Therapeutic Recreation Needs Assessment in Hospitalized Adolescents
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ABSTRACT

Adolescence is marked by various psycho-social developmental tasks including the definition of personal identity, the constant search for social acceptance and approval, and the establishment of sexual identity. Autonomy, identity development, self-advocacy, body image and exploration are all components of the process an adolescent must face, and these processes make adolescence a challenging time. When adolescents are faced with hospitalization, either due to a chronic illness or an acute occurrence, these developmental challenges can be heightened, and their ability to cope and adjust to life stressors may be compromised. Hospitalization can result in a loss of control, loss of independence, decreased self-esteem due to changes in body image, and increased risk of social isolation. This study sought to establish the needs of hospitalized adolescents with the aim of tailoring therapeutic recreation programming and interventions to better suit those needs. Through hour long, semi-structured interviews, six hospitalized adolescents were asked to share their leisure and life experiences and to reflect upon how hospitalization had affected their lives and what changes they would suggest for making the current medical system more "adolescent friendly." Common themes throughout these interviews were the need for social interaction, the request for resources that establish normality, and the heightened need for privacy and respect by the medical community.

INTRODUCTION

While hospitalized adolescents are admitted for a range of causes including chronic illness, acute illness, injury, or surgical requirements Boice (1998) suggests that the developmental and emotional needs of hospitalized adolescents can be generalized across specific diagnoses, and thus the design of interventions and programming for adolescents can be planned accordingly. Therapeutic recreation strives to use leisure and recreation as a functional intervention to meet the needs of its clientele. In the case of hospitalized adolescents, the importance and influence of leisure on their development and the functional outcomes that leisure-based interventions can provide this age group were addressed. Through the interviewing process, four main need-based themes emerged: body image and self-esteem, need for social interaction, and self-advocacy.

REVIEW OF LITERATURE
Adolescents and Leisure

Carter, Van Andel, & Robb (2003) argue that “Adolescents meet their developmental needs through recreation and leisure, thus illness, disease and injury interrupt development” (p. 438). Phoenix (2001) suggests that the developmental processes during adolescence are focused around identity formation. Adolescents seek out new opportunities that center around both establishing themselves as individuals and seeking social relatedness from their peer groups. The identity formation process is achieved when alternatives of identity have been explored and the adolescent commits to a particular concept of self. (Shaw, Kleiber and Caldwell, 1995). The adolescent explores options that require both autonomy from parental figures and dependence and acceptance from peers.

Shaw et al., sought to show the relatedness between identity development in adolescents and their participation in chosen leisure activities. The authors examined leisure participation in four subcategories, physical activities including sport, watching television, social activities, and other free-time activities. They found that time spent participating in leisure activities had both a negative and positive effect on identity formation, depending on the activity and the gender of the participant. For example, television watching did not contribute to identity formation or self-esteem at all, while for males identifying themselves with a particular sport contributed significantly to identity formation and self-esteem. While this does not show that one specific source of leisure will always promote identity formation, it suggests that it is affected directly by the leisure participation patterns of adolescents. As such, these findings support the applicability of leisure as an intervention for hospitalized adolescents, as identity formation is so critical and so difficult for this population.

Development

Adolescents, unlike their younger pediatric counterparts, have the ability to understand the causes and effects of their condition and of treatment (Boice, 1998). Understanding this is critical in approaching the care of an adolescent in an appropriate and effective manner. The medical community surrounding these patients has a duty to present medical information in a developmentally appropriate way and to foster the decision-making skills that these patients possess.

Boice explains that hospitalization may magnify the developmental stressors; indeed, Wong and Whaley (1996) identified a number of stressors associated with hospitalized adolescents including “loss of control, bodily injury and pain, and separation-especially from peer group” (p. 296). They go on to explain that some typical responses to hospital stressors can be, but are not limited to, boredom, loneliness, depression, and even overconfidence. Knowing that hospitalization brings additional stress to an adolescent and knowing the potential for their reactions is critical in the design of interventions to treat these symptoms brought upon by hospital stress.

