus is so difficult to deal with is because it's what they call an invisible disease" (p. 51).

Five factors are attributing to psychological effects of chronic illness; (1) uncertainty about life expectancy or what the chronic illness will do, (2) a disease with irregular and unpredictable effects can be more stressful than one with chronic and persistent symptoms, (3) the stress level caused by the disease or through developing complications (Woodgate, 1998), (4) the level of chronic condition visibility in how it impacts relationships with peers (Goffman, 1963; Thompson & Gustafson, 1996), (5) and the type of chronic illness and its impact on physical functioning (Wallander & Varni, 1995). These factors contribute to how successfully a patient can adjust to their chronic illness.

Adjustment to a chronic illness refers to how an individual deals with his or her anxiety, self-identify and control, describes, and one's feeling of loneliness and depression (Woodgate, 1998). Therefore, coping strategies, which include an individual's cognitive and behavioral abilities to respond to the chronic illness, are essential as they relieve stress (Eiser, 1993; Tansella-Zimmerman, 1995). Adapting to the illness requires social competence and a positive self-concept, as these adolescents must be very disciplined because a chronic condition can cause restrictions in every form of their lifestyle (Tansella-Zimmermann, 1995). In addition, parental physical and emotional
well-being is an important factor in helping adolescents deal with their illness (Tansella-Zimmermann, 1995). Furthermore, adolescents have to be more disciplined as chronic conditions cause restrictions and lifestyle changes.

Daily treatment regimens and exercises, symptom regulation, and medication management (dosage and frequency) require planning (Funk et al., 2001). These additions make life more complicated and hard to lead a normal life. "When a chronic illness cannot be prevented, the goal is to manage it successfully- to minimize its impact and progression and maximize normal functioning" (Funk et al., 2001). Several studies have indicated that adolescents with a chronic illness, especially brain-related injuries or physical disabilities are at risk for academic problems (Cadman et al., 1987; Rutter et al., 1970).

Cadman et al. (1987) found that "forty-two percent of children with illness and disability had repeated a grade compared with 15% of children with chronic illness without disability and 12% of healthy children" (Thompson & Gustafson, 1996, p. 123). Attendance is associated with academic performance. Thus, adolescents with chronic illnesses are more likely to have a higher number of absences. Chronic illness stress may also impede a students' ability to concentrate which impacts daily life for both the adolescent as well as their families. Besides the everyday worries related to family, friends, and school, a chronic illness impacts physical development.
2.4.4 - Physical Development

Hormone production in the adolescent years activates changes in both body stature and behavior. In addition, there is a heightened sense of emotional affect which impacts individuals' body image. Teenagers often think that they have an "imaginary audience" that watches their every move (Elkind, 1967). When a teenager has a visible chronic condition caused either by the disease itself or treatment, his sense of always being watched amplifies vulnerability. Some chronic diseases contribute to this more than others. Anorexia, for example, can delay puberty. Since puberty is a necessary transition for everyone to go through, failure or delay in this process can cause stress and anxiety for them (Caroll et al., 1983; Miauton, Narring, & Michaud, 2003).

Blum (1992) discovered that the timing of puberty depends on the illness. For example, spina bifida and neural tube deficits causes puberty to start 15 months earlier than the norm (Blum, 1992; Boice, 1998), while cystic fibrosis, and Crohn's disease may cause a delay in puberty. The process of puberty itself is not affected, but merely the "timing or tempo" (Boice, 1998, p. 365). In sum, chronic conditions not only impact adolescents' health status and emotional well-being, but they also impact the adolescents in their immediate environment (Sawyer et al., 2007; Miauton, Narring, & Michaud, 2003).
2.4.5 - Physical Environment

"Adolescents present many challenges to those who care for them, and professionals involved in caring for them must have a clear appreciation of their particular needs to try to help restore some degree of normality for them" (Hollis & Morgan, 2001). The immediate environment, which includes building design, urban design, social environment, and natural environment, should support adolescent needs. Space that allows adolescents to voice their anger and feelings and promotes emotional, peer, family, and health care professional support for young adults is essential (Hollis & Morgan, 2001).

'Emerging adults' receive care through their primary care physician or an adolescent medicine clinic. Both types of outpatient clinics deliver care, disease self-management education, and health and well-being promotional strategies to their patients from an exam room. For a chronically ill adolescent who has many doctor appointments a space that doesn't promote autonomy, engagement, and peer discussions and support may hinder the path towards wellness. The environment should make the teenager feel normal. “Clinics typically revolve around the physical exam and lack dedicated spaces for newer functions like care planning or chronic disease education” (The Advisory Board, 2013). Additionally, exam rooms can stimulate angst in patients as this is
"The place where clinical procedures are done and it reminds them of sometimes painful procedures, which make it hard for them to concentrate on what they are told" (Kyngas, 2003).

Poor design can contribute to feelings of hopelessness, anxiety, and frustration in patients (Blumberg & Devlin, 2006; Ortega-Andeane, 1991).

The physical environment's impact on behavior is directly related to how particular stimuli influences patients to think and develop attitudes towards their illness (Dilani, 2010). In fact, the strongest memories are related to place and environment (Dilani, 2010). When a space is well-designed through meeting the needs of its stakeholders, it can improve the quality of life and improve the person's experience (Richardson, 2012), which are vital to the healing process.

Healing requires a holistic understanding by looking at the individual as a whole person opposed to only addressing the discrete physical problems (Hsu et al., 2008). Holistic health is defined as a balance between the body, the spirit, and the mind. The healing environment should encourage that balance. The goal of healing is recovery or restoration and reaching a personal balance. The environment directly influences this process. For example, already in the 19th century, Florence Nightingale stressed the relationship between the physical environment and the health care provider by saying that the patients should be put in the "best possible condition so that nature can act and
healing can occur" (University of Minnesota, 2013). Place, after all, should be a catalyst for wellness (Richardson, 2012).

Facilities should adhere to 'emerging adults' needs by providing a sense of normalcy through socialization, music, games, and by providing a place to receive education (Hollis & Morgan, 2001). Facilities design must be human-centered to house the appropriate adolescent services and to treat chronic disease (Siegel, 1987). Interior spaces and elements such as light, space, color, shape, texture, music, aromas, and artwork, should reflect the preferences of adolescents and adhere to wellness by stimulating a holistic approach to care by reaching to the senses (University of Minnesota, 2013). Despite the many needs chronically ill adolescents have, this age group has been "underrepresented in health care design research" (Blumberg & Devlin, 2006).

Of the limited 'emerging adult' research that has been conducted, findings reveal that positive environmental stimuli and specific design changes in health care environments can reduce stress and reduce negative feelings (Dilani, 2010; Ulrich, 1981; University of Minnesota, 2013). 'Emerging adult' patients like a quiet space as well as one that promotes a positive experience place (Kyngas, 2003). Visual colors can provide positive stimulation leading to patients feeling more comfortable thus permitting a quicker recovery (Park, 2009). "The surfaces on which color is applied have a great
influence on the mood and perception of the space as well” (Feinberg & Keller, 2010, p.121). Adolescents prefer mid and a paler color palate with blue-green colors being the most popular (Ullan, et al., 2012). Regardless of age, “learning spaces that are physically and psychologically comfortable promote a sense of well-being, keep minds focused, and limit distractions” (Kyngas, 2003).

Space and interior elements of adolescent areas work well if they are multipurpose (Cranz & Cha, 2006). Interior elements, such as temperature, sound, lighting, and furnishings, that can be adjusted by the patient, help make the space more comfortable (Herman Miller, 2008). Music can also help a patient's comfort level by "feeling connected and energized by a certain amount of noise" (Cannon Design et al, 2010). Furniture must adhere to a "variety of postures including sitting, standing, reclining, lying, and leaning as well as the range of social activities- reading, taking notes, or browsing the Internet (Cranz & Cha, 2006).

The findings, though limited, do point towards the need for more 'emerging adult' centered design. This is particularly important because it contributes to better health through impacting emotional responses, experiences and connections (Dilani, 2010). Apart from the environment in which direct medical services are delivered, comprehensive health care to meet this patient demographic must also incorporate their
learning needs and provide access to self-help groups, advocacy organizations, and educational materials (Siegel, 1987, p.32).

2.4.6 - Learning Environment

The learning environment is imperative in delivering patient education, which is a critical component in caring for chronically ill patients. For 'emerging adults' patient education encompasses disease knowledge, treatment procedures, self-care skills, coping abilities, and social support. "Patient education, as some studies advocate, improves the patient's quality of life, their compliance with health regimes, and coping with the chronic disease" (Coates & Ryan, 1996; Klein et al., 2001; Kyngas, 2003). In sum, studies show that the most effective patient educational program is the one tailored to meet the patient's individual needs (Bradbury & Jenkinson, 1998; Divertie, 2002). Unfortunately, most research shows that education isn't tailored to the individual patient. Patient education rather consists largely of routines and tends to be based on the professional knowledge of the physicians and nurses rather than the adolescents' needs.

There is no best practice on how to facilitate the knowledge, but patient education programs should be based on an appraisal of each adolescent's needs rather than relying upon the application of a package suitable for all (Kyngas, 2003). Patient education supports an 'emerging adult's' willingness to take responsibility for their own care through
disease self-management and leading a healthy lifestyle. Most adolescents feel that the more they know and the more skills they have, the more independently they can live (Kyngas, 2003).

"Emerging adults' want a trusting and encouraging environment. An encouraging environment means that health educators motivate, respect, and promote questions. This helps patients to feel responsible for their care and at the same time they experience confidence with their medical regime" (Kyngas, 2003). Education should be interactive and the space itself should be flexible in order to adapt to various clinical and educational activities and communication methods.

Provider-patient communication should include cultural and lifestyle practices as well as environmental exposure (Worstell, 2000). It is important for medical professionals to provide clear, detailed information. It also may be necessary to provide adolescents with an opportunity to discuss the illness without parents so the young patient may engage in an open dialogue with the health care provider.

