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# Inadequacy and impact of facility design for adolescents and young adults with cancer

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### **Abstract**

As cancer remains the leading disease-related cause of death in adolescence, designers must consider the influence of health facility design on social support and quality of life, while considering the changing psychosocial needs of adolescents and young adults (AYAs). Both the stress of treatment and the environment in which treatment occurs can influence AYAs during a time of significant social, biological, and cognitive developmental transitions. A questionnaire developed and provided to 104 AYA-aged survivors of AYA cancer revealed significant inadequacies across 22 features of the cancer treatment environment. Results of a regression analysis suggest a significant relationship between adequacy of the built environment, social support, AYA-specific resources, and health-related quality of life. Recommendations are provided for the design of an inpatient or outpatient cancer facility for young people, such that designers must create space to balance desired and achieved social interaction.

### **Keywords**

*Adolescence; young adulthood; built environment; oncology; quality of life; health design*

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## 1. Introduction

Cancer is the number one disease-related cause of death in adolescence, surpassed only by accidents, suicide, and homicide. In 2011, nearly six times the number of adolescents were diagnosed with cancer than children, though adolescents are generally treated at the same facilities as younger pediatric patients (National Cancer Institute, 2015). This can be problematic if the facilities are not well-adapted for multiple life stages, as both the physical and psychological needs of adolescent cancer patients differ from those of childhood patients.

Beginning with Roger Ulrich's landmark study of patient recovery and views of nature (1984), researchers have suggested that evidence-based design of the built environment can promote healing. Under Gibson's affordance theory, a well-designed environment encourages and supports certain behaviors without any additional sensory processing from the user (Gibson, 1977). A supportive healthcare environment will provide for social behavior without requiring explicit understanding of the possibilities of the environment. Similarly, Ulrich's theory of supportive design (1991; 2001) posits a healthcare environment can promote wellness, reduce stress, and improve outcomes if patients have the following: a sense of control, access to social support, and access to positive distractions. Understanding the continuum of socialization needs both across the lifespan and between healthcare facilities will provide designers with evidence to create these adaptive facilities that allow for positive, supportive care through the adolescent development period.

In many instances within the healthcare domain, the boundaries of adolescence do not line up with the boundaries proposed in developmental psychology. Many facilities and agencies discuss AYA (Adolescent and Young Adult) cancer resources, proposing an extended age period usually bound by ages 15 to 39. This recommendation is based in cancer biology, as the types of

1 cancer experienced between ages 15-39 are unique in their origin and treatment (Bleyer, 2007).  
2 In developmental psychology domains, the cognitive and social differences between 15-year-old  
3 adolescents and 39-year-old adults are extensive. As such, boundaries this large are rarely ever  
4 used for the purpose of research on the lifespan. In 2013, the AYA Oncology Progress Research  
5 Group recommended continued use of ages 15 to 39 to define this population, while conceding  
6 that it may be flexibly applied, specifically mentioning developmentally based definitions as  
7 more appropriate in the psychosocial domain (Smith et al., 2016).

### 8 **1.1 Adequacy of the Built Environment for AYA Populations**

9 Previous studies have investigated adolescent and young adult preferences in the built  
10 environment, though most studies rely on younger pediatric participants. In a study of 12- to 14-  
11 year-olds in a hospital, participants preferred colors they considered cheerful and bright, but  
12 disliked elements they considered to be more childish, including teddy bears and balloons.  
13 Private bedrooms, bathrooms, and entertainment opportunities (like television and DVDs) were  
14 highly preferred (Blumberg & Devlin, 2006). Similarly, in a qualitative study of 11- to 19-year-  
15 olds in a physician's office, participants preferred a less childish environment with home-like  
16 characteristics and age-appropriate entertainment (Tivorsak, Britto, Klostermann, Nebrig, &  
17 Slap, 2004). In this study, however, participants preferred neutral colors – likely because the  
18 participants' age range was older than studied by Blumberg & Devlin (2006). A study of 4- to  
19 16-year old patients in an English hospital resulted in a list of visual cues signifying “babyish”  
20 spaces (plastic toys, balloons, play areas, etc.) and spaces for older children and teenagers  
21 (computers, posters, televisions, and music) (Birch, Curtis, & James, 2007). A quantitative study  
22 of art preferences among hospitalized youth revealed a significant preference for representational  
23 nature images, rather than impressionist or abstract images – particularly among ages 14-17

1 (Eisen, Ulrich, Shepley, Varni, & Sherman, 2008). In an ethnographic study of ward use in an  
2 adolescent-designated unit, adolescents often created their own space within the ward, using  
3 personal effects to disrupt feelings of homogeneity within the space (Hutton, 2010).

4 In 2001, clinical nurses in a teenage oncology unit in the UK reflected on the gap in  
5 services provided to AYAs with a brief mention of the ideal treatment environment (Hollis &  
6 Morgan, 2001):

7 The unit can become a familiar place, with familiar faces in surroundings that should  
8 exude hopefulness, normality, and professionalism. It should become a place to which the  
9 patient has no fear of returning and where there is mutual trust. It is a place where  
10 patients find out that they are not alone, and mutually supportive relationships can form  
11 with peers.

12 Because of the lack of facilities (and literature to support the design of these facilities),  
13 this study aims to **measure the discrepancy between AYA patient needs and the current**  
14 **state of the built environment (Aim 1)**. In previous interviews with AYAs, participants  
15 described inadequacies in the built environment (blinded for peer review). Hypothesis #1 states  
16 that participants will report discrepancies between features important to patients and those  
17 effectively provided in the treatment environment.