Body Image/Self-Esteem
Denholm (1989) compared hospitalized and non-hospitalized adolescents on self-esteem and body attitude. He found that there were few differences between the groups in terms of self-esteem. Additionally, in terms of body attitudes, Denholm found that in some male adolescents their body-image was better than their non-hospitalized peers. This was hypothesized to be due to “surviving” the hospital experience. Visibility of hospital effects also played a role in the self-scoring of body attitudes, with adolescents without visible effects scoring average or above average, and adolescents with visible effects scoring below average as predicted.

Hospitalization may magnify the physical and emotional adjustment to the bodily changes that occur during adolescence. For example, in the case of chronic illness, “the timing of puberty may vary depending on the illness...and chronically ill adolescents express more concern about their height and weight” (Boice, 1998, p. 931). A chronically ill adolescent may face stunted growth, delayed sexual development, and other issues that affect their perception of self. Further, Denholm suggests that surgical procedures that result in visible physical changes in appearance can be an additional stressor. When illness frequently changes the outward physicality of an adolescent, his or her ability to function socially may also be compromised.

**Social Interaction**

Hospitalization, by its very nature puts adolescents at risk for social isolation, cutting them off from their customary peer group (Carter, Van Andel, & Robb, 2003). Stevens (1989) sought to identify the perceived coping strategies of hospitalized adolescents before a surgical procedure and what coping strategies were actually used. In this study, 68% of adolescents thought that seeking social support would be the coping mechanism they would rely on while in the hospital, followed by using sleep to distance themselves from the situation. Stevens found that social support was localized mostly in the support of the mother figure, and not as much on outside (peer) social support. Additionally, Stevens concluded that while there were no significant relationships between anticipated and actual coping strategies, that the identified and utilized coping strategies of this study merit further investigation. Understanding the relationship between social support from family and friends and the ability of an adolescent to cope in the hospital setting may further suggest the importance of providing opportunities for social interaction and forming relationships while in the hospital.

**Self Advocacy**

Carter et al. (2003) suggest that hospitalization inherently involves a loss of independence and privacy which means for adolescents the psycho-social tasks of individuation and self-determination are virtually impossible to achieve. As a result, Carter et al. recommend giving adolescents the appropriate medical knowledge and understanding so that they are empowered to make their own decisions in the hospital setting, in turn increasing their sense of control over an uncomfortable and potentially frightening situation. Burghen, Haluska, Steen, and Hinds (2004) suggest that it is a mistake to exclude the adolescent from the decisions that involve their health because of the misguided assumption that they do not understand their medical condition sufficiently (Pawelko, 1997).
Special consideration needs to be given to the terminally ill adolescents in terms of their involvement in end-of-life decision making. Burghen et al., found that the involvement of a dying child in decision making will “allow them to make informed decisions that will be less likely to cause regret to parents, patients, or providers at a later date” (p. 181). Self-advocacy, in the form of asserting one’s last wishes, is an important responsibility that should be given to the terminally ill adolescent in all ways possible.

**PURPOSE OF STUDY**

Hospitalized adolescents have the potential to need special programming and interventions based on their developmental status, their need for self-advocacy, the potential for negative body image, and the importance of social/peer interaction and support. This study sought to understand and better structure future interventions based on the self-stated needs of hospitalized adolescents themselves. By using a semi-structured interview guide, these adolescents were asked questions about their experience in the hospital and what they would like to see done differently. The goal of this study was to attain new insight into hospitalized adolescents’ unique needs, and to identify the best way to meet those needs through Therapeutic Recreation.

**METHODS**

A semi-structured interview guide was developed to analyze the self-stated needs of hospitalized adolescents. This asked them about their ability and need to socialize in the hospital environment, their leisure interests and how those interests did or did not translate into the hospital environment, their sources of support and coping during hospitalization, and their recommendations on how the needs of their age group could better be met.

Over a two-month period adolescents within the ages of 13 and 21 were approached by the staff of Pediatric Palliative Care at a major southeastern university medical center. An informational letter about the interview process was presented to each potential candidate, and their consent sought. Age was the only restriction to recruitment and no other information was collected or considered. Of the over 15 adolescents that were approached, six were interviewed. These interviews took place in their hospital room and the patients were all accompanied by at least one parent. The interviews lasted approximately one hour and were audio taped and subsequently transcribed. The interviews were transcribed verbatim. Input from the patient’s parents and siblings was encouraged in instances where additional family were present during interview process.

