Quality of Life Among Adolescents With Cancer

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The purpose of this study is to enable adolescents with cancer to self-evaluate their quality of life (QoL). Data were collected using a newly developed Likertscaled QoL instrument. In addition, each participant could comment on how the variable impacted his or her *OoL. Demographic data were self-disclosed to describe* the sample population of 75 adolescents (41 males and 34 females). Overall QoL scores ranged from 27 to 48 (mean = 41.27, SD = 4.31) of a possible 48. Quality of life scores were lowest among those who were female and presently receiving therapy. Overall reliability for the instrument is acceptable (r = .77). These data reveal that adolescents are aware that their QoL is affected by cancer and its treatment. This instrument demonstrates scores that are statistically different (P = .000) between those presently receiving treatment compared with those not receiving treatment. Although not statistically significant, mean scores for females were lower than for males (P = .030), regardless of other variables. Further administration and psychometric testing of the instrument is planned.

Key words: adolescent, cancer, quality of life

Advances in the diagnosis and treatment of cancer have made the possibility of surviving childhood cancer greater than ever. Pogany and associates (2006) state that these increased survival rates have challenged health care professionals to maintain quality of life (QoL), so successful treatment is appreciated by these individuals. Studies surrounding the concept of OoL and how it is affected by treatment have been well documented in the pediatric hematology/oncology research literature (Bradlyn, 2004; Bryant, 2003; Hicks & Lavender, 2001; Hinds, 1990). Qualitative studies that explore individuals' perceptions of their diagnosis and treatment of many oncology disorders are abundant (Adamson et al., 2004; Coyle, 2004; Persson & Hallberg, 2004; Schulmeister, Quiett, & Mayer, 2005). Quantitative studies using a variety of instruments and surveys that purport to measure QoL are also plentiful (Bode, Lai, Cella, & Heinemann, 2003; Hacker, 2003; Hahn & Cella, 2003; Holzner et al., 2004; Soni & Cella, 2002). These instruments are adult oriented or evaluate QoL of children using proxy data obtained from the parent, guardian, or caregiver. Additional research has demonstrated that adolescents who have cancer have a unique perspective into their disease (Hicks, Bartholomew, Ward-Smith, & Hutto, 2003). A review of the research literature reveals no instrument that quantitatively allows adoles-

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cents with cancer to self-evaluate their QoL and comment on how variables directly impact QoL. Thus, the Adolescent Quality of Life (AQoL) instrument was developed and pilot tested to capture these data.

The AQoL is a 16-item Likert-scaled instrument designed to allow adolescents with cancer to selfevaluate their QoL in the 5 domains evaluated in other QoL instruments: normal activities, social/family interactions, health status, mood, and meaning of being ill (Grant et al., 2006; Pogany et al., 2006; Varni, Burwinkle, & Seid, 2005; Varni et al., 1999). In addition, a blank line was available after each item where participants could clarify their responses.

Methods

Sample Selection

Participation in this study was solicited from each individual meeting inclusion criteria. Participation was open to all registered patients in the hematology/oncology clinic at the study site, between the ages of 9 and 20 years, capable of reading English and providing assent to participate in the study, and having a parent or guardian present who would provide consent. After data collection began, enrollment was continuous until the sample size was achieved. All study solicitation, distribution of study materials, assistance in completing the AQoL, and collection of study materials were performed by the child life specialist employed at the study site. All data were collected prior to clinic appointments, placed in secured envelopes, and mailed to the data manager. Power analysis indicated that a sample size of 72 would provide the ability to set the P value at .05 and detect a moderate effect (Munro, 1997).

The Adolescent Quality of Life Instrument

The AQoL is a 16-item Likert-scaled instrument adapted from a process of selecting, reducing, and reviewing items from established QoL instruments. An initial review of these instruments produced 152 items thought by the researchers to be relevant to adolescents with cancer. Collapsing, revising, and rewording these items created a 76-item survey. Piloting this survey among 7 volunteers who met the inclusion criteria provided data that highlighted items of most and least concern. This produced a 17-item instrument in which 1 item was redundant. Removing this item resulted in the present 16-item instrument used in this study (Table 1).