## 18 **1.2 Social Support during Adolescence and Young Adulthood**

19 While adolescents are affected by different types of cancer than children, they also have  
20 different psychological needs to fulfill, including a transition in social support needs. In general,  
21 social support is the perceived or actual social resources available to a person from non-  
22 professionals (Gottlieb & Bergen, 2010). This can incorporate resources from peers, siblings, and  
23 parents, and span both formal support groups and informal relationships. This study investigates

1 *perceived* social support from peers – the individual’s beliefs about the availability of social  
2 resources (Gottlieb & Bergen, 2010). This distinction is important, because perceived support (as  
3 opposed than actual support) has a demonstrated buffering effect on adversity (Barrera, 1986).  
4 The social support required for positive outcomes has a demonstrated relationship with the  
5 context in which it occurs, including a person’s life-stage (Cutrona & Russell, 1987).

6       Because social support needs (and the avenues through which social support is received)  
7 change as children transition to adolescence and to young adulthood, healthcare design must  
8 change to facilitate different facets of social support. Both boys and girls experience a shift in  
9 perceived support during adolescence, as peer support increases in early adolescence (ages 12-  
10 16), decreases in late adolescence (ages 16-18), and becomes comparable to support from parents  
11 into adulthood (ages 18+) (Helsen, Vollebergh, & Meeus, 2000). Results from this study,  
12 however, echoed the importance of parental support, while suggesting a minimal relationship  
13 between peer support and emotional well-being. As the positive influence of parental support is  
14 well-documented, the current study hopes to expand on the influence of peer support,  
15 particularly for adolescent cancer patients.

16       In a study of perceived emotional support among 45 adolescents with cancer (ages 12-  
17 18), the most frequently reported sources of support were mothers and friends (Ritchie, 2001). A  
18 qualitative study of 15 adolescents with cancer (ages 12-18) found similar results, such that  
19 adolescents indicated their families, health team, and friends provided their main sources of  
20 support (Woodgate, 2006). Tremolada et al. (2018) found AYA survivors who were older and  
21 had established strong relationships with health professionals at the clinic displayed a positive  
22 comprehension of the events with a pragmatic acceptance of the follow-up procedures. A strong  
23 relationship with health team was associated with a better psychological wellbeing.

1           A systematic and critical review of the literature on social support among adolescents  
2 with cancer revealed substantial methodological challenges in this domain, however. With most  
3 studies limited by small sample sizes, there is little information on gender and age differences in  
4 social resources. Many studies rely on descriptive qualitative data with very few studies  
5 employing a validated quantitative social support measure. Future researchers were urged to  
6 consider the relationship between social support and other outcomes (Decker, 2007).

### 7 **1.3 Social Support and Quality of Life**

8           Social support has a demonstrated relationship with health-related quality of life  
9 (HRQoL). In a recent study of adult breast cancer survivors, women without partners  
10 demonstrated lower levels of social support and poorer HRQoL (Leung, Smith, & McLaughlin,  
11 2016). In a large study of cancer survivors ( $n = 1768$ ), social support had a significant  
12 relationship with physical and mental HRQoL for both genders (Westby, Berg, & Leach, 2016).  
13 This relationship has been echoed in domains beyond cancer. A study of HIV-infected men  
14 suggested a similar association between increased social support and increased health-related  
15 quality of life (Shrestha et al., 2017). In rheumatoid arthritis patients, lower levels of social  
16 support were associated with lower HRQoL (Gong & Mao, 2016).

17           Only recently has research been initiated that investigates the nuances of peer social  
18 support and quality of life. One very recent study has demonstrated the influence of peer social  
19 support in a young adult population of Korean medical students. As a source of social support,  
20 friends were most significantly correlated with *overall* quality of life, while significant others  
21 were most influential on psychological and social quality of life (Hwang et al., 2017). Even  
22 fewer studies have looked specifically at adolescent or young adult populations. In a recent study  
23 of perceived social support and HRQoL, young adult cancer survivors reported greater HRQoL

1 but lower levels of perceived social support from both peers and family, compared to a control  
2 group of non-patients (Tremolada, Bonichini, Basso, & Pillon, 2016). This unusual finding begs  
3 more research specifically investigating social support and HRQoL in adolescence, as well as the  
4 external influences on these factors, like facility design. The Adolescent and Young Adult  
5 Oncology Progress Review Group specifically called on researchers to perform studies  
6 investigating HRQoL among the adolescent and young adult population (Smith et al., 2016).