After the transcription process the interview content was analyzed and the thematic elements of each interview were identified in accordance with constant comparison (Strauss & Corbin, 1992). After the initial open coding of the individual interviews, the transcripts were compared and consistent themes among the interviews were labeled and analyzed. The initial themes were discussed and confirmed by another researcher familiar with the study. Selective coding then followed whereby the theoretical linkages among the themes were explored.
RESULTS

Four themes emerged from the coding process: a) the need for social interaction and support, b) concerns regarding body image, c) the need for respect and privacy from medical personnel, and d) the need for age appropriate leisure options in the hospital setting.

Need for Social Interaction and Social Support

The importance of peer interaction has been well established during adolescence, but within the scope of these interviews, not one participant had seen or interacted with another hospitalized peer during his or her admission. During time when social support, acceptance, and interaction is so important, it can be an invaluable tool for promoting adjustment to hospitalization. For example, a mother of Sara, a 20 year old female patient stated,

"She'd like to chat with other people her age that are going through the same thing she is going through. To look at them and see them without hair. That would probably help a lot. Talk to someone that feels sick like you feel sick."

The concerns surrounding body image and self-confidence can limit an adolescent’s motivation for social interaction, but all participants interviewed craved it just the same. All six participants stated that if there were a program for teens their age that they would be interested in participating. Carrie, a 17 year old inpatient, and Sara both said that the thing they were looking to most about getting home was seeing their friends and family. Sara said simply, "I can’t wait to see my friends."

The request for a separate area for teens was also a theme when asked the question, "If you could create one activity or idea in the hospital, with no restrictions, what would it be?" For instance, the mother of Aaron, a 16 year old outpatient said,

"The treatment room down the hall is for all ages, but when the little kids start screaming and you are not feeling good, you don’t want to hear that...a separate treatment room would be great. You know, you don’t hear the older ones crying and screaming."

Likewise, James a 16 year old, said he would create a teen lounge with, "a pool table, pin ball, and all of that. That would be really cool." Sara’s Mom agreed and had this to say about a separate area for adolescents,

"Now that she’s getting better I can get her up in a wheelchair and get her up and out, but there is no where to take her. All they have is a playroom here with a couple of aquariums and some toys. So I take her outside, and she likes to go outside and look at the trees and stuff, but there is no interaction. I mean what do I do when I
am able to take her places, there is no where to take her."

With no peer interaction in the hospital setting, transition back into social life outside of the hospital walls could be daunting, scary, and overwhelming for an adolescent that has so much of his or her self-concept hinged on the acceptance of a peer group. Sara was highly medicated during the interview, but her mom said this on her behalf,

"One of her fears is what happens after the hospital, where is she going to go from here? How am I going to be physically and emotionally? Her friends have moved on, there’s a life that has kept going without her for 5, 6, 7 months. She is going to go to rehab after this, and then it is going to be even more. So close to a year has gone by and life has just passed her, and how does she get back into it. And she is afraid of that.

**Concerns Regarding Body Image**

All six of the interviewees had some outward physical characteristic that was related to their diagnosis. While their diagnosis was not specifically discussed or disclosed, their responses to questions reflected the reality of dealing with a visible and noticeable medical condition. While the interview guide did not directly address body image in any of the questions, the theme emerged naturally through the responses of patients and their parents, which demonstrates just how important it is among hospitalized adolescents.

James spoke of his embarrassment in response to the large groups of medical residents coming into his room and asking him to take his socks off to examine his feet. James said, "I have had doctors come in and they want me to take my stockings off and sometimes, you know, I just don’t feel like it. They keep pushing me. And you know, no should be enough."

The concerns surrounding body image certainly affect their willingness to interact with their peers and to take part in recreational activities out of their hospital room. If the body image element is not addressed or acknowledged, these adolescents may miss out on the critical social component of hospitalization.