Communication should be tailored to individual learning styles and encompass various facilitation methods such as face-to-face interaction, electronic, written, and verbal. "Adolescents are not yet fully socialized to learning only abstractly, so they may need to retain movement in order to learn. Moreover, different styles of learning
differentiate individuals- visual, auditory, and kinesthetic- so having all learning environments with options for different postural attitudes would be ideal" (Feinberg & Keller, 2010; Cranz & Cha, 2006, p. 49). In addition, "teaching strategies should be durable and flexible, they also need to "morph" as the learning process requires" (Loomis, 2008, p. 10).

Learning can happen from anywhere, so if a patient is unable to physically be present for education due to their chronic illness, there must be other communication methods available. Currently, the adolescent providers will call these patients on the phone to conduct patient education. This makes it especially challenging to engage patients in self-care when they are distant. This method of communication, however, could be enhanced as 'emerging adults' begin to use of technology as an integral part of their everyday life.

Adolescent patient education hasn't fully harnessed the power of technology yet. In fact, many adolescents wonder why modern technology isn't used more commonly as a method of patient education (Kyngas, 2003). As 'emerging adults' take ownership of their own health, there is a demand for additional educational resources aside from the physician’s knowledge (Bourgeois, et al., 2008). The Internet, in addition to more technology-driven tools can dramatically change the learning environment by making resources more accessible and interactive.
The Internet provides key sources of information in addition to an avenue to integrate disease self-management and behavior change by offering resources outside of the traditional outpatient care setting (Bourgeois, et al., 2008). Technology can help 'emerging adults' set goals and develop effective strategies for managing their chronic illness as well as helping them gain access to support systems outside of their doctor's office (community resources, peer support groups) (Bourgeois, et al., 2008). For example, in one study an electronic support group (ESG) helped 18 adolescents with cystic fibrosis connected to one another to discuss health issues (Johnson, Ravert, & Everton, 2001). The ESG gave these chronically ill adolescents a way to relate to others about "both typical adolescent issues and those specific to cystic fibrosis" (Johnson, Ravert, & Everton, 2001). In addition, the use of a patient health record, "enables [patient's] ability to become an active collaborator in one's own care" (Basch, 2005, pg. 13).

Research shows that patient health records have the ability to improve patient-provider communication, disease self-management, increase overall satisfaction with care, and education/lifestyle change (Archer et al., 2011). However, some research indicates that despite the advantages of a patient portal, that adolescent patients don't consistently use it (Bull et al., 2005). In summary, technology as a means of patient education within the adolescent care setting is lacking.
Within the current exam room design, occasionally a desktop computer is present, though the majority of time this is used only as a resource to view and enter patient data into an electronic medical record or for clinicians to communicate with other members of the care team. At times secure email systems are available for 'emerging adult' patients to interact with their pediatric care team. Alas this type of communication can only be done with other clinicians within the same healthcare organization as modern health IT systems are not interconnected and interoperable (Billings, 2013). Consequently this is the reason that it's difficult for care teams from different healthcare organizations and geographic locations to transfer patient health information. Despite the lack of technological methods to facilitate patient education, the pediatric care team does its best to stress the importance of disease self-management to build their confidence in handing the disease more autonomously through a program called the Adolescent Transition Program.

Section 5 - The Adolescent Transition Program

Though the adolescent years can be a difficult time for the chronically ill, awareness of normal developmental transitions and provisions for comprehensive health care services can facilitate a teenager's move into adulthood. Turning 18 isn't the only determinate for this move. Pediatric providers determine if a chronically ill patient is ready for the transition, based on their developmental needs, self-efficacy ability, and
level of autonomy. Once the provider feels the patient is ready to move from the pediatric to adult care setting, they start a process called *The Adolescent Transition Program*.

The Adolescent Transition Program (ATP) is a globally recognized transition service and a facet of care coordination in the outpatient primary care setting. Transition is “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centered to adult-oriented health care systems” (Blum et al. 1993). The Adolescent Transition Program teaches disease self-management skills (among other skills) to chronically ill 'emerging adults' (ages 18-26) who are transitioning from the pediatric to adult care setting. Typically, The Adolescent Transition Program is housed in a primary care office or an adolescent medicine outpatient doctor office. The program can also be housed in an interdisciplinary clinic as they provide comprehensive care by allowing the patient to see all of their entire care team (PCP, specialty providers, social workers, etc.) at the same time.

The Adolescent Transition Program goals are to teach the patient disease self-management care skills so that they can care for themselves independently and can access resources to be more independent and develop a structure for the transfer of care and medical information between the pediatric and adult care team. This knowledge is vital to successful health care outcomes. Typically an ambulatory private practice or a health
care organization manages the program. According to the Health care Transition SIG, the Adolescent Transition Program's mission is

"to create a forum to promote discussion, collaboration, research and innovation among scientists, clinicians, advocates, policy makers, as well as youth and families who are interested in improving the health and health care of adolescents and 'emerging adults' as they transition from adolescence to adulthood and from child health systems to adult health systems" (Health care Transition Organization, 2012).

The program's overarching goal is to teach 'emerging adult' patients ages 18-26 years old disease self-management skills needed to move towards a state of wellness, which is a shared goal among all primary care and adolescent clinics who serve. At the present time, the most effective way to achieve a smooth transition has become a subject of considerable debate. This is because whatever solution is adopted will require a comprehensive program that reflects physical, psychological and social development, rather than merely providing a physical transfer from pediatric to adult care" (Crowley et al., 2011).

Services offered are always patient education driven, but how and where they are facilitated as well as the types of service offered may differ greatly. Wellness workshops such as family therapy, individual or group therapy, living well with chronic condition courses, problem solving, anger management, and communication sessions are offered to 'emerging adult' patients at Children's Hospital at Lehigh Valley Health Network (2013)
whereas other healthcare organizations offer education and coaching through the standard patient/provider interaction within an exam room. A variety of health frameworks and approaches to streamline and "improve the processes and structure of transitional care have been proposed, but it is not yet clear how effective these may be in improving health outcomes. Thus there is wide variation in provision both geographically and according to disease condition" (Freyer & Kibrick-Lazear, 2006). Some of the proposed frameworks include the Chronic Care Model, the Medical Home Model, and the Integrated Health Model.

The Chronic Care Model promotes "effective team care and planned interactions, self-management support through use of community resources, integrated decision support, patient registries, and other supportive information technology (IT)" (Coleman et al., 2009). Next, the Medical Home Model is "a team-based approach to patient care through the continuum of care. In this model, the PCP leads the care with the patient at the center. In a medical home, the primary care physician assists patients who need specialty care, maintains electronic records of all patient/provider interactions, communicates with all of a patient's clinical caregivers, and tracks the patient's progress (AcademyHealth, 2009). Finally, the Integrated Health Model emphasizes collaboration among caregivers rather than working in a silo. This promotes care coordination as a whole care team. Each of these models serve as a foundation to enhance care delivery through a more human-centered focus, promote better communication, encompasses
collaborative strategies that strengthen the provider-patient relationship, and improve health outcomes. Nevertheless the lack of structure within the program as well as the overall transition from the pediatric to adult care setting for 'emerging adults' continues to develop as a growing concern in health care.

"Young adults find transition disjointed and difficult as they must adjust to an increasing number of self-care responsibilities" (Crowley et al., 2011; Dovey-Pearce et al., 2005; O'Connell et al., 2003; Anthony, et al., 2009). "Transition to adult services can result in poor health indicators and a loss of important information about the chronic diseases" (Crowley et al., 2011). Regrettably, the quality and accessibility of psychological services for chronically ill adolescents and their support system varies greatly within The Adolescent Transition Program and within healthcare in general. For example, "less than 20% of adolescents with a chronic illness receive the support of social or mental health services", which impacts their ability to successfully transition (Garrison & McQuiston, 1991).

Section 6 - Discussion

Based on the literature review, chronic illness has an enormous impact on adolescence into 'emerging adulthood'. Chronic illness adds another level of stress to an already stressful stage of adolescent development. This is because a chronic illness doesn't merely impact the physical health of an adolescent, but also their psychological
well-being, their psychosocial status, and cognitive development. In this light, 'emerging adults' and their families must adjust to living and managing family member's chronic illness. Support systems are imperative in aiding and coping with the difficulties of attempting to maintain a healthy lifestyle. Additionally, the inpatient and outpatient medical care teams play a huge role in ensuring the 'emerging adult' understands his/her chronic disease, its symptoms, progress, and predicted outcome. Furthermore, the physical environment has an enormous and crucial effect on self-management of a chronic illness and its predicted outcome. As a chronically ill patient moves through the various transitions in their life, The Adolescent Transition Program attempts to meet the needs of this patient population through transferring critical disease self-management knowledge and secondly it attempts to set expectations about the adult care setting.

Research, however, consistently shows that The Adolescent Transition Program has gaps. For example, patients feel lost due to lack of clinician-patient communication, disease self-management conflicts, and/or they do not feel ready to make the transition. To address these gaps, we have to change the way we think about the program structure and the way we are delivering care for these unmet needs through challenging assumptions.

In conclusion, to obtain a very conducive learning environment it might be helpful to restructure how and where doctors, clinicians, and patients engage with one
another within the physical environment. The learning experience is much better for any learner when the environment is designed to support them (Loomis, 2008). The importance of the educator-adolescent relationship that underpins interactions in the clinical context might be the key (Kyngas, 2003). Ideal patient education should train the patients to perfect the skills they need to take care of themselves and problem solve in different situations. Ideal patient education includes emotional support for coping with one's feelings. Clinicians should also create a comfortable atmosphere for their patient education sessions. According to Bradbury & Jenkinson, 1998, this is obtained when the educational program is tailored to meet the patients' unique needs. "The service should be organized to encourage a return to school, college, or work as soon as possible, or to enable the patient to carry on with such activities throughout treatment if that is feasible" (Hollis & Morgan, 2001).