#### 7 **1.4 Influence of the Built Environment on Social Support and Quality of Life**

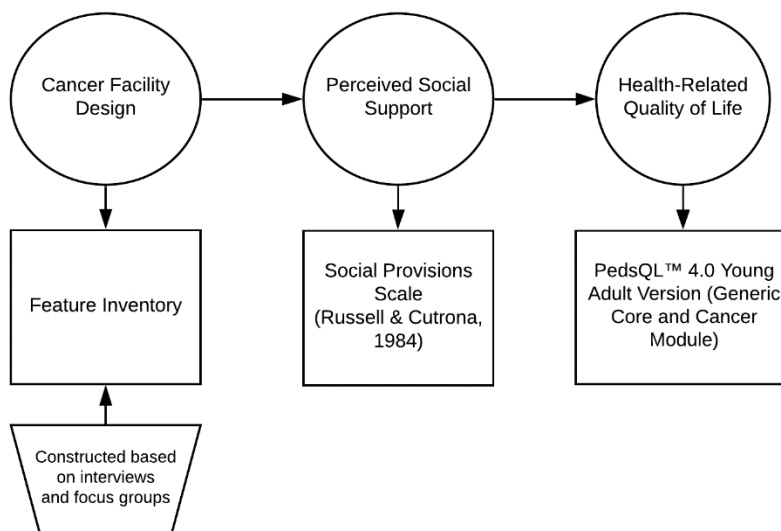
8         The psychosocial standard of care for pediatric oncology stresses the importance of  
9 providing opportunities for social interaction – and even briefly implies the built environment  
10 may facilitate psychosocial care (Christiansen et al., 2015). To receive the Center for Excellence  
11 award designated to AYA cancer facilities, a facility must provide (among other qualifications)  
12 psychosocial support for its patients (Health Care Rights Initiative (HCRI), n.d.). The Center for  
13 Excellence designation, however, only requires a center establish several formal support services  
14 and provide certain resources, making no mention of the facility design that may critically  
15 support the efficacy of these resources. In meetings of the AYA Oncology Progress Review  
16 Group in 2006 and 2013, researchers and practitioners alike noted the importance of  
17 understanding the unique burden of cancer on adolescents, as well as the importance of  
18 providing developmentally-oriented care (Adolescent and Young Adult Oncology Progress  
19 Review Group, 2006; Smith et al., 2016). Like the Center for Excellence standards, however,  
20 there is no mention of the built environment.

21         The relationship between the built environment and social support has been previously  
22 established, although in community and not medical settings. The presence of porches, for  
23 example, positively influenced perceived social support in a Hispanic neighborhood, with



1 perceived social support mediating the relationship between the built environment and  
 2 psychological distress (Brown et al., 2009). In a Swedish neighborhood, residents reported a  
 3 significant increase in social support during a 10-year longitudinal study after community  
 4 development projects improved the schools, playgrounds, shops, and youth activities (Dalgard &  
 5 Tambs, 1997). Older adults living in deteriorated neighborhoods report lower social support than  
 6 those living in well-maintained neighborhoods (Thompson & Krause, 1998).

7 **At the facility scale, this study aims to measure the mediating effect of perceived**  
 8 **social support on the relationship between the built environment and health-related quality**  
 9 **of life for AYAs (Aim 2).** Because of the established relationship between social support and  
 10 quality of life, Hypothesis #2 states that the relationship between adequate facilities and health-  
 11 related quality of life is mediated by perceived social support, such that adequacy of the built  
 12 environment will influence perceived social support, while perceived social support influences  
 13 quality of life (see Figure 1).



14 *Figure 1.* The conceptual framework of the study demonstrating the constructs and measures  
 15 being investigated and their hypothesized relationship (Aim 2).

## 2. Material and Methods

Institutional Review Board approval was obtained from [UNIVERSITY REDACTED] prior to beginning questionnaire development or research with human participants.

### 2.1 Questionnaire Development

Health-related quality of life was measured using an adaptation of the previously validated Pediatric Quality of Life Inventory™ (PedsQL) Generic Core Scale for Young Adults (Varni & Limbers, 2009) and the corresponding Cancer Module for Young Adults (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). The original PedsQL for Young Adults was intended for and tested with participants aged 18 to 25. The core scale includes items in four categories: Physical Functioning, Emotional Functioning, Social Functioning, and Study/Work Functioning. The cancer module includes an additional eight categories: Pain & Hurt, Nausea, Procedural Anxiety, Treatment Anxiety, Worry, Cognitive Problems, Perceived Physical Appearance, and Communication. To best fit the age range of the proposed sample, this questionnaire used the adaptation of the PedsQL created by Ewing, King, and Smith (2009) in their validation study involving cancer and blood disorder patients aged 16 to 32. Ewing et al. validated this adaptation of the PedsQL with a Cronbach's alpha ranging from 0.81 to 0.98. This adaptation was also approved by the original developer, James Varni, as indicated by Ewing, King, and Smith (2009). It has been recommended for use by the Adolescent and Young Adult Oncology Progress Review Group for studies investigating HRQoL (Smith et al., 2016).

While the PedsQL contains five items on social functioning, these do not represent the level of perceived peer support from other patients in the facility. To investigate perceived peer support, the Social Provisions Scale (SPS) (Russell & Cutrona, 1984) was also administered. The discriminant validity of the SPS has been previously investigated and it has been determined to

1 be distinct from measures of social desirability, introversion-extraversion, and neuroticism. It has  
2 also been previously used in studies of the elderly, showing a significant relationship between  
3 SPS scores and several health outcomes, particularly when participants were under high stress  
4 (Cutrona & Russell, 1987). The Social Provisions Scale was adapted slightly, as it currently  
5 reads "...Think about your current relationships with friends, family members, co-workers,  
6 community members, and so on." To better address the construct of peer social support, the  
7 instructions were amended to "Think about your current relationships with peers in this facility,"  
8 "Think about your relationships with peers in your facility while you were being treated," and  
9 similar sentiments.

10 Participants were also asked about the importance and effectiveness of features from a  
11 design inventory, following the structure used by Shepley et al. 2017. Consideration was given to  
12 adapting the Physical and Architectural Characteristics Inventory (PACI) (Timko, 1996) as a  
13 tool, but in its original form the PACI contains only one section regarding "social-recreational  
14 aids," and only suggests two features within these categories – the presence of small tables and  
15 the presence of a patio or courtyard. As such, a novel inventory was best suited.

16 The inventory was constructed using information gathered during the previous  
17 interviews, site visits to identified facilities, and a survey of healthcare design professionals.