Carrie and Sara both made references to losing their hair. Sara’s mom addressed Sara’s scars and left-side paralysis. Aaron spoke of his inability to get up and play football with his friends anymore. Within each interview there were undertones and references to the effect the change in outward appearance had made on their lives.

**Need for Respect and Privacy from Medical Personnel**

The privacy needs for an adolescent are sometimes overlooked by medical personnel in a pediatric setting. So many of their patients are too young to care about knocking before entering and revealing examinations, that sometimes adolescent patients are put in uncomfortable positions. Additionally, giving adolescents the ability to advocate for themselves in the hospital is an invaluable tool as it can provide them with an increased perception
of control which can in turn reduce anxiety in the hospital setting.

James speaks of his frustration regarding the large groups of medical students that come into his room at once, and their lack of information when they arrive:

"As far as like, and I understand this is a teaching hospital, but the residents, whenever they come in, I mean it's like every time they want to know what's wrong, but there's a chart right in front of them. Also, there could be one or two that come into our room at a time, but when they all come in it makes you feel like you're on display or something."

Carrie’s reaction to the frequent intrusions into her room was, "Yeah, when I change I stand right behind the door so no one can come in." Carrie’s reaction is not uncommon as many teens feel that their hospital room is not a private or personal space. Also many teen age girls feel very self conscious about their bodies and this lack of privacy appears to be magnified in the hospital setting.

Sara’s mom speaks of the benefit of having nurses that are around the same age as her daughter, as it seems they are more receptive and understanding of her needs. They can provide support not only by giving good medical care, but by being peer who truly understands what Sara is going through.

**Need for Age Appropriate Leisure Options**

The need for and benefit of leisure during adolescence has been well established. A healthy leisure lifestyle can result in decreased anxiety and stress, increased self-determination, improved sense of identity, and provide a sense of normalcy in the hospital setting. Overwhelmingly the interviews showed a lack of age appropriate leisure options, and the effects that their absence had on their hospital admission. Aaron’s mom stated,

"I think that they just take for granted that they are older and they can find something to do, either their family brings them a book or something like that to occupy their time, but there is only a playroom and resources for the little ones."

For an adolescent, electronics are a major interest. Every single interviewee stated the need for DVD players in their room, and a movie selection that had age appropriate movies. Currently, only G movies are offered in the inpatient setting. The need for laptops also came up as the Internet can provide not only accessible contact with peers outside of the hospital setting, but also provide a sense of normalcy and a link to the outside world.

Music also provided commonality between each of the participants. While their music tastes varied, each participant could defend their favorite artist and preferred musical style. Three of the participants participated in band at their school, and Carrie stated that playing in the band during football games was one of the things she was missing out on while she was in the hospital. Four of the participants said that music was something they used
to cope with being in the hospital, implying the importance of this particular leisure component.

When asked to create any activity they wanted in the hospital setting, many responses were centered on changing their environment. Carrie stated, “Get rid of the white walls, let the kids paint them...I mean you’ve got a picture of a kite and colored pencils. Not only are those things not interesting to look at, but they are little kid things.” Sara’s mom stated,

I think they should cater the environment to the patient. I think the environment should be age appropriate. I think this is cute, but it is not appropriate for her. I think there should be a Gwen Stefani poster on the wall, or something that would allow the room to be interchangeable for different patients, depending on their age.

Making their environment their own may provide a leisure activity that focuses around self-determination, control, and decision making.

**DISCUSSION**

The importance of peer acceptance in adolescents is well documented and understood. Adolescents form their identity through the outside influence of peer interactions, which is a critical element in the developmental tasks of adolescents (Kidwell, 1995). These interviews supported the idea that hospitalized adolescents crave this acceptance and interaction as much, if not more, than their healthy peers (Stevens, 1989). Juxtaposed with the desire for social interaction, the interviews also supported the reality of social isolation in the hospital setting as all six interviewees had not interacted with other patients their age during their admission. However, there may be constraints to social interaction that should be addressed. Heightened concern over body image may decrease an adolescent’s motivation and/or comfort with interacting with peers. Providing a space that allows for safe social interaction could stimulate that motivation, and provide the social support and interaction that hospitalized adolescents so desperately need (Francis et. al, 1988).