Section 7 - Summary

"Adolescents have barely been consulted as consumers of health services (Jedeloo et al., 2010)” (Ullan, et al., 2011). Health care facilities, both inpatient and outpatient, often do not meet the needs of chronically ill adolescents for several reasons. First, they don't consider an adolescent's developmental needs. Second, since the adolescent patient population is in between stages; (they are not children, but they are also not adults), the physical environment design is either too child-like or too clinical.
"Health-and-wellness design is getting a long overdue rethink. We are part of that process, because we incorporate wellness into all the spaces we design. Community connections are important especially in building lifelong relationships with patients. Creating an environment that caters to all life phases and conditions, such as a place one likes to come back to. A patient journey supported by the setting at every junction. Socializing, learning and collaboration are equally valid for caregivers (Richardson, 2012).

The relationship between the patient-to-provider, pediatric-to-adult care teams, and the environment is key in transforming the current-state of The Adolescent Transition Program. The hope is that The Adolescent Transition Program can become a more adaptive service. In this light, a program which strives to change the 'emerging adult's' experience from a mindset of only treating the disease to a more holistic perspective, one that strives to achieve comprehensive wellness. Ultimately, the goal is to design an adolescent-centered learning environment that supports multiple activities. The Adolescent Transition Program needs to include accommodations for an 'emerging adult' population which need to socialize (emphasis on peer relations), to learn (disease self-management and how to be independent), and heal. Chronic disease education should actively engage the patient and provide them with the essential tools to lead a healthy life.

In sum, it's no longer about delivering a service, but rather about how the clinician can tailor the treatment plan to the social and educational needs of the chronically ill person. In addition designers must assure that the physical environment acts as a vehicle to create a space that allows these activities to occur. The Program is more than a
service; it's about helping the patient move towards wellness and thinking about it from a-life-experience perspective. Essentially, it is about designing for the patients' experience as they learn about their disease and how the environment supports that learning process.

"Experiences, like goods and services, have to meet a customer's need; it has to work; and it has to be deliverable. [The relationship to the environment] unites customers with the event" (Pine & Gilmore, HBR, 1998). This requires active participation from stakeholders as well as integrating personalization according to the needs, response, and behavioral traits of chronically ill 'emerging adults’ "(Pine & Gilmore, 1999). Clinicians have to stage the experience through sets, props, and dialogue scripting which is tailored based on each patient. The experience must be truly interactive and personalized to that person's needs to promote trust and bonding in order to open up and fully engage (Pine & Gilmore, 1999).
CHAPTER 3

METHODOLOGY

Section 1 - Introduction

What defines a good experience within the learning environment? How can a chronically-ill individual become an active participant in learning and knowledge facilitation? What is the connection that the environment plays to the learning experience and the ability of the patient to learn? How does the patient experience the space? What are the essential design components that allow the participant to actively engage?

Every one of these questions challenges a design researcher to look at healthcare and design through the lens of the sample population, clinicians and 18-26 year old individuals, to fully grasp how the learning and built environment can be enhanced. These questions were chosen to determine the various facts of education and what an individual needed in order to obtain and process knowledge. Ultimately, determining what the collective needs entail from multiple perspectives aids in understanding how the current space functions in relation to the activities it holds and where the opportunities to improve lie. By tapping into these unmet needs, a human's overall experience can be transformed.
Section 2 - Research Methodology

To better understand clinicians and 18-26 year old people's teaching and learning experience, design thinking was used. Design thinking or human-centered design is a collaborative and iterative process through which deeper emotions, needs, and motivations of people are unearthed (IDEO & +Acumen, 2013). Assumptions are questioned which help explore various possibilities and discover new opportunities. Direct observations of humans in their natural environments as well as other qualitative research methods helps to explain what people want and need in their lives or how they interact with a product or service, which powers innovation (Brown, 2009). Design thinking/human-centered design has 5 phases which run parallel to each other and aid in extracting deep experiences that impact people's lives (Boswijk et al., 2007).

The first phase, define: sense intent/problem framing (what is), involves creating an innovative concept and uncovering where new value lies (ITT Technical Institute, 2006). The second phase is research: know context (what if) and know users. Research: know context helps to frame the opportunities while research: know users utilizes ethnographic methods to identify user needs (ITT Technical Institute, 2006). Third, analysis: frame insights generates value through identifying themes and patterns from data collected (ITT Technical Institute, 2006). Next, synthesis: explore concepts (what wows) occurs when insights suggest new ideas, services, business models, environments, and much more (ITT Technical Institute, 2006). Lastly, realization: make plans (what
works) entails finalizing solutions through creating a business plan (ITT Technical Institute, 2006).

Figure 6: Design thinking/human-centered design approach

As a researcher moves through each of these phases, an "individual's personal experience: his or her everyday world and societal context" will surface, which leads to observing the world in new ways (Boswijk et al., 2007; Brown, 2009). These experiences are stories that help us to remember, transmit, and spread ideas. Furthermore, these human stories enable us to connect with people especially through co-designing solutions with the target audience.

Co-design is a "creative cooperation between diverse experts such as researchers and stakeholders during the design process" (Steen et al., 2011). It helps bring multiple perspectives together. Co-design along with human-centered design's 5 phases drives
ethnographic research methods and conveys value in an innovative way. Last of all
design thinking/human-centered design and co-design extract stakeholders' views to help under-stand their story, how they move through the current space, and identify unmet needs.

3.2.1 - Phase 1, Define: Sense Intent/Problem Framing

As my brother took steps towards recovery, I realized that he wasn't connected to resources that could aid with the psychological stress of living through a chronic illness, determining how to obtain independence after being so reliant on our parents, and how to adjust back into 'normal' everyday life. Without adequate support, direction, and health education from his pediatric care team, he felt lost and confused in the adult care setting. This experience led to forming the thesis problem statement; transition from the pediatric to adult care setting for patients ages 18-26 is fragmented and continues to develop as a growing concern in health care. In order to dive deeper into the problem statement and understand more about the context and 18-26 year old patients, the second design thinking/human-centered design approach was used.

3.2.2 - Phase 2, Research: Know the Context and Know Users
“Always design a thing by considering it in its next larger context—a chair in room, a room in a house, a house in an environment, an environment in a city plan” (Saarinen, n.d.). The second phase, research: know the context and know users, consists of understanding where opportunities or constraints might lie within the healthcare system. A combination of the literature review (secondary research) plus ethnographic research methods (primary research) assisted in comprehending the context and the primary stakeholders; the clinicians and 'emerging adults'. The data collected from primary and secondary research produced insights.

Figure 7: Research: Know the Context and Know Users
The literature review explored the current-state of adolescent health and medicine by systemically examining global, national, the outpatient care setting, and the Adolescent Transition Program. The larger context revealed that transitions and care coordination across the continuum of care are fragmented for all patient populations. It also exposed that The Adolescent Transition Program is in a state of flux and is not meeting the education requirements of chronically ill patients ages 18-26. The literature review helped lay the foundation to grasp normal developmental and educational needs of the patient population and challenges faced by having a chronic disease. Finally, Phase 2, Research: Know the context and know users utilized a survey and ethnographic research methods to determine the unmet needs of the target demographic.

Section 3 - Methods

A survey and ethnographic methods such as in-context immersion, observations, and interviews were conducted to identify 'emerging adult' and clinician needs through data collection. An ethnographic study "provides a description and interpretation of the culture and social structure of a social group. It has its roots in anthropology, involving an immersion in the particular culture of the society being studied" (Robson, 2011, p. 142). The best way to understand a person's unmet needs is to observe him/her in their natural environment and directly talk them. The "personal experiences" of 'emerging adults' and clinicians" determine the value, motives that are relevant, and give meaning
and direction” (Boswijk et al., 2007). In-context immersion was conducted at 3 adolescent health clinics (1 free-standing adolescent clinic and 2 clinics located within high schools), observations were conducted in libraries, a university, and the adolescent clinics, while a survey and interviews aided in extracting 'emerging adult' and clinicians' experiences in learning and the built environment.

**Figure 8:** Survey and Ethnographic Methods

3.3.1 - In-Context Immersion

In-context immersion involves “meeting people where they live, work, and socializing. This involves immersing yourself in their context, which reveals new
insights and unexpected opportunities‖ (IDEO & +Acumen, 2013). A Nurse Practitioner (NP) was shadowed for a few days to experience her workflow and process. This led to gaining a better understanding of what clinicians think and feel. Through witnessing the NP interact in her own environment, needs, barriers, and constraints surfaced.

Figure 9: Adolescent Health Clinic, Roanoke, VA

3.3.2 - Observation

"Observation is a ethnographic method where the actions and behaviors of people are watched to understand what they do. The data is recorded and then used to describe, analyze, and interpret" (Robson, 2011, p. 315). Observation aided in recognizing the current-state of various learning environments; libraries and outpatient adolescent health clinics. Specifically, Cesar Chavez Library, Ocotillo Library, South Mountain Library
Branch, and Arizona State University in Tempe, AZ were observed. South County Library and 3 adolescent clinics in Roanoke, VA were also studied. To ensure that the same data was collected in each setting, an observation protocol was developed.

The observation protocol examined the physical environment specific to spatial layout, lighting, furniture, and the overall atmosphere. Interactions with objects were observed in particular the type of equipment used for communication and learning. Next, interactions with people were watched to discover the type of verbal and non-verbal exchanges such as recurrent words/sentences that the education facilitator used, details about care plans and disease self-management, communication methods, types of printed material, and toolkits (if any) given. Lastly, the observation protocol recorded the broken telephone issue which looked for information that was lost or misunderstood within the communication chain. Observations helped to collect specific details and understand various levels of interactions within each learning environment. Examples are shown below.
Appendix A The observation protocol was used throughout all observations to ensure consistency. Observations examined the interactions within the physical environment, interactions with objects, interaction with people, and the communication issues (broken phone issue).
Environmental responsive building materials

Figures 10 & 11: Ocotillo Library (Durkin + Durkin Architects), Phoenix, AZ

Figure 12: South Mountain Library (Richard + Bauer Architects) Phoenix, AZ
Figures 13, 14, 15: Both South Mountain Branch Library (Richard + Bauer Architects) and Ocotillo Library's (Durkin + Durkin Architects) interior mimics the natural environment through color palate, and interior building materials.