18 **2.1.1 Expert survey.** To ensure a comprehensive feature inventory, 11 experts were  
19 provided a list of inpatient features for AYA patients that they rated on a 5-point Likert scale for  
20 importance and asked to provide recommendations for missing features. Paper surveys were  
21 distributed to attendees at the Healthcare Planning, Design, and Construction (PDC) Summit in  
22 Nashville, TN in March 2018 using a snowball sampling technique, in which one participant  
23 (identified prior to the PDC Summit) assisted in identifying other experts attending the summit.

1 Experts who did not attend the PDC Summit were asked to complete an online version of  
2 the same questionnaire through Qualtrics – these participants were also identified through  
3 snowball sampling. Participants were both male and female, ages 29 – 70, experts in the fields of  
4 healthcare planning and design (several with experience in projects related to AYA cancer), with  
5 titles ranging from interior designer to architect to principal and architectural intern to senior vice  
6 president.

7 The feature inventory was adjusted based on open-ended feedback on the expert  
8 questionnaire. The wording “quiet room” was changing to “meditative space,” “open/enclosed  
9 nursing station” was removed due to confusion, and “artwork” was added. One expert noted the  
10 importance of thermal comfort, so “temperature control” was added. Experts also suggested  
11 several other features, including infection control and a space for clinicians, but these were not  
12 included as they were not directly patient-related.

13 **2.1.2 Pilot study.** The questionnaire was piloted with six participants ages 18 – 28 to  
14 evaluate the tool prior to deployment. Members of the Young Adult Support Group of the Cancer  
15 Resource Center of the Finger Lakes in Ithaca, NY participated in the pilot study. Pilot feedback  
16 resulted in the addition of a new section addressing patient-patient social interaction, using the  
17 following questions: “Were you satisfied with your ability to interact with other patients your  
18 age?” (Yes/No, I would have preferred more/No, I would have preferred less); and “How did you  
19 meet other patients your age?” (In the hallways of my treatment facility/In the common areas of  
20 my treatment facility/During outpatient treatment/I was introduced by someone else/In a support  
21 group/Through involvement with an organization/Online/Other).

## 22 **2.2 Participants**

23 Eligible participants were ages 15 to 39, both male and female, and have received (or

1 currently receiving) treatment for a cancer diagnosis. Exclusion criteria for participants included  
2 co-morbid diagnoses, any major developmental disorders, receiving end-of-life care, and/or  
3 diagnosed less than three months' prior (adapted from Ewing et al., 2009). The questionnaire  
4 was provided in both English and Spanish.

5 Participants were recruited through outreach by various AYA cancer organizations,  
6 including the Ulman Fund, Teen Cancer America, The Samfund, First Descents, and True North  
7 Treks. These organizations shared the study information on various social media channels,  
8 private Facebook groups, and listservs. Distributing the questionnaire publicly on social media  
9 led to an unforeseen challenge – an influx of ineligible (or spam) respondents, likely incentivized  
10 by the \$10 Amazon gift card reward. These spam respondents were not deterred by the  
11 implementation of a CAPTCHA nor by a question that required participants to email the PI to  
12 receive a password. To systematically remove ineligible participants without compromising the  
13 sample, the following criteria were implemented: 1) If a participant indicated that they were still  
14 receiving treatment, they must not have reported an age at which treatments were completed, 2)  
15 If a participant reported a number instead of listing a site name when asked to indicate where  
16 they were treated, they were excluded, and/or 3) If a participant selected that their treatments  
17 were completed “over two years ago,” but their reported current age and the age at which their  
18 treatments were completed were within a year, they were excluded.

### 19 **2.3 Questionnaire Methods and Analysis**

20 Participants were first asked to rate the importance of environmental *qualities* in an AYA  
21 treatment environment. Ratings were provided on a 5-item Likert scale. All participants ( $n =$   
22 104) were then asked to rate the importance of environmental *characteristics*, but only those who  
23 were currently being treated or had completed treatment within the last two years ( $n = 56$ ) were

1 asked to rate the effectiveness of those characteristics. All participants' responses are included  
2 for mean ratings of importance, while mean ratings of effectiveness are only reported for the  
3 cohort of participants with the most recent experience in a treatment setting ( $n = 56$ ). To test  
4 Hypothesis #1, paired *t*-tests between importance and effectiveness were performed using only  
5 the data from the participants with the most recent experience. Although Wilcoxon's signed-rank  
6 test (a non-parametric approach) is often recommended for Likert-style ordinal data, *t*-tests have  
7 been shown to reduce Type II error in simulations of Likert data, even with small sample sizes  
8 when assumptions have been violated (Meek, Ozgur, & Dunning, 2007).

9 To further investigate inadequacy and test the mediating relationship predicted in  
10 Hypothesis #2, participants' difference scores between importance and effectiveness for all 22  
11 characteristics were averaged to create a single "adequacy" score for each individual. A series of  
12 simple regression analyses were performed to examine zero-order relationships between (1)  
13 adequacy of the built environment and health-related quality of life, (2) adequacy of the built  
14 environment and social support, and (3) social support and health-related quality of life.

15 A multiple regression was then performed to predict health-related quality of life from  
16 adequacy of the built environment, access to AYA resources, satisfaction with patient-patient  
17 interaction, and perceived social support.

## 18 3. Results

### 19 3.1 Participant Demographics

20 104 participants completed the questionnaire. At the time of the survey, 85% of  
21 participants were categorized as late young adults between the ages of 25-39, though 33% of  
22 participants were first diagnosed prior to age 25 during adolescence and early young adulthood.  
23 Participants were treated at 42 different inpatient facilities and 55 outpatient facilities across the

1 US, ranging from large academic health systems to private specialty clinics. Most patients had  
 2 experience with both inpatient and outpatient facilities, and 38% of participants also had  
 3 emergency room experience. Twenty-five percent of participants had access to a specialized  
 4 AYA program or AYA resources. Of the participants that provided a diagnosis, Hodgkin's and  
 5 non-Hodgkin's lymphoma were most commonly reported, comprising 29% of the sample (see  
 6 Table 1).