Also related to a heightened concern over body image is the idea of privacy and self-advocacy in the hospital setting. The need for privacy in the hospital setting can be amplified by concern surrounding their appearance. Connected to the heightened need for privacy is the adolescent’s ability to advocate for their needs in terms of privacy and space. An adult caretaker may be unaware of the appropriate limits for an adolescent patient if those limits are not communicated effectively by the patient. The ability for an adolescent patient to advocate for themselves stretches beyond their need to ask for their space and set limits for their privacy; self advocacy penetrates deep into the medical processes for these patients.

Three of the interviewees made references to the need for privacy and respect in the hospital setting, and all interviewees spoke of the need for an age appropriate hospital environment. Adolescents as a generalized group are developmentally able to reason abstractly and can understand and interpret the accurate causes and implications of their conditions (Boice, 1998). Constraints that can limit adolescents’ ability to advocate
for themselves can be a lack of medical information to make decisions with, over involvement of parents in
decision making, and the potential for feeling anxiety surrounding asserting their opinion to authority figures and/
or parents (Burghen et. al, 2004).

The need for leisure in the hospital setting was undoubtedly the most highly vocalized request among all six of
the interviewees. Age appropriate leisure and recreational activities and experiences can provide an adolescent with
a sense of normalcy, connection to the outside world, and increased accessibility to social support
through technology, and the participants voiced the need for changes in this area. All six interviewees also
addressed their use of music as a coping mechanism while in the hospital, providing a tangible and
realistic implication for practice. Four out of the six participants asserted their desire for a separate area that
could better meet their social, physical and leisure needs while in the hospital. There are obviously constraints
in terms of the financial and realistic view in making these leisure options more accessible to adolescents;
however, the need for changes in this area cannot be understated.

SUGGESTIONS FOR FUTURE RESEARCH

The first implication for future research is to conduct a similar needs assessment on a larger scale. This study
was conducted recruiting participants from two different recruitment pools: children referred to the palliative
care program, and the other being an outpatient environment. Oftenthe patients referred from palliative care
were asleep, medicated, or in too much pain to take part in the interviews. The outpatient population, after
being referred to the study, were often discharged before the interview could take place. These were the two
major obstacles on patient recruitment for this study, and due to these constraints only six interviews
were conducted.

While the constraints to the provision of leisure resources and interventions have been briefly addressed in terms
of social, body image, advocacy and leisure interests themselves, the reality of these constraints warrant
further research. While the developmental process of the adolescent years is very well researched and
documented, the implications for these developmental tasks in a hospital setting have not been directly
addressed empirically. The design of age appropriate medical care and treatment interventions is contingent on
the knowledge of how hospitalization directly affects development.

CONCLUSION

The purpose of this study was to provide hospitalized adolescents with the opportunity to give a voice to the
research that suggested that their emotional, social, and physical needs were unique and deserved
special consideration. Based on each of their individual experiences, individual diagnosis, and individual
backgrounds, common thematic elements from their interviews emerged, thereby supporting the contention that
the needs of hospitalized adolescents can be generalized and these needs require addressing. Through the
interviews, social isolation, concerns regarding body image, the need for privacy, and the need for age appropriate environment and leisure options were addressed.

The findings of this study support the literature with the thoughts and experiences of six individual and unique voices. Francis et al. (1988) identified the need for and the benefits of age appropriate environments and a separate space for adolescents; the participants agree and outwardly spoke of their frustration surrounding their childish surroundings. Likewise, Stevens (1989) found that social support was crucial for effective coping to hospitalization; the participants of this study agree unanimously. Denholm (1988) stated that body image was negatively affected when medical conditions brought about changes that were outwardly visible; all six participants made reference to the physical limitations of their condition, and the way that these limitations affected their lives. Finally, Phoenix (2001) suggests that Therapeutic Recreation is well equipped to promote identity formation in adolescents and provide the functional outcomes related to these services. Based on these interviews, Therapeutic Recreation interventions seem more than adequately suited to meet the needs of these individuals. The hope is that this study provides a unique glimpse into the self-stated needs and issues surrounding hospitalized adolescents and will stimulate further research on this topic, as it is too important to ignore.

REFERENCES


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