Figures 16, 17, & 18: Cesar Chavez Library (Line + Space, LLC) and South Mountain Branch Library's (Richard + Bauer Architects) interiors ventilation system allows for good air flow.
Figures 19-24: Cesar Chavez (Line + Space, LLC), Ocotillo Library (Durkin + Durkin Architects), and South Mountain Library (Richard + Bauer Architects) demonstrate how both artificial and natural light can be used in tandem within an space.
Figures 25 & 26: Florescent lighting is common in the observed adolescent clinics. Very few of the clinics have windows, like the ones found in one of the adolescent community clinic.

Figures 27, 28, & 29: Cesar Chavez (Line + Space, LLC), South Mountain (Richard + Bauer), and Ocotillo Library (Durkin + Durkin) have separate study rooms with the ability to close the door for more privacy and noise control.
Figures 30, 31, & 32: Cesar Chavez (Line + Space, LLC), Ocotillo (Durkin + Durkin Architects), and South Mountain Libraries (Richard + Bauer Architects) offer chairs with desk for individual contemplation and study.
Figures 33, 34, & 35: Education and community outreach are incorporated into each library setting. Cesar Chavez (Line + Space, LLC) (top 2) and Ocotillo Library (Durkin + Durkin Architects) are featured above.
3.3.3 - Interviews

"Interviewing is widely used in social research. It involves asking questions and receiving answers from the people being interviewed" (Robson, 2011, p. 278). A combination of fully structured and semi-structured interviews were used in this study. Fully-structured interviews have "predetermined questions with fixed wording" whereas semi-structured interviews "follow an interview guide that serves as a checklist of topics to be covered and default wording" (Robson, 2011, p. 278). The major differences between the 2 is that a semi-structured interview organization is often modified based on the flow of the interview and unplanned questions are asked in order to dive deeper into what an interviewee says.

Interviews were conducted with 5 Adolescent Medicine clinicians (2 Nurse Practitioners (NP), 1 Licensed Practicing Nurse (LPN), 1 licensed social worker (LSW), and 1 patient educator) to gather a variety of perspectives. Questions aimed towards uncovered best practices for adolescent healing environments, the required physical and electronic communication methods, and disease self-management techniques. Appendix B shows a detailed view of the specific questions asked in the interview. Interviews were recorded and transcribed.
3.3.4 - Survey

A survey is an approach to social research which collects data in a standardized form (Robson, 2011). This research utilized a sample survey since this type of survey's aim is to gather data from a smaller population size to represent a larger group (Robson, 2011). Specifically, the 23 question survey targeted 18-26 year old individuals to understand how they learn, what environment is best suited for them to learn, and what tools they need to learn. Refer to Appendix C for the specific survey questions. The survey was uploaded into Survey Monkey to allow for easy access for participants across the United States. The survey was sent to 30 individuals through Facebook, however only 16 participated.

Participants were recruited through family and friends. Selection criteria was limited to 'emerging adults' ages 18-26 and who were not mentally impaired. Participants were healthy, however some may have chronic illnesses, but that criteria was not directly sought nor collected in order to recruit more people. Identities of individuals as well as identifying factors such as gender and location were omitted to allow for the utmost amount of privacy and to ensure that insights generated from answers would be unbiased. The purpose of abstracting the views of 18-26 year olds was to create a generalized understanding of their learning needs and not to design an environment that catered to only a sub-population. Since different cultures have very dissimilar understanding about health, illness, death, and dying, ethnicity was specifically excluded.
from the survey questions. The identity of the participants is unknown unless they chose to leave their contact details for future follow-up.
CHAPTER 4
FINDINGS

Section 1 - Phase 3, Analysis: Frame Insights

Analyze: frame insights is accomplished through distilling collected data to determine the value. Insights are "interpretations of what was observed about people and context that reveal something surprising and valuable" (Kumar, 2013, p. 141). These insights are then sorted, clustered, and organized into data buckets, which reveal overlapping patterns. "The contextual data and patterns point to untapped opportunities" (Kumar, 2013, p.11). Data clustering and brainstorming, two analyzing techniques, helped to reveal these opportunities in the observations, surveys, and interviews.

Data clustering is "gathering all of the research insights on sticky notes and sorting them based on common themes. Themes were determined based on which insights were similar in terms of shared meanings. Data is clustered and re-clustered until a stable clustering pattern is reached" (Kumar, 2013, p. 140). The second analyzing technique, brainstorming was "used to generate and select alternative solutions, for developing ideas about aspects of a project rather than as a research method itself" (Robson, 2011, p. 299). Both techniques enabled "patterns to emerge which help to move from "messy" data to general, abstract, and easily grasped modules of how a context works data" (Kumar, 2013, p. 132).
Figure 36: Data Clustering

Common themes all related to transforming the current healing environment to better support, enhance, and contribute to the teaching and learning experience. Insights were formed from these overlapping themes, which determined the key ingredients to create a meaningful experience. The subsequent insights highlight ways in which to transform the way "one thinks, relates and acts" through spatial reconfiguration (Boswijk et al., 2007).
Figure 37: Analysis Framework
4.1.1 - Observation Key Insights

*Insight.* Exterior building materials complement the landscape. Colors, outdoor views, and gardens make the space comfortable by appealing to the senses.

*Figures 38, 39, 40:* South Mountain (Richard + Bauer Architects) (left and middle) and Cesar Chavez Libraries (Line + Space, LLC).
Insight. Libraries and schools cater the spaces to meet various learning needs as well as ages. Each of these environments was staged with props such as furniture and education materials to adhere to the 'emerging adult' or clinician. In all cases, the location and neighborhood determined how the space functioned. For example, every library was broken into 3 spaces; children, teen, and adult. Cesar Chavez Library has a high population of middle-high school students since it is close to a high school so it catered to teen after school programs. Ocotillo Library meets the community needs by providing professional development courses and access to job searching tools. South Mountain Branch Library is located near a community college and was primarily designed for 18+. South County Library holds many events to cater to its large retired population. Lastly, Arizona State University is designed to meet the needs of a higher education population.

Figures 41 & 42: Cesar Chavez Library (Line + Space, LLC) reaches out to its main customer demographic, teens, by asking them for feedback about how to better cater the environment and library services to their needs. The educational shelf at Ocotillo Library (Durkin + Durkin Architects) serves as an important resource for job seekers.
**Insight.** Computers, whiteboards, TVs, and projectors with screens cater to a variety of learning styles and are accessible throughout the libraries.

**Figures 43 & 44:** Multiple computer spaces allow more humans to leverage technology at Cesar Chavez Library (Line + Space, LLC). The whiteboard is used frequently by groups of students to help each other with homework assignments.

**Figure 45:** A TV set at South Mountain Library's (Richard + Baer Architects) teen area enables young adults to interact with their peers by playing video games and watching movies.
**Figure 46:** The conference room at Roanoke's South County Library (HBM Architects) accommodates larger groups and houses lecture series that are available to the community. Picture taken from Google Image.

*Insight.* Furniture is designed to meet the activity or the age demographic.

**Figures 47 & 48:** Formal workplaces at Cesar Chavez (Durkin + Durkin Architects) and South Mountain Libraries (Richard + Bauer Architects) create spaces that have a defined intent. Both furniture arrangements have more table space allowing a person to spread out.
Figures 49-52: Informal workplaces at Cesar Chavez (Durkin + Durkin Architects) (top pictures) and South Mountain Library (Richard + Bauer Architects) (bottom pictures) can be used for a multitude of activities and comfort levels.
**Figures 53 & 54:** Personal or work use couches at Cesar Chavez Library (Durkin + Durkin Architects) are inviting spaces that encourage library goers to spread out or lay down.

*Insight.* There is a clear space division through signage, furniture style and function, paint colors, and age appropriate books. All of the pictured children's spaces use bright colors to attract children to the space. Furniture has been customized to meet a smaller stature and the use of shapes and artwork in certain areas encourage play.
Children’s Corner

Figure 55: Cesar Chavez's (Durkin + Durkin Architects) 'read' sign is often used by children to climb on or use as a reading spot.

Figure 56: Ocotillo's (Durkin + Durkin Architects) children's library stands out with its use of building block book shelves, toys, and bright colors.
**Figures 57 & 58:** South Mountain Library (Richard + Bauer Architects) in Phoenix, AZ (left) and South County Library (HBM Architects) in Roanoke, VA (right) children's' corners also uses bright colors and smaller furniture build to attract kids to the space. South Country Library taken from Google Images.

*Teenager to young adult environment.* Multi-purpose furniture are key as they can move based on the activity. The furniture style shapes how the space could function. Lower to the ground seating creates space for a group of people to congregate as well as more comfort and relaxation.
Figures 59 & 60: Both pictures taken at Cesar Chavez Library (Durkin + Durkin Architects) demonstrate how the space is catered to teens/young adults. The teen area offers comfort and various interaction levels.

Armchairs with individual desks provide individual work spaces. The signage and space divider direct teen customers towards spaces that have been designed specifically with a certain age demographic in mind.

Figures 61 & 62: Dividing space to specify areas designated to appeal to various age demographics. South Mountain Library (Richard + Bauer Architects) used a chain space divider, while South County (HBM Architects) used more teen/young adult lounge furniture types and arrangement. South County picture taken from Google Images.
**Adult space.** Both spaces shown can be informal or formal spaces as well as catering to group or individual activities. Notice how the colors are more muted and cool than the children or teen spaces, which elicits a calming effect.

![Adult space images](image)

**Figures 63 & 64:** Cesar Chavez Library (Durkin + Durkin Architects), Phoenix, AZ and South County Library (HBM Architects) Roanoke, VA create an adult and quiet space by using more muted colors and comfortable seating. South County Library picture taken from Google Images.


4.1.2 - Interview Key Insights

Six themes emerged from the clinician interviews in regards to successful transitions elements, adolescent clinic role in patient health, communication, health education facilitation and challenges, and physical environment needs.