7 Table 1

8 *Frequency Statistics by Demographic Variables*

Characteristic	<i>n</i>	%
<i>Age at time of survey</i>		
< 15	0	0
15-18	1	1.0
19-24	6	5.7
25-39	88	84.6
> 39	9	8.7
<i>Age at first diagnosis</i>		
< 15	4	3.8
15-18	10	9.6
19-24	20	19.2
25-39	70	67.3
> 39	0	0
<i>Age when treatments completed</i>		
< 15	0	0
15-18	10	9.6
19-24	14	13.5
25-39	63	60.6
> 39	1	1.0
Currently receiving treatment	16	15.4
<i>Time since last treatment</i>		
Within six months	9	8.7
Within last year	12	11.5
Within last two years	16	15.4
Over two years ago	48	46.2
Currently receiving treatment	16	15.4
<i>Type of cancer (SEER categories)</i>		

Carcinoma	11	10.6
Sarcoma	8	7.7
Myeloma	1	1.0
Leukemia	13	12.5
Lymphoma	30	28.8
Mixed Types	0	0
Unspecified	41	39.4
<i>Type of facilities</i>		
Inpatient only	8	7.7
Outpatient only	24	23.1
Inpatient and outpatient	33	31.7
Inpatient and emergency	3	2.9
Outpatient and emergency	3	2.9
Inpatient, outpatient, emergency	33	31.7
<i>Access to AYA program or resources</i>		
Yes	26	25.0
No	54	51.9
Unsure	24	23.1

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## 2 3.2 Adequacy of the Built Environment

3 “Autonomy over decisions” and “interaction with significant others” were considered the  
 4 most important qualities by participants, while “opportunity to continue classes,” “interaction  
 5 with other patients,” and “career exploration” were considered least important (see Table 2).

6 Table 2

7 *Mean Ratings of Importance for Environmental Qualities in an AYA Setting*

<i>Qualities</i>	<i>M (SD)</i>
Autonomy over decisions	4.47 (0.72)
Interaction with significant others	4.40 (0.76)
Independence	4.28 (0.88)
Privacy	4.24 (0.95)
Interaction with outside friends	4.21 (0.82)
Autonomy over appearance	4.06 (0.96)
Opportunity to explore interests and hobbies	3.81 (1.03)



Physical contact with others	3.71 (1.14)
Interaction with parents	3.81 (1.08)
Opportunity to continue classes	3.69 (1.18)
Interaction with other patients	3.69 (1.18)
Career exploration	3.66 (1.20)

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Participants indicated a significant discrepancy between mean importance and effectiveness for all 22 environmental characteristics ( $p \leq .004$ ), supporting Hypothesis #1 (see Table 3). Because many participants rated outdoor space so high in importance, there were several negative outliers in the ratings for outdoor space that remained in the data for analysis. The difference scores for the importance and effectiveness were approximately normally distributed as assessed by examination of a Normal Q-Q plot for each characteristic. A negative  $t$ -value indicates that the participant rated the characteristic as less effective than it was rated important (implying an inadequacy in the built environment).

Because of the considerable implications of these findings, we conducted a post hoc power analysis in G\*Power 3.1.9.2 (Erdfelder, Faul, & Buchner, 1996). The effect size of these comparisons ranged from  $d_z = 0.40$  to 1.72. The power to detect the smallest of these effect sizes  $\alpha = 0.05$  was 0.84, critical  $t(55) = \pm 2.00$ ; observed  $t(55) = -3.00$ ,  $p = .004$ . For the largest of these effect sizes, the power approached 1.00, critical  $t(55) = \pm 2.00$ ; observed  $t(55) = -12.87$ ,  $p < .001$ . When the alpha level was adjusted to  $\alpha = 0.002$  using Bonferroni's correction, critical  $t$  was adjusted to  $t(55) = \pm 3.25$ . All but one of the  $t$ -tests remained statistically significant.

Table 3

*Adequacy of the Built Environment*

	<i>M (SD)</i>		95% CI of Difference		<i>t</i>	<i>p</i>	<i>d<sub>z</sub></i>
	Importance	Effectiveness	Lower	Upper			
Private bathrooms	4.76 (0.65)	3.13 (1.82)	-2.09	-1.16	-7.02	< .001	0.94
Private bedrooms	4.70 (0.65)	3.45 (1.64)	-1.78	-0.93	-6.39	< .001	0.85
Daylight	4.68 (0.64)	3.18 (1.13)	-1.85	-1.19	-9.19	< .001	1.23
Internet and computer resources	4.67 (0.63)	3.43 (1.26)	-1.59	-0.94	-7.82	< .001	1.04
Temperature control	4.61 (0.69)	2.32 (1.43)	-2.63	-1.77	-10.20	< .001	1.36
Outdoor space	4.42 (0.75)	2.07 (1.26)	-2.81	-2.05	-12.87	< .001	1.72
Visitor beds in patient rooms	4.26 (0.84)	2.29 (1.37)	-2.39	-1.61	-10.31	< .001	1.38
Therapy area (PT, OT, art, music)	4.23 (0.84)	2.48 (1.56)	-2.11	-1.28	-8.20	< .001	1.10
Recreation (TV, games)	3.91 (1.04)	3.07 (1.44)	-1.22	-0.24	-3.00	.004	0.40
Small number of patients per unit	3.88 (0.95)	2.95 (1.38)	-1.37	-0.56	-4.77	< .001	0.64
Staff-patient consulting area	3.79 (0.97)	2.88 (1.42)	-1.42	-0.65	-5.39	< .001	0.72
Family-patient lounge	3.76 (0.97)	2.30 (1.31)	-1.91	-1.13	-7.76	< .001	1.04
Moveable seating	3.63 (1.01)	2.95 (1.20)	-1.23	-0.52	-4.90	< .001	0.65
Meditative space	3.62 (1.01)	1.66 (1.15)	-2.39	-1.58	-9.76	< .001	1.30
Personal desk space	3.60 (1.13)	1.70 (1.01)	-1.52	-0.87	-7.39	< .001	0.99
Personal closet space	3.53 (1.14)	2.59 (1.55)	-1.49	-0.69	-5.46	< .001	0.73
Artwork	3.53 (1.08)	2.43 (1.19)	-1.33	-0.56	-4.95	< .001	0.66