Directions for the AQoL instruct the participant to respond to each item on the AOoL using the previous week as the time frame. The AQoL items assess normal activities (3 items), social/family interactions (4 items), health status (2 items), mood (3 items), and meaning of being ill (4 items). All responses are Likert-type, ordered responses, ranging from *not at all* to *very much*. These responses were formulated into numerical responses providing interval data. Negatively worded items were reverse-scored such that a larger score correlated with a more positive QoL. Examples of items of the AQoL are "I am able to go to school (normal activities)" and "I am coping with my illness (meaning of being ill)."

Data obtained through the open-ended blank line placed after each item were written directly by the participation or recorded verbatim by the child life specialist. These data provided a description of how the variable, in the perspective of these participants, directly impacted the item under investigation. Examples of these items are "What prevents you from going to school?" (normal activities) and "What makes you feel this way?" (meaning of being ill).

Demographic data were self-disclosed and obtained from each study participant after completion of the AQoL. This method complies with present Health Insurance Portability and Accountability Act guidelines and is used only in aggregate form to describe the study population. These data consisted of age, gender, year in school, type of cancer, and present disease treatment status.

Administration Procedures

In addition to securing appropriate institutional review board approval before initiating any data collection, all personnel associated with data collection successfully completed human subjects research education. This program verifies that the person is familiar with maintaining confidentiality and appropriate handling of all research data. Potential participants were identified weekly by a review of the upcoming appointment schedule, and the names of those meeting

Table 1: Child/Adolescent Survey

Below is a list of statements that other people with your illness have said are important. Circle one (1) answer per line, showing how true each statement has been for you *during the past 7 days*. Write on the line below the item what influences your response.

1.	I am coping with my illness	Not at all	Somewhat	Very Much
	What makes you feel this way?			
2.	I am able to enjoy life	Not at all	Somewhat	Very Much
	What prevents you from enjoying life?			
3.	I lack energy	Not at all	Somewhat	Very Much
	What prevents you from doing what you want?			
4.	I am bothered by treatment side effects	Not at all	Somewhat	Very Much
	What bothers you?			
5.	I am frustrated by things I cannot do	Not at all	Somewhat	Very Much
	What prevents you from doing what you want?			
6.	I feel sad	Not at all	Somewhat	Very Much
	What makes you feel sad?			
7.	I am able to go to school	Not at all	Somewhat	Very Much
	What prevents you from going to school?			
8.	I feel close to my friends	Not at all	Somewhat	Very Much
	What makes you feel this way?			
9.	I get emotional support from my family	Not at all	Somewhat	Very Much
	What makes you feel this way?			
10.	My family has accepted my illness	Not at all	Somewhat	Very Much
	What leads you to believe this?			
11.	I enjoy doing things for fun	Not at all	Somewhat	Very Much
	What do you do for fun?			
12.	I am discouraged about my illness	Not at all	Somewhat	Very Much
	What discourages you?			
13.	I have plans for the future	Not at all	Somewhat	Very Much
	What are those plans?			
14.	I have emotional ups and downs	Not at all	Somewhat	Very Much
	What causes this to happen?			
15.	I feel isolated from others	Not at all	Somewhat	Very Much
	What isolates you?			
16.	I am content with my quality of life	Not at all	Somewhat	Very Much

inclusion criteria were circled. This information was confidentially forwarded to the child life specialist, who performed study enrollment and data collection. The assistance of this individual resulted in no missing data. None of the researchers were involved in study enrollment or data collection, eliminating the Hawthorne effect from occurring. Each participant received a gift certificate to a local fast-food establishment upon completion of study participation.

Statistical Analysis

All data were entered into SPSS 14.0 (SPSS, 2006). Results from the AQoL instrument were treated as interval data, indicating that there are differences between the scores and no natural zero (Polit & Beck, 2003). Analyses were performed on the sample as a whole, then stratified based on sex and whether treatment was active. Descriptive statistics were performed on all demographic data. Data from the blank lines were compiled in lists. This allows the most frequent responses to be identified and reported.

After the reliability of the instrument as a whole was determined, factor analysis was performed. This method evaluates the tool for construct validity (Polit & Beck, 2003) and allows for identification of constructs and patterns in correlation (Knapp, 1998) that might explain data variances. Because knowledge in the area of child and adolescent self-reported QoL is limited and this study aimed to perform initial testing of the instrument, exploratory factor analysis is the appropriate statistical method (Kline, 1998).