There are not many chronically ill adolescents in Roanoke, VA. "Except for the occasional chronic illness, teenagers are healthy" one clinician stated. "Those that do have a chronic condition are a much smaller percentage and are referred to specialists for such illnesses as cancer, endocrine issues, cystic fibrosis, etc.", another said. The most common chronic illnesses that are seen by the clinics are diabetes, asthma, hypertension, and obesity. The most common reasons for visits are physical exams, immunizations, STDs, and pregnancy. Within an adolescent clinic there are two focuses, clinical and community outreach, both which require dedicated resources for patients to access care and health knowledge.

"As far as the healthcare knowledge", the LPN stated, "we are here to teach them". The patient is reliant on the care provider (NP/doctor) to facilitate health knowledge. The entire outpatient care team which consists of a LPN, NP, doctor, medical office assistant, and social worker (if patient is referred) are responsible for health education. The health educator is also responsible, but is focused on community outreach and educating patients on non-clinical topics such as emerging health care
trends and healthy lifestyle choices such as nutrition. Collaboration between the adolescent care team members is essential in positively impacting health outcomes.

Figures 65 & 66: Adolescent health education demonstration tools

Figures 67 & 68: Adolescent Health Promotion Posters
Each clinician plays a different role in facilitating disease self-management and each is integral to move towards wellness for chronically ill adolescents. Nurse Practitioners (NP) are responsible for the primary clinical education, Licensed Practical Nurses (LPN) assist, Licensed Social Worker (LSW) facilitate the mental health portion, and the health educator facilitates health promotion through lifestyle and behavior change. The providers, LPN, and LSW work together with the health educator to reach patient in clinic setting and community to provide care and educate about reaching wellness. Disease self-management entails coping skills, emotional and education elements, counseling, positive reinforcement, goal making, looking to future, understanding consequences and maintenance, maintaining timelines, and making sure decisions are consistent. Although each patient differs in care plans and disease states, chronic disease education and self-management are started at the time of the diagnoses.
The amount of accountability and level of responsibility, however, is based on the patient's age, support system, and care components. Late adolescence or emerging adulthood (18-26) is typically when the clinician will emphasize more accountability and less parent involvement to prepare the patient for transitioning to the adult care setting.

**Figures 70, 71, & 72:** Several adolescent health clinic's chronic disease visual aids and written material education tools.
Adolescent transition programs are not common. Interviewees revealed that they do not have a formal transition program like The Adolescent Transition Program. In fact, 4 out of the 5 clinicians had never heard of it. They did, however, all mention that when they do transition any patient, whether they are chronically ill or not, that there has to be an agreed upon way to do it and a common dialogue among all specialties caring for the patient to create consistency in care coordination. Expectations can then be appropriately set for the adolescent care team to understand each health care professional’s role in transition education and follow up.

All stressed the importance of having the adolescent provider or Primary Care Provider (PCP) as the primary coordinator to connect the patient to the appropriate resources (insurances, people, and care management). They help put the pieces together and are the central hub for transmitting patient data securely, maintaining confidentiality, and providing transition education. Collaboration between both the pediatric/adolescent and adult care teams will help in ensuring the patient understands that the services continues, but accountability falls on the patient’s shoulders for disease self-management, follow up with doctors, getting questions answered and decision making.

Adolescent patient education and chronic disease management are not 'one size fits all'. The pediatric/adolescent care is not only chronic disease specific, but it also caters to the patients’ learning style, developmental stage, and often their culture. "We
adhere to where they are", one of the interviewed clinicians mentioned. The care team assesses patients' learning styles by asking them questions and facilitating knowledge based on whether they are a visual, auditory, or kinesthetic learner.

Environments that are conducive to visual learners contain whiteboards, projectors and screens, reading materials, and any education tools that help them watch a process. Auditory learners require good acoustics for listening and reciting notes. Kinesthetic learners favor environments that have use tactile objects or interactive experiences that allow them to move. The clinicians use visual props like lungs to demonstrate how asthma impacts the ability to breath, encourage patients to take notes about effective disease self-care skills, and, when available, shows a patient on a computer how to navigate to important online resources. Lastly, clinicians gauge a patient's understanding and information processing ability by using repetitive techniques, the teach-back method (a way to confirm that the patient understands the information by explaining it back to you), and reiteration.

As far as a standardized way to deliver care and education, there is not one best practice that applies to all patients, because not all patients are in the same developmental stage (early, middle, and late adolescence). One NP said that the adolescent medicine in general is a challenging specialty. She said,
"Other specialty clinics only focus on one disease state and give care accordingly. When you are in adolescent medicine, you're not talking about one disease state that you can give a biological explanation of x, y, z and a treatment response. You aren't going to get that in adolescence and that's what makes it a challenge."

The SW said, "chronic illness isn't cut and dry and not easy. Not sure if anyone will ever be successful in pinning one approach."

The clinicians all agreed that they do focus on a wellness approach which includes collaboration between the clinician to patient and clinician to clinician to align the patient with the right resources to practice healthy behavior, goal-setting, and self-care every day. Common educational material include; written (pamphlets, brochures), Internet sites (WebMD, CDC, medical journals, Institute of Health) and printing information for the patient from the Internet, peer-to-peer messaging (billboard campaigns done by patients on particular subject matter to create awareness), and chronic disease specific (apps and websites). 'Emerging adult' education can be challenging.

The current exam room meets the clinical needs; however from an education standpoint the environment is limited and nonflexible. According to all of the clinicians, the current exam room houses the essential elements and tools needed to practice medicine and provide clinical care to adolescent patients. Elements include cleanliness, in-room temperature control, BP cup, weight scale, sharps container, contamination bin, a height chart, confidentiality and privacy, a sink and bright lighting.
for infection control. One clinician said, "We have to practice with what we have". "The doctor" in the current set up "is seen as an authority of health knowledge especially as s/he is looking over the patient as the patient is lying on the exam table". This arrangement which works well for clinical exams, does not work while trying to facilitate knowledge. "Patients", notes the social worker, "think the provider is lecturing rather than encouraging active participation, which can be accomplished by talking at the same level as the patient". It can cause intimidation and be harder to create a trusting relationship. Herein lays the issue as all interviewees agreed that the environment could be reconfigured to better suite educational needs of the adolescent patient population.

The physical environment must be larger, multipurpose, and flexible. The current exam room is too small and it's hard to interact with patients. The "exam room has to be a place where you can facilitate disease self-management. You could do it in an office, but we don't have enough space". Another clinician said that there is "only so much we can do with our current space. We can bring in props, but the space isn't flexible for various education activities". "It's not even big enough for real furniture, like a couch or larger workspace" another clinician added which helps to create a comfortable environment for the patients and has the potential to "foster collaboration and engagement both between clinician to clinician and clinician to patient". "This is all we have, which makes it hard when we [are in charge of] bringing health care to the patient". The current layout and environment do not meet these needs.
Figures 73 & 74: Adolescent Health Clinic Exam Room

Figures 75 & 76: Exam Room, Adolescent Health School Clinic, VA
Figures 77, 78, & 79: Adolescent Health School Clinic exam room and an attempt at creating positive stimuli for patients within one of the exam rooms.

Figures 80 & 81: Provider Office in the Adolescent Health Clinic and the School Clinic Office Space
4.1.3 - Survey Key Insights

Sixteen individuals were recruited to participate in a 23 question online survey. All 16 individuals participated, however some did not answer all of the questions. Participant ages varied between 18- 25 years old; 18- 19 (20%), 20- 22(60%), 23- 25 (80%), and 26- 30 (0%). Survey questions targeted learning environment needs, engagement, education needs, and technology and yielded results that aid in better understanding an 18- 26 year old individuals’ learning experience. See Appendix B.

*Learning spaces should be multifunctional and adhere to various learning styles.* Results showed that learning spaces needs are individualized, but that most respondents reported that they needed the following; interactive activities (38%), cleanliness (19%), good acoustics and visibility to educational components (31%), large workspace/desk (31%), well lit (natural light and bright) (25%), technology resources (printer, outlet accessibility, computers) (19%), few distractions (19%), collaboration with teacher or peers (13%), and colorful and happy (13%). Almost all of the 15 respondents (1 did not answer) conveyed that they need technology to learn (13 or 81%), which includes projectors (10 or 63%); computer (5 or 31%), PowerPoint presentations (4 or 25%), white board (4 or 25%), laptop (3 or 19%), and 3/19% reported that they don’t need technology to learn. Furniture needs included comfortable chairs 10 out of the 16 or 63% , comfortable furniture 5 out of the 16 or 31%, desk/table that is large enough
to cross legs and to fit a laptop 4 out of 16 or 25%, and not too comfortable, which could cause laziness 3 out of 16 or 19%.

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<td>&gt; Colorful and happy</td>
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**Figure 82:** Survey Key Insights

Eleven participants reported that they preferred demonstration as a method to engage them in learning, 9 out of 11 or 82% prefer face-to-face interaction, 7 out of 11 or 64% like verbal instruction, and 5 out of 11 or 46% like written material. Nine respondents reported that they have not heard of new ways to education and engage over the last year, 4 or 45% said they have, and 2 or 22% did not respond. New learning methods that some of the participants have heard about involved leveraging mentoring as a means to determine if facilitation methods meet students' needs, peer-to-peer lessons
through utilizing online modules and education through experience, recent and continued controversy of standardized tests usage, utilizing electronics to track learning patterns and using iPads for learning disabilities as well as brain injuries, and some teachers prohibiting smart phones within their classroom as a way to engage students more with in-person activities.

*Learning spaces should engage the participant and allow for knowledge facilitation.* Education needs varied among the individual. Top responses included having teachers who engage and facilitate knowledge rather than just lecturing 3 out of 15 or 20%, established clear objectives during the course to direct focus 2 out of 15 or 13%, learning practical application to real world 2 out of 15 or 13%, and a small class size 2 out of 15 or 13%. Other needs included clear explanation of subject matter, a good relationship with the teacher, cheaper textbooks, accountability, professor availability and their investment in the students' success, technology and portability, and consistent feedback from professor. Most surveyed responded that they think education should be tailored to meet their education needs. This includes engaging students in subject matter through an active collaboration, asking for feedback, and knowledge facilitation not lecture, adhering teaching to meet various learning styles, returning homework in a timely manner, being available to students for questions during office hours, providing inexpensive course materials, and teaching subjects of interest and application to real world.
Table 1: 'Emerging adults' learning style preferences gathered from the survey.
Table 2: 'Emerging adults' learning engagement preferences gathered from the survey.
Tables 3: 'Emerging adults' homework assignment preferences gathered from the survey. This showed what communication methods this population prefers when they receive information.