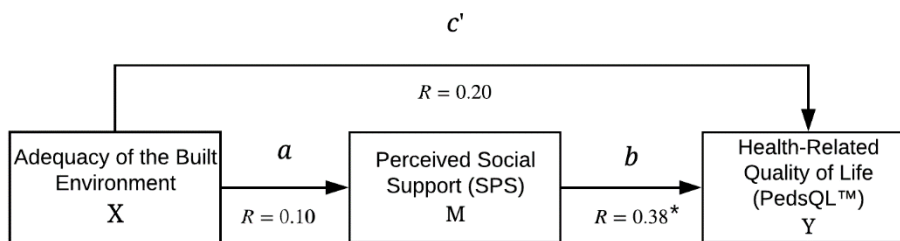
INADEQUACY AND IMPACT OF FACILITY DESIGN FOR AYAS

Access to kitchen	3.39 (0.99)	1.88 (1.11)	-1.91	-1.20	-8.81	< .001	1.18
Personalizable rooms	3.32 (1.02)	1.80 (1.20)	-1.96	-1.61	-9.23	< .001	1.23
Motivational message board	3.18 (0.94)	2.11 (1.28)	-1.88	-1.13	-8.01	< .001	1.07
Patient-only lounge	2.98 (1.06)	1.45 (0.83)	-1.89	-1.29	-10.58	< .001	1.41
Classroom	2.74 (0.95)	1.45 (0.93)	-1.62	-1.03	-9.01	< .001	1.20

### 3.3 Influence of the Built Environment on Social Support and Quality of Life

HRQoL scores were approximately normally distributed. There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.94. Linearity and homoscedasticity were demonstrated by visual inspection of a plot of studentized residuals versus unstandardized predicted values for each factor. There was no evidence of multicollinearity as assessed by tolerance levels greater than 0.10. Although there were several leverage points, there were no outliers in the data and calculation of Cook's Distance indicated no points with a high degree of influence (Cook's Distance < 1.00).

Addressing the mediating relationship predicted in Hypothesis #2, results of a simple regression showed no evidence of a zero-order relationship on path *c* (adequacy of the built environment and HRQoL),  $F(1, 38) = 1.54, p = .22$ . There was also no evidence for a zero-order relationship on path *a* (adequacy and perceived social support),  $F(1, 38) = 0.35, p = .56$ . There was a significant positive correlation on path *b* between perceived social support and HRQoL,  $r_s = .383, p < .001$ ;  $F(1, 66) = 3.49, p = 0.66$  (see Figure 2).



\* = significant at  $p < 0.001$

Figure 2. Visual representation of the correlations between adequacy of the environment, social support, and HRQOL.

Though adequacy of the built environment as a whole was not significantly associated

1 with social support or HRQoL, the efficacy of several specific environmental features  
 2 demonstrated a significant positive correlation with perceived social support, with coefficients  
 3 ranging from  $r = .26$  (private bedrooms) to  $r = .30$  (recreation) (see Table 4).

4 Table 4

5 *Summary of Significant Correlations between Features and Perceived Social Support*

<i>Feature</i>	<i>r</i>	<i>p</i>
Recreation (TV, games)	.304	.023
Internet and computer resources	.286	.033
Moveable seating	.265	.048
Private bedrooms	.258	.055
Private bathrooms	.259	.054

6

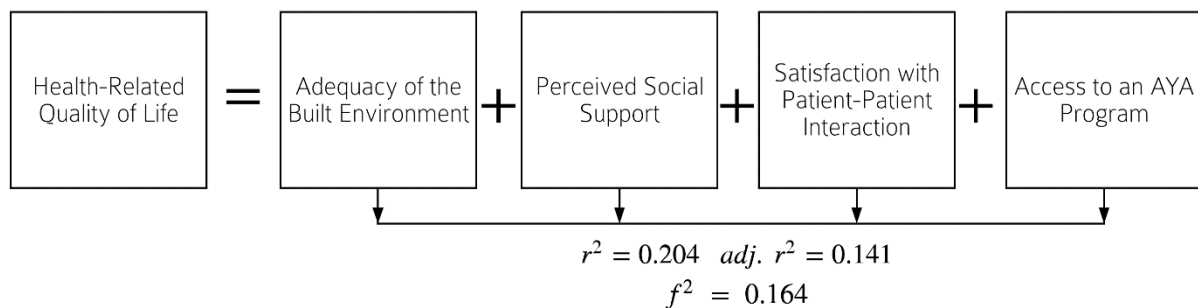
7 In the multiple regression model, adequacy of the built environment, access to an AYA  
 8 program, satisfaction with patient-patient interaction, and perceived social support significantly  
 9 predicted HRQoL,  $F(4, 51) = 3.26, p = .019$ .  $R^2$  for the overall model was 20.4% with an  
 10 adjusted  $R^2$  of 14.1%,  $f^2 = .164$  – a medium effect size, according to Cohen (1992). Further, in  
 11 clinical outcomes studies with high ecological validity (as opposed to those conducted in  
 12 controlled environments), a model with an  $R^2$  value of 0.204 can indicate clinical relevance  
 13 (Hamilton, Ghert, & Simpson, 2015). A summary of the regression model is found in Table 5  
 14 and Figure 3.