Figure 1. Types of Cancer Reported by Participants (N = 75)

Results

A total of 75 individuals participated in this study. The response rate was 95%, with refusals related to choosing to do homework or play video games instead. The child life specialist reported there were no adverse effects noted as a result of the study and that 13 participants required assistance.

Descriptive statistics reveal that there were 41 males (54.7%) and 34 females (45.3%). Ages of these participants ranged from 9 to 20 years, with a mean age of 12 years and 4 months. At the time of data collection, 41 (54.7%) were currently receiving treatment, and 34 (45.3%) were in a pretreatment or posttreatment mode. Types of oncological conditions varied, with 37 (50%) indicating leukemia as their type of cancer. Other cancer conditions, in decreasing order, were bone/joint tumors (n = 13, 17%), lymphomas (n = 7, 9%), neurological (n = 7, 9%), Hodgkin's tumors (n = 4, 5%), and miscellaneous types of cancer (n = 7, 9%). The types of cancer for these participants are shown in Figure 1.

Scores obtained by each item were normally distributed, with mean scores ranging from 1.7 to 3.0 (mean = 2.58). Total AQoL scores ranged from 27 to 48 (mean = 41.27, SD = 4.31) of a possible total score of 48. Research field notes indicate assistance in completing the instrument surrounded the inability to write, the result of intravenous line placement into the dominant hand or other medical devices that limited writing skills.

Differences in scores were gender influenced. Male mean total score was 42.24 (SD = 3.67) and female mean total score was 40.09 (SD = 4.77). Although not statistically significant (P = .030), the lower female scores might have clinical relevance.

Comparing scores between those presently receiving therapy and those not receiving treatment revealed a statistical difference (P = .000). Participants receiving therapy reported a total mean score of 39.39 (SD = 4.15), whereas those not receiving therapy reported a mean score of 43.53 (SD = 3.35). This was anticipated because it is reasonable to expect QoL scores to be lower during treatment.

Factor analysis was undertaken on each of the 16 items to identify interrelationships between the items. The principal component extraction method with each variable rotated to a varimax solution was the method used with eigenvalues set at 1. Six factors obtained eigenvalues greater than 1, and these items represented 66.5% of the variance.

The framework used for item construction was employed to initially label each component. Items that formulated component number 1 focused on the social and family interaction and relationships that were different as a result of being ill. The second item was developed from the 4 items that assessed the meaning of being ill and the specific worries of these participants. The third component assessed the participants' ability to maintain a "normal" life and compared activity level-participation in school and social eventsbefore disease to the present. The fourth component correlated with items that inquired about the mood states of the participants, specifically their perception of how they were coping with their disease process and whether they felt depressed. The fifth component addressed concerns related to their present health status, its stability and whether recurrence or disease progression is a concern. The sixth component appears to evaluate QoL directly. Further research will be conducted before confirming these components.

Discussion

The results of this study indicate that QoL, as selfevaluated by children and adolescents with cancer, is impacted by treatment. Although this is not a new discovery, the instrument appears to be sensitive enough to assess this phenomenon. Analysis indicates that the QoL of female patients is affected by the diagnosis of cancer to a greater degree than male patients. These individuals are at risk for physical and psychosocial consequences of having cancer. Routine interventions such as wigs, scarves, or caps; inclusion in school activities as much as possible; and access to psychological support are needed.

Analysis of the open-ended responses to the items on the AQoL supports the statistical analysis of the instrument. The more frequently recorded responses described the social isolation experienced as a result of low blood counts, being hospitalized, frequent outpatient visits, and the inability to participate in activities as a result of fatigue. Nausea and vomiting were also frequently mentioned as negatively affecting their QoL. These participants were discouraged as a result of having cancer and being different from their peers. The inability to play sports was most frequently mentioned by both sexes as impacting their QoL. The possibility of death was the most frequently mentioned variable that impacted these participants' mood and QoL.

Implications for Clinicians

The results of this study suggest that adolescents with cancer are aware that their QoL is affected as a result of the diagnosis and treatment. The concerns expressed in this study support the findings of previous research (Grant et al., 2006; Pogany et al., 2006). Directly asking adolescents to evaluate their QoL would be important clinical data. Allowing these individuals to self-evaluate their QoL provides data directly from the person affected by the disease and its treatment. Including the perspective of the adolescents empowers them to participate in health care treatment and might impact compliance.

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