Most participants indicated they like to learn in a group setting. Results were mixed when asked about ideal teacher to student ratio. Top respondents revealed that they preferred a 1:30 or less teacher to student ratio; 3 or 19% preferred 1:20, 3 or 19% preferred 1:30, 2 or 13% preferred 1:12, and 2 or 13% preferred 1:15. The other respondents reported ranges less than 15 or higher than 30.
Technology is not required to learn, however it should be readily accessible within a learning space. Fourteen reported that they owned a laptop and used it daily for school, personal use, and work. Social media is a key communication method for people ages 18-26. Respondents reported that they use social media sites like Facebook, LinkedIn, and Instagram, to talk, connect, and keep friends, post pictures, network for work, and keep up with the latest news. In addition, all reported that they owned a smart phone and used it daily to text, surf the net, talk, and email.

![Image of survey results](image)

**Table 4:** Survey results for social media use.
Various educational materials should be available for 'emerging adults' to choose their learning method. Half of the participants said that they preferred reading a printed book opposed to an electronic book. Reasons included that a book is tangible and can hold and touch it, accessibility, better to read something opposed to looking at a screen, and that they like to write notes in them. For those that preferred an online book opposed to printed book, top respondents reported that books are too bulky (6 out of 16 or 38%), downloading a book from the Internet is more convenient(3 out of 16 or 19%), and less of a hassle than going to the store to buy a book (5 out of 16 or 32%). Results revealed that 7 people or 44% have used a Kindle to read, 4 or 25% haven't ever tried to read a book online, and that it's easier to travel with an online book opposed to printed book (2 or 13%). By having different types of educational materials, learners can chose the method that best accommodates their style.

In summary, each of the 14 insights gathered from observations, interviews, and surveys demonstrated the importance of customizing the learning experience. The overall learning experience is different for each person, however the teacher has to craft the knowledge in a way that caters to everyone's learning style. Learning that is flexible is best as it allows 'emerging adults' to chose the tools that allow for the level of interaction they want such as choosing written versus electronic educational material. These learnings laid the foundation for the 4th design thinking phase, synthesis: explore concepts and frame solutions.
Section 2 - Phase 4 Synthesis: Explore Concepts, Frame Solutions

Based on the data collection and analysis, design recommendations can be created within the fourth phase synthesis: explore concepts and frame solutions. Insights learned from the literature review and qualitative research demonstrate that there are two dimensions of experiences; customer participation and connection to the environment which unites people with the event (Pine III & Gilmore, 1998).

**Figure 83**: Phase 4, Synthesis: Explore Concepts and Frame Solutions.

'Emerging adults' think that there is a connection between the ability to learn and the physical environment. Physical environments give people signals about how to behave and feel (IDEO & +Acumen, 2013), altering the environment in which disease
self-management is taught, and helps send a fresh message about how people should feel and interact within the outpatient environment. From a service perspective, human-centered design examined The Adolescent Transition Program from the way in which it operates to how it is delivered. By understanding the people The Adolescent Transition Program is serving, their needs and desires, limitations, and motivations were discovered (IDEO & +Acumen, 2013).

Section 3 - Design Recommendations

The physical environment plays an important role in helping patients feel comfortable in seeking care, confiding in clinicians, and moving towards wellness. Ideally the exam room or an alternative environment should adhere to both clinical and educational needs of both the facilitator (clinician) and the learner (patient). To address the complex needs of 'emerging adults' the research proposes that the clinical exams should remain in the current environment as they are designed to control infection and contain all the clinic tools a health care professional requires to deliver care. However, chronic disease management and health promotion education should move into a new environment, one that encompasses all of the 5 design recommendations to ensure that the adolescent clinic and 'emerging adult's are met.
Flexibility, the first design recommendation, means that the environment must be multi-functional to meet each of the specific clinical discipline's needs. The space must be conveniently located near or next to the exam room, but should be larger and have an open-planned spatial configuration so that it mirrors more of a classroom setting. An open-planning spatial configuration as well as an adaptive design can be achieved through the use of modular and movable wall systems. The wall systems allow the environment to be "quickly reconfigured to different activities and levels of interaction" (Gentler, 2005).

Outpatient clinics will become the primary point of patient contact and therefore the environment itself must be reactive to change to meet the demands of treating a multitude of chronic conditions and health education activities. Patients and the care team can transform the environment themselves through customizing the environment the way they need to for the activity they want to accomplish. "Using moveable walls is perhaps the single most important step in creating a flexible clinic. They adapt as providers, procedures, and specialties change. And they offer privacy and structural support" (Cardoon, Herman Miller, 2011). Tables that can fold out to create either an individual environment or conference room to support peer groups. Other flexible furniture would include furniture (couch, chairs, and shelving) on wheels, "shelving on casters, sled-based chairs, a multitude of electrical receptacles distributed throughout the room, light fixtures designed for task flexibility, modular acoustical partitions and sound-
dampening materials, and minimal fixed walls and features " (Feinberg & Keller, 2010, p. 113).

The increased square footage will also support a higher volume of patients or can become smaller to create a more intimate learning experience for those 'emerging adults' who value a smaller student to teacher ratio. "Adjustable walls create intimacy required for focused ideas, while limiting distraction, and a place to calmly connect with others" (Dooley & Without, 2012). Additionally, the environment will cater specifically to 18-26 year old patients in The Adolescent Transition Program.

Figures 84, 85, & 86: Clinic environments like these could be repurposed to meet the chronic disease management and health promotion needs.
The second design recommendation is to leverage the design thinking methodology to co-design the environment with 'emerging adults' and adolescent health clinicians. By involving the patient in the design, the environment can be tailored to meet their needs and it will provide a level of comfort. The patient demographic is typically one of the harder populations to get in for appointments, so by leveraging co-design between all stakeholders, patients will be encouraged to share their thoughts. Thus an encouraging atmosphere [can be] created when the clinicians motivate the adolescents to actively engage in the design process (Kyngas, 2003). Adolescents will feel respected and their opinions valued which will aid in forming independence. This collaboration will also create an opportunity for the clinicians and patients to create a holistic healing environment that creates a balance between the body, spirit, and mind, appeals to all senses, and adheres to clinical needs and learning styles.

Aesthetically, showcasing patient artwork or interests serves as a positive distraction. Decorating the walls with the patients' art preferences could also illustrate their adjustment to the environment (Strange, Banning, & Delworth, 2001; Hansen & Altman, 1976). Painting the walls a color other than white would draw patients in by creating a more meaningful experience through having a personal investment to the environment.
Since "color is subjective, the most appropriate environment for young people might be one that is muted, quiet, warm, and soothing or cheerful, bright, and lively" (Feinberg & Keller, 2010, p. 119). For a healing environment, it may be better to choose a warm color to create a more inviting environment, one that takes warm colors from the outdoor environment and weaves them into the color palate of the interior environment creating continuity and harmony. The attractiveness of the room can influence the mood, energy level, and can encourage people to spend more time in the environment, which will promote a more positive environment (Strange, Banning, & Delworth, 2001; Maslow & Mintz, 1956; Sommer, 1978).

Furniture choice should be well-built piece, have easy to clean material for infection control, comfortable chairs and couches that are flexible to use for both formal or informal education sessions, and patterns on the furniture to add to the warmth and environment ambience (Feinberg & Keller, 2010). Other interior elements that should be considered for an 'emerging adult' environment are sound-absorbent materials for good acoustic quality, and large enough workspaces to house interactive electronic tools to engage the patient in her or his health. "Incorporating music into the healing environment- if the patient enjoys the music- can have an analgesic effect, reducing blood pressure, heart, and respiration rates" (Allnurses, 2008; Foates, 2008). These cues plus lighting will help to make an inviting environment that not only adheres to 'emerging adults' patients, but to the clinicians.
Clinicians should have the ability to adjust the lighting depending upon the reason for visit to allow for either a more clinical or educational setting. For example, adjustable lighting will allow a more clinical activity which requires a brighter light to occur or a softer light for a support session between the patient and the LSW. The environment should have natural light. "Natural light improves the working environment through increased concentration and learning and it can have an uplifting effect on feelings of well-being and health" (Cannon Design et al., 2010). Adjustable lighting through the wall switch and shades on windows will allow various levels of privacy and adhere to various activities. An adaptive room design is effective in moving towards a wellness approach through facilitating disease-self-management skills and healthy lifestyle education.

*Design recommendation 3 advises that the environment should "be a tool to create meaningful collaboration"* (Doorley, S. & Witthoft, S., 2012, pg. 5). Learning styles differ between visual, auditory, and kinesthetic, so "teaching strategies should be durable and flexible, they also need to "morph" as the learning process requires' (Loomis, 2008). It's hard, all interviewed clinicians stated, to "try to get patients to understand consequences on health, as well as the importance in investing in nutrition, healthy behavior, and lifestyle". To address this challenge, education should be more interactive through hands-on and face-to-face stimulation, two learning components that 'emerging adults' value. Refer to Appendix D.
Clinicians can continue to use props to educate about disease states, but they could also engage the patients in healthy behavior knowledge. The environment could house a kitchen to demonstrate healthy eating through cooking classes and engaging the patient in learning rather than merely lecturing about healthy behavior. The hands-on activity and use of a kitchen would "trigger the senses through an environment rich in sensory experiences to help students retain and retrieve what they learn" (Cannon Design et al, 2010, p. 177). Learning would then take place "within a series of relationships-between faculty and student and students and their peers" (Loomis, 2008). An interactive learning experience can also be achieved through the use of technology.