15

1 Table 5  
 2 *Summary of Multiple Regression*

Variable	<i>B</i>	<i>SE<sub>B</sub></i>	<i>β</i>	<i>t</i>	<i>p</i>
Intercept	63.36	17.85			
Perceived Social Support	0.28	0.15	.24	1.87	.068
Adequacy of the Built Environment	2.95	2.61	.16	1.13	.264
Satisfaction with Patient-Patient Interaction	14.17	5.74	.35	2.47	.017
Access to an AYA Program	0.522	4.098	.371	.371	.712

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*Figure 3. Visual representation of the multiple regression.*

10  
 11

#### 4. Discussion

##### 4.1 Adequacy of the Built Environment

13 Supporting Hypothesis #1, all 22 environmental characteristics were found to be  
 14 significantly inadequate, with “outdoor space,” “patient-only lounge,” “visitor beds in patient  
 15 rooms,” “meditative space,” “temperature control,” and “personalizable rooms” considered the  
 16 most inadequate (see Table 3).

1           **Special considerations.** The importance of outdoor space has long been touted in the  
2 health design community, though many facilities still provide inadequate opportunities. When  
3 considering how outdoor space may be implemented, it may be more nuanced than simply a  
4 healing garden – in some studies, participants have indicated value for *any* space that allows  
5 patients to spend time outside of the hospital room or ward (Whitehouse et al., 2001; Birch et al.,  
6 2007). In an oncology setting, this flexible definition of “outdoor space” may be necessary, as  
7 immune-compromised patients may not be afforded the opportunity to access a ground-floor  
8 garden, nor are patients receiving certain typical cancer medications allowed in direct sunlight.

9           Given the lack of literature on the health design preferences of AYAs and the small  
10 number of AYA-dedicated facilities in the United States, these findings are unsurprising but  
11 indicate a need for age-specific design guidelines. More consideration for the role of the built  
12 environment and social behavior is given in the following section. Similarly, the role of  
13 “temperature control” and “personalizable rooms” are discussed further in the following section,  
14 as they relate to salient issues of control and choice.

#### 15 **4.2 Influence of the Built Environment on Social Support and Quality of Life**

16           Results of the regression model demonstrate the importance of social connections with  
17 other patient-peers as it pertains to health-related quality of life. Given these results (and the aims  
18 of the current study), we were then surprised to see “interaction with other patients” rated one of  
19 the least important environmental qualities and “patient-only lounge” rated one of the least  
20 important environmental characteristics. These results were even more unexpected because 86%  
21 of participants indicated they would have preferred more interaction with other patients their age.  
22 Only 11% of participants indicated they had as much as interaction with other patients as they  
23 desired. These contradictory findings may result from a desire not simply for social

1 opportunities, but for *privacy* – a balance between desired and achieved social interaction.

2       **4.2.1 Optimization between desired and achieved social interaction.** In the current  
3 study, the correlations between certain environmental characteristics and social support  
4 emphasize the important balance of social interaction. While recreation areas, Internet access,  
5 and moveable seating all contribute explicitly to social opportunity, the correlation between  
6 social support and private bedrooms and bathrooms hints at the optimization process between  
7 achieved and desired social interaction. This optimization process can be considered privacy  
8 regulation.

9       In an oncology setting, providing privacy is arguably even more important than simply  
10 affording social interaction. In a study of 243 young adults, 82% of participants reported seeking  
11 privacy when they were distressed. 81% of those participants reported “feeling better” after  
12 seeking privacy (Newell, 1994). In a previous qualitative study (blinded for peer review), when  
13 asked to describe their ideal treatment facility, a number of AYAs described this balance. As one  
14 example, an AYA participant mentioned:

15       *You might have visitors, you might not. If you have visitors, you might want more privacy*  
16       *but if you wanted to socialize with other people, it’s super awkward, it’s like you’re*  
17       *violating HIPAA. So, it may be some sort of compromise between the two things.*

18       Perhaps it is unsurprising, then, that patient-only lounges were rated so low in importance  
19 compared to other environmental characteristics that may contribute to privacy regulation more  
20 explicitly. When asked to describe their privacy needs, a group of adolescents previously  
21 hospitalized for cancer treatment emphasized the importance of the environment, indicating their  
22 appreciation for curtains, in-room telephones, and en-suite private bathrooms (Hutton, 2002). An  
23 ethnographic study of 40- to 79-year-olds being treated for cancer suggested that patients often



1 seek refuge from fellow patients – and that their ability to seek refuge depends on the ward  
2 architecture, as patients were observed using different rooms in the hospital to regulate privacy  
3 (Larsen et al., 2014).

4 **4.2.2 Issues of choice and control.** As personal privacy is related to control (Malcolm,  
5 2005), these findings may extend to broader issues of choice and control, such that patients  
6 desire control over their environment – social and otherwise. Participants indicated significant  
7 inadequacies in “temperature control,” “personalizable rooms,” and “access to kitchen” –  
8 characteristics that contribute to a sense of autonomy. Likewise, “autonomy over decisions” was  
9 ranked the most important environment quality by participants in the current study. Previous  
10 research shows an association between cancer and a loss of personal autonomy in decision-  
11 making (Denieffe & Gooney, 2011). In a study of patients ages 4-16 at an English hospital,  
12 participants were less concerned with aesthetic characteristics and more concerned with their  
13 ability to control lighting, temperature, noise, and smell (Birch et al., 2007).

14 **4.2.3 Barriers and facilitators.** Even with ample consideration for choice and control, it  
15 is not simply enough to build a space, as the results of the regression model imply. Beyond the  
16 adequacy of the built environment, the presence of AYA-specific programming was also  
17 important in determining HRQoL (see Figure 3). This seems to suggest AYA-focused social  
18 activities are a crucial element when considering strategies to improve social support and quality  
19 of life for AYAs. Even for healthy adolescents, the absence of organized activities results in  
20 young people spending most of their time alone, usually watching TV (Larson, 2001).

21 Encouraging participation in activities with other patient-peers is not without its own  
22 challenges, however. Earlier interviews with 16 AYAs indicate a number of barriers to peer  
23 interaction in health facilities, including HIPAA restrictions, lack of information from clinicians

1 and care providers, and body image issues. Many AYAs are left to seek peer-patient connections  
2 on their own (blinded for peer review). In the current study, nearly half of all participants met  
3 same-age patients through support groups, involvement with an AYA organization, or online.  
4 Over one-third of participants, however, indicated they met peer-patients during outpatient  
5 treatment, or in the hallways and common areas of their treatment facility, further emphasizing  
6 the role of the built environment in facilitating peer-patient interaction.

7 For this reason, “family-patient lounges,” “access to kitchen,” and “visitor beds in patient  
8 rooms” become important as opportunities for informal social connection, bridging the gap  
9 between public and private spaces, and enabling patients to meet on their own terms without  
10 HIPAA concerns. In a previous study, the dining room functioned in this way for patients  
11 seeking interaction – patients considered the dining room “a welcome opportunity to interact  
12 without obligation” (Larsen, Larsen, & Birkelund, 2014). Likewise, architect Charles Jencks’  
13 Maggie’s Centres for non-medical cancer support (UK) are designed with a central kitchen,  
14 functioning as a welcoming social space (Van der Linden, 2016).

### 15 **4.3 Limitations and Future Research**

16 As this study is the first of its kind to address AYA care environments, there are several  
17 limitations of note and numerous opportunities to expand our collective understanding of design  
18 for AYAs. A number of variables likely play a role in moderating the patient experience with the  
19 built environment and should be explored in future studies. Because gender influences the nature  
20 of social support during adolescence and young adulthood (Colarossi, 2001), we may reasonably  
21 expect gender to moderate the results of this study. Participants were not asked to identify their  
22 gender as part of this study, but future research should investigate gender (and other  
23 demographic) differences in social support needs during treatment.

1 Information on disease severity and prognosis was not collected in the scope of this  
2 study, but previous research suggests quality-of-life is influenced by cancer disease features  
3 (Isikhan, 2001). Similarly, the acuity of the care environment (inpatient, outpatient, emergency)  
4 likely also serves as a moderator of the patient experience. Indeed, early research in the field  
5 suggests individuals receiving inpatient treatment for cancer report lower quality-of-life than  
6 those receiving outpatient treatment (Padilla et al., 1983). Many of the environmental  
7 characteristics explored in this study pertain to inpatient care, though the majority of participants  
8 received treatment in both inpatient and outpatient settings, and for varying amounts of time.  
9 23% of participants received outpatient treatment only.

10 The authors theorize a difference in needs for patients depending on the acuity of  
11 treatment, such that patients receiving inpatient care may require a higher degree of control but  
12 desire less social interaction than those receiving outpatient care. It may be possible, therefore,  
13 the path from the built environment to HRQoL is not mediated by social support for inpatients,  
14 but rather by choice and control. An extension of this study should restrict the scope to inpatient  
15 (or outpatient) experiences only. Administering the questionnaire during active treatment may  
16 address this limitation, as well.

17 It is unknown how AYAs not recruited for the study may have answered this  
18 questionnaire. Recruiting participants required outreach from AYA support organizations –  
19 AYAs who have not connected to these resources (electively or otherwise) did not have the  
20 opportunity to complete this survey. There may be important distinctions and needs for AYAs  
21 who do not (or choose not to) engage with outside organizations. Additionally, it is unknown  
22 how participants' answers may have changed with less time between treatment and completion  
23 of the questionnaire. A number of participants were reflecting on their cancer experience after

1 several years. Future research may consider administering the questionnaire during active  
2 treatment.

### 3 **5. Conclusion**

4 The current study demonstrated the inadequacy of the built environment for adolescents  
5 and young adults with cancer, while emphasizing the importance of AYA-specific resources and  
6 opportunities for social support. When designing an inpatient or outpatient cancer facility for  
7 young people, designers must consider creating space for social interchange such that patients  
8 can engage with others when desired while still ensuring privacy.

9 Future research in facility design for adolescents and young adults should take a more  
10 nuanced approach by considering the full spectrum of social regulatory activities from isolation  
11 to casual interactions to planned interactions – and with whom those activities occur. A  
12 behavior-mapping study, for example, could reveal the ways in which the built environment  
13 affords social regulation among AYAs. While the current study specifically considered cancer  
14 facilities, these findings may be generalized to other inpatient and outpatient facilities treating  
15 young people – particularly those that provide care for patient populations across the adolescent  
16 and young adult lifespan, like university health facilities and juvenile behavioral health centers.  
17

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