*Technology is an important instrument used to facilitate knowledge is the fourth design recommendation.* Technology isn't needed for all learners, but it does provide an alternative educational tool for clinicians to use for chronic disease management and healthy lifestyle and behavior support. "Technology is a piece of the broader educational experience. You want to make sure you're not substituting technology for the classroom experience. Without the interaction and richness of that experience, it becomes empty and unproductive" (Arieff, 2012).

Internet access, several moveable computer stations, a projector and screen, a printer on wheels, and a lot of outlets built into the walls will allow accessibility to technology education tools. Smart boards or electronic white boards will be built into
the moveable walls to provide flexible learning environments and learning from anywhere in the room (Loomis, 2008). The smart boards or electronic white boards will foster interactive learning between the clinician and the patient.

Clinicians can help patients navigate to chronic condition websites, examine their electronic medical record, find online health apps that pertain to health promotion, and print the patient's medication list. The clinician and patient can use the smart board or electronic white board to evaluate the patient's progress for self-care activities like blood glucose monitoring and could use it as an interactive communication method to talk to all members of the care team across specialties to discuss the patient's care plan or transition to adult care setting (Strange, Banning, & Delworth, 2010). Lastly, the smart board and electronic white board also have the ability to expand teaching and learning virtually (Cannon Design et al., 2010).

This would be especially advantageous as it would accommodate the patients who can't physically be at the clinic for their appointment. There is also an opportunity for the adolescent clinic to create a secure social media site like Facebook to further engage patients in health related activities outside of the traditional outpatient office setting. Technology integration within the environment will support "effective team care and planned interactions, self-management support through use of community resources,
integrated decision support, patient registries, and other supportive information
technology (IT)” (Coleman et al., 2009).

The fifth design recommendation is that the place should be a "catalyst for
gwellness" (Richardson, 2012). The environment should be designed with the
developmental needs of patients ages 18-25 in mind. A patient's developmental stage
will be taken into consideration as patients will approve and help design educational
material. All of the clinicians stated that it is the utmost of importance to aid their
adolescent patients in decision making and thinking about the future is impacted by
decisions they make now, and how they manage their chronic condition. The NP and
health educator said, that they help patients "to think in terms of a wellness perspective,
because the goal is to develop healthy habits that they will maintain as an adult" (2014).

The adolescent care team helps patients become adults and develop responsibility
when it comes to their health care. The "adult", one clinician stated, "is the coordinator
of care and there is not much hand holding in the adult care setting". This helps stress the
importance for preparing the patient for the transition out of the pediatric care
environment to the adult, which is determined by the patient's readiness or termination of
parents' insurance policy which occurs at age 26.
In conclusion, through careful design and involving my sample population ('emerging adults' ages 18-25) in helping me to design an environment that will meet their needs, I believe these design considerations will transform care delivery, improve communication, foster learning, and build relationships between all stakeholders; pediatric and adult care teams and patients. The alternative design meets various chronic disease education needs, will provide privacy when needed or peer support through the means of moveable walls, and enhances provider-patient and provider-provider communication through improved HIT. After all, "collaboration and creation aren't bound to designated areas; they evolve throughout a space, absorbing different people, places, and perspectives" (Doorley, S. & Witthoft, S., 2012, pg. 5). Lastly, the design recommendations must go through the 5th design thinking phase, realization: make plans, for validation by the 'emerging adults' and clinicians, which will ensure they are sustainable.

Section 4 - Phase 5, Realization: Make Plans

Next, realization: make plans, occurs when a business plan is created to implement the idea through securing funding, involving a developmental team, and moving the concept into realization (IIT Institute of Design, 2006). Normally, post the design recommendations, a researcher would validate them through conducting a pilot study. The beta solutions would be implemented to validate their value with clinicians and 'emerging adult' patients through continuous prototyping. Phases 2, 3, and 4, within
the design thinking process may be repeated to dive deep into the data to determine the next steps.

Based on my research findings, the design recommendations can be leveraged to create a physical environment that would better adhere to 'emerging adults' learning needs in an outpatient clinic. The design recommendations, however, would need to be validated with chronically ill 'emerging adults' and ethnicity/gender criteria would need to be considered. The design recommendations may need to be tweaked and improvements measured to know if the recommendations worked. Lastly, a strategic roadmap and business plan would be created. This phase, however, is out of scope for this graduate work. There is a possibility that the design recommendations could be taken to the next level through a PhD program.
CHAPTER 5

CONCLUSION

Section 1 - Summary

In summary, as patients learn to adjust to their chronic illness, move towards a path of recovery, and prepare to take on adult responsibilities, an environment that better supports their learning and clinical needs is critical. The traditional outpatient exam room does not adequately meet patient education activities as it is too small and offers a limited amount of flexibility. Clinicians and 'emerging adults' agree that the environment has to support a diverse range of learning styles and more "interactive, hands-on education tools that will aid the patients in assuming more major responsibilities for their health and well-being" (Strange, Banning, & Delworth, 2001, p. 151-152). To adhere to these education needs, the physical environment must increase and become more flexible.

Increased square footage in the healing environment can accommodate a greater volume of patients and health education activities. This creates better efficiency in the room as well as the overall facility. Moveable walls allow for the environment to be quickly transformed meeting chronic disease management, health promotion, and 1:1 counseling activities. Flexible furniture adds another dimension to the environment by providing various levels of interaction and comfort. Additionally, an adaptive design permits more open dialogue between providers and patients, space for smart or electronic
white boards for provider-patient hands-on learning, and creates a more inviting environment through the ability to tailor it. Ultimately, designing an adaptive outpatient healing environment for chronically ill 'emerging adult' patients would meet their learning needs as well as sustaining a more integrated and coordinated care approach to care delivery.

Section 2 - Recommendations

For designers who intend on designing a environment for chronically ill 'emerging adults, the following design recommendations were developed as a result of this project:

- First, multi-functional environments are best for adolescent health clinics as the physical setting can be quickly rearranged to meet multiple chronic disease requirements as well as individual patient's developmental needs. An open space planning design with moveable walls allows the clinician or patient to customize the environment to meet various activities, care delivery styles, and levels of interaction. For example, a more intimate environment will allow 1:1 interaction for counseling and disease self-management education whereas more square footage can better accommodate healthy lifestyle promotion to a group of patients.

- Second, leverage the design thinking methodology to co-design the environment with 'emerging adults' and adolescent health clinicians. By involving 'emerging adults' and adolescent health clinicians in the design process and soliciting their
feedback, the environment will create the optimal learning and healing experience. It will also encourage patient engagement and investment. Clinicians and patients will be able to 1) define how the environment will be used (clinical versus educational programming) and 2) communicate their learning and teaching needs. Use these stakeholders' responses to create insights and design through their lens.

- Third, an 'emerging adult'-centered environment should create "meaningful collaboration" between clinicians and patients. Teaching disease self-management and health promotion skills to patients are essential in ensuring they are ready to transition to the adult care setting. The environment must foster collaboration through hands-on activities to help patients process and retain information and cater to various learning styles.

- Fourth, technology must be incorporated into the overall design as it is an important instrument to facilitate knowledge and improve provider-to-patient and provider-to-provider communication. Internet access, a projector and screen, and interactive technology such as a smart board are important tools to aid in learning and knowledge facilitation. Specifically, clinicians can help patients navigate to chronic condition websites, examine their electronic medical record, find online health apps that pertain to health promotion, and print the patient's medication list.

- Fifth, the environment should help move the patients towards wellness. Designing with the developmental needs in mind as far as learning styles,
promoting more independence by taking ownership of health early help the patient think about wellness. This can be accomplished through allowing the patient to move the walls based on their mood, having access to technology for independent chronic disease management, and creating a tranquil and comfortable setting will help patients more towards wellness.

Section 3 - Implications for the Design Field

As the health care industry changes, everyone must play their role in moving towards wellness and enhancing care delivery by promoting healthy behavior. Health care professionals and designers must revisit initial assumptions to ensure that they are still sustainable predictors of success. A change in direction can create new paths which may be challenging, but ultimately will help health care organizations reach their goals. “In order to innovate" states MIT Professor Edgar Schein, "organizations have to resurrect, examine, and then break the frame created by old assumptions" starting with the design of adolescent health clinics (Culturebot Arts & Media Inc., 2013). Great care must go into designing an environment that supports psychological, psychosocial, and development needs. There is a huge opportunity for designers as they have the ability to influence experience by transforming the atmosphere in which care is delivered.
Design has the ability to shape human behavior through interior and exterior architecture. Designers can create a more wellness and learning focused environment, one that draws in from the surrounding natural landscape, full of light, and community activities that allow ‘emerging adult’ patients and clinicians to engage with one another. The environment has to be a means to help move them to wellness. In order for the designed environment to meet its intent, designers must ask the right questions and involve the right people.

For an ‘emerging adult’ environment, designers should utilize and validate the design recommendations with chronically ill 18-26 year old individuals. The environment may also need to be tweaked based on race/ethnicity and gender differences. These considerations, however, will differ based on location and context, but the designer should take human needs into account for each care setting and project. Therefore design research, specifically ethnographic methods, must be incorporated into standard project planning.

In my research, I leveraged design thinking as a problem-solving method which allowed me to understand the learning needs of ‘emerging adults’ and outpatient adolescent clinicians. Health care professionals should also use design thinking to leverage various research methods that are innovative, evidenced-based, and human-centered as chronically ill patients can’t afford poorly designed environment that are
based on assumptions. Design thinking/human-centered design can transform the adolescent's health care delivery and experience. "Transforming is rethinking about what we know about the health care system and looking for opportunities for disruption and improvement. [After all], health and well-being should be at the individual, community, and population level" (AHRQ, Innovation Exchange Team, 2014).

Design thinking/human-centered design emphasis on leveraging ethnographic research methods allowed deep insight to surface. Design thinking/human-centered design helped tap into 'emerging adults' and adolescent clinicians' unmet learning needs as well as clinicians' education facilitation needs. The sample population's unmet needs framed the current-state, which was vital in understanding how the built environment needed to be transformed to deliver better care and enhance communication. Health care professionals along with designers can leverage existing best practices for designing for adolescents in other industries to apply those learnings to the health care setting and tweak them as needed to meet the specific individual's needs. Finally, design teams that are multidisciplinary in nature and involve the client or customer in the design process help to capture various perspectives told through the design of the environment.
Section 4 - Afterword by the Researcher

The extensive research conducted through the literature review and the qualitative research helped illustrate a much clearer picture of the current-state of adolescent health and medicine. I realize that there isn't just a deficiency in services for this vulnerable population, but an overall lack of understanding that they have much different needs than their younger cohort. Although, I wasn't able to secure patient interviews, the 'emerging adult' population I did reach through the survey helped me realize how they learn and what's important in a learning environment. Learning environments outside of health care were rich sources of data.

Libraries and higher education facilities demonstrate how to create a space that caters to various age demographics, learning styles, and is multifunctional to accommodate numerous activities. Observation in these settings created awareness of how the space can either limit or encourage different interaction levels and can impact mood through furniture arrangement and type. Moreover, observing the clinicians daily responsibilities and interviewing them exposed their care delivery needs and what was desired to facilitate patient education.

As I watched both the clinicians and patients move through the clinics, it reminded me of my brother's experience with cancer from the time of his initial diagnoses to his transition to the adult care setting. A well-designed environment could
have helped him tremendously in navigating through the challenges of living with a chronic disease, surviving, and learning how to maintain a healthy lifestyle. The connection between physical environment, learning, and healing is even more apparent. Further research, however is still needed.

Going forward, if I decide or perhaps another researcher decided to take my research to the next level, would need to address outpatient trends in light of Obama Care as well as chronically ill 'emerging adults' and clinicians' needs. They could also leverage my design recommendations to create adolescent environments as there are not a lot that currently exist. Chronically ill 'emerging adults' would need to be recruited to validate design recommendations.

Workshops facilitated by the design researcher could focus on creating a journey map to show the path from illness to wellness for a chronically ill 'emerging adult'. Additionally, a service blueprint could highlight the current-state of The Adolescent Transition Program and then through further research as well as stakeholder feedback, a future-state or ideal service blueprint could be created. This would yield untapped opportunities and could show how the learning environment now functions within The Adolescent Transition Program. Also, I would create a prototype of the environment to observe how the clinicians and patients move through it as well as use furniture and other interior elements. Then I would create focus groups with clinicians and patients to
discover if they like the environment and how it could be enhanced. Lastly, I would revise my design recommendations, if needed, to include the insights gathered from this additional step.

Even now, as I sit in the library, I am encouraged to think that as we advance design research and expose the benefits of a more human-centered design approach, that in the future, outpatient clinics will adequately meet adolescent needs by actively engaging them in the design process. A more flexible design concept can adapt to the changing health care setting and truly provide an environment that will move with patients in their journey towards wellness.
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150


156


158


Testimonial about the transition experience. Data gathered on 4.18.12


161


Viner, R. (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck. *Arch Dis Child, 81*: 271- 275. DOI: 10.1136/adc.81.3.271


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APPENDIX A

OBSERVATION PROTOCOL
<table>
<thead>
<tr>
<th>What do you want to know about this topic?</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Environment</td>
<td>What kind of teaching tool is used? Describe the type of lighting in the room. How does the room feel? What kind of atmosphere is it?</td>
</tr>
<tr>
<td>Interactions with Objects</td>
<td>Describe the type of equipment used for communication and learning.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What do you want to know about this topic?</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interactions with People</td>
<td>Note any recent words or phrases that the patient used. Be very detailed. What does this clinician mean? What is the patient about his care plan and disease management? What type of methods does the clinician use to communicate? i.e. Electronic Medical Record, phone, internet/support groups, face-to-face, information? What printed materials are given to individuals to help them learn? What else (if any) are given to individuals?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What do you want to know about this topic?</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Broken Telephone Issue</td>
<td>Look for any story about a misunderstanding in one of the parties of the communication chain.</td>
</tr>
</tbody>
</table>
APPENDIX B

SURVEY QUESTION
1. How old are you?

18-19  20-22  23-25  26-30  30+

2. What type of social media accounts do you have? Circle all that apply.

Facebook  LinkedIn  MySpace  Other (please describe):

3. What kind of activities do you do with social media?

4. Describe what types of electronic gadgets do you own, how often you use them, and for what (i.e. desktop computer, laptop, iPad, Smartphone, etc.).

5. What was the last thing you did on your computer and when did you do it?

6. What do you like about printed books vs. online?

7. What do you dislike about printed books vs. online?

8. Have you tried any other ways of reading (i.e. eBook Reader, iPhone, Audio books)? Why? Why not?

9. What is your learning style? Select all that apply.

Visual (see)  Auditory (hear)  Kinesthetic (touch)

10. When learning, what do you prefer? Select all that apply.

Face-to-face interaction  Written Material  Verbal Instruction

Demonstration  Other (please describe):

11. Describe the best ways to engage you in learning.
12. Have you heard about new ways of educating and engaging students in the past year? How have you heard about them?

**Facilitation**

1. What is your ideal teacher/student ratio?
2. What are your education needs?
3. How should professors tailor education to meet your needs?
4. How do you prefer to receive homework assignments? Circle all that apply.
   - Printed Handouts
   - Written on whiteboard/PowerPoint
   - Blackboard
   - Other (describe):

**Physical Environment**

1. Do you think there is a connection to the physical space and your ability to learn? Explain.
2. Where do you like to learn? Circle all that apply.
   - Classroom
   - Home
   - Lectures
   - Library
   - Discussion Groups
   - Other (describe):
3. Within a learning space, what is important to you?
4. What types of technology do you think are required to facilitate knowledge within a classroom setting?
5. What type of furniture do you think is important in a learning environment?
6. If you could design a space that would make you feel comfortable and allow you to learn, what would it look like? Cost is not an issue. Tell me about how you would decorate the interior, technology you would like, equipment that would help you navigate, and types of resources that would be available to you.

7. May I contact you if I have additional questions? Please leave your contact information below. Thank you!
APPENDIX C

'EMERGING ADULT' CHRONIC ILLNESS EDUCATION INTERVIEW-CLINICIANS
Hello, I wanted to meet with you to learn more about your experience working with chronically-ill patients ages 18-26 who are currently going through The Adolescent Transition Program. I am trying to improve the education experience for this patient demographic so they ultimately are successful in managing their disease and having better health outcomes. I’m interested in what works well and what doesn’t work well for both the patient and you as a provider trying to treat them.

Introduction

Q: Tell me about your role in adolescent health/medicine.

Q: Describe a patient’s outpatient care team. I'm interested in knowing about the types of roles and responsibilities.

Q: How (if at all) is a pediatric care team different than an adult care team?

Q: Adolescent medicine is often underrepresented in today's health care system. Please tell me about how you envision the future of adolescent medicine especially in relation to treating chronic illness.

The Adolescent Transition Program

Q: Tell me about your current organization’s Adolescent Transition Program.

Q: What does disease self-management entail?

Q: Are any approaches or models, like the Chronic Care Model or Integrated Health, used as best practice within the Adolescent Transition Program? If so, please tell me
more about the approach including the background of why it was chosen, and how it is working within your organization?

Q: Do all chronically-ill adolescents go through the Adolescent Transition Program? Why?

Q: What are key components of the Adolescent Transition Program in regards to ensuring that a patient can successfully manage their disease as they transition to the adult care setting?

Q: What barriers do you see in disease self-management and within The Adolescent Transition Program?

Q: What components are done well within The Adolescent Transition Program?

Support System

Q: I understand that a support system is the key when living with a chronic disease. How do you transition parents/caregivers to relinquish some of the care of a chronically-ill patient and allow the patient to manage their disease?

Q: What resources do you give adolescents to help them understand and manage their disease?

Q: Peer support is an extremely important element in an adolescent's life. Are group therapy sessions conducted? If so, please describe.

Q: How do you engage the community?

Q: Tell me about the relationship between adolescent medicine clinics and school clinics.
Facilitation

Q: At what age, do you begin facilitating disease self-management?

Q: What clinical roles are responsible for patient medical education? How is the conversation between clinician to patient captured for other members of the care team to view?

Q: How do you facilitate disease self-management? Individual versus collectively?

Q: If the patient can’t physically meet with you, how do you communicate the knowledge?

Q: How do you assess a patient’s learning style?

Q: How do you determine if a patient understands? Do you or your colleagues use a health literacy assessment, the Teach-Back method, motivational interviewing, etc.?

Q: Once you finish teaching a patient about their disease, how do you determine that they understand how to successfully self-manage their disease?

Q: Have you heard about new ways of educating and engaging patients in the past year? How have you heard about them?

Education

Q: What materials do you give patients? Can you give me physical examples? Do you feel like the materials you have and are using are effective in terms of being actionable and promoting self-management?
Q: How do you help patients modify their behavior to ensure they are able to find a balance between their disease and daily life?

Q: In regards to chronic disease management, what do you think patients struggle with the most? The least?

Q: What is the area most difficult to educate your patients about? Where do you feel they have problems in terms of their education?

Q: What are the types of questions patients come back to you about that they didn’t understand or want more help?

Q: If you were going to solve the problem of educating chronically-ill patients going through The Adolescent Transition Program so they could be successful what would you do?

Communication Methods

Q: What communication methods are used to discuss patient data and progress between clinician to clinician?

Q: For the most part, would you say your patients have smart phones, cell phones? If so, which ones?

Q: Other than in-person appointments, what communication methods do you use with your patients (i.e. electronically through a secure email functionality, online support group, social media, etc.)?
Environment

Q: Tell me about the physical environment in which adolescent patients are taught about their disease.

Q: How do you tailor both the disease education and the physical environment itself to adhere to a chronically-ill patient's needs?

Q: Within the clinical setting, what are the required elements that every physical environment must have when facilitating disease-self management and The Adolescent Transition Program?

Q: Often it's challenging to engage a patient in her/his health especially when it requires multiple visits to their primary care physician (PCP). Are there any environments outside of the PCP/Adolescent Medicine Clinic where disease self-management is taught?