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Barriers to Pain Management among Adolescents with Cancer

Suzanne Ameringer
Virginia Commonwealth University

Abstract

Patient-related barriers to reporting pain and using analgesics (e.g., fear of addiction) can detrimentally affect pain management for adolescents with cancer. However, adolescent barriers have not been systematically investigated; furthermore, no instrument exists to measure these barriers. The purposes of this study were to examine the psychometric properties of the newly developed Adolescent Barriers Questionnaire (ABQ) and to describe adolescent barriers to pain management. The study was guided by a barriers model which suggests that barriers (beliefs) influence coping (hesitation to report pain and use analgesics, and adequacy of analgesics), which in turn affects outcomes (pain severity and quality of life). Sixty adolescent patients with cancer aged 12 to 17 years completed the ABQ; twenty-two of which reported pain and also completed measures of hesitation, analgesic use, pain severity, and physical and psychosocial function. Initial testing provided evidence that the ABQ is reliable and valid. Internal consistency estimates for the total scale ranged from 0.91 to 0.94, and for the subscales ranged from 0.54 to 0.96. Test-retest reliability over a 2-week period was $r = 0.82$. Construct validity was supported by a significant positive relationship between barriers scores and coping (hesitation to report pain and use analgesics). However, coping did not mediate the relationship between barriers and outcomes. All the adolescents reported some barriers. Barriers scores did not vary by age or gender. The leading barrier was concern that social activities would be restricted if pain was reported. Clearly, adolescents have barriers that can interfere with pain management. Interventions are needed to identify and help adolescents overcome these barriers.

Keywords

Adolescents; Barriers; Pain management; Pain; Cancer

Introduction

Pain is one of the most frequently occurring symptoms in adolescents with cancer and is often rated as moderate to severe in intensity (Collins, et al., 2000; Ljungman, Gordh, Sörensen, & Kreuger, 2000). Optimal pain management is critical because unrelieved pain impairs quality of life and is linked to poor outcomes such as delayed wound healing, infection, and death (Anand & Hickey, 1992; Schechter, Berde, & Yaster, 2003). Nonetheless, studies of symptom prevalence in adolescents with cancer show that the under-treatment of pain remains a problem despite major advances managing such pain (Collins, et al., 2000; Wolfe, et al., 2000).

Correspondence to Suzanne Ameringer, PhD, RN, Assistant Professor, Virginia Commonwealth University, School of Nursing, 1100 East Leigh Street, Richmond, VA, 23219. (804) 628-7551 (Office), (804) 828-7743 (Fax), swameringer@vcu.edu.

The under-treatment of pain has been attributed to numerous factors, including patient-related attitudinal barriers—an individual's beliefs that interfere with reporting pain and using analgesics. For example, the fear of becoming addicted to pain medications may limit one's use of analgesics. To evaluate such barriers, researchers developed a barriers model, which posits that individuals' beliefs about pain management have a considerable influence on how they cope with pain, which, in turn, affects outcomes (Gunnarsdottir, Donovan, Serlin, Voge, & Ward, 2002; Ward, Carlson-Drake, Hughes, Kwekkeboom, & Donovan, 1998). The model suggests that focusing on barriers (beliefs) can improve understanding of patients' coping behaviors. Findings from a large body of research demonstrate that barriers in adults interfere with reporting pain, using analgesics, and are linked to greater pain intensity (Breitbart, et al., 1998; Gunnarsdottir, Serlin, & Ward, 2005: Lin, 2000; Paice, Toy, & Shott, 1998; Ward, et al., 1998). Results from the few studies that have explored adolescents' beliefs reveal that adolescents have barriers that are similar to adults (Kotzer, Coy, & LeClaire, 1998; Ljungman, Gordh, Sörensen, & Kreuger, 1999). For example, adolescents have reported fears of addiction and concerns about analgesic side effects (Ameringer, Serlin, Hughes, Frierdich, & Ward, 2006; Kotzer, et al., 1998; Woodgate & Degner, 2003), and they hold fatalistic beliefs that cancer pain is an expected part of having cancer and has to be accepted (Ameringer, et al., 2006; Woodgate & Degner, 2003).

Moreover, adolescents have additional barriers that go beyond those seen in adults (Klopfenstein & Young-Saleme, 2002; Roberts, 2005; Walters & Williamson, 1999). For example, because adolescents want to be involved in the decision-making process regarding pain management (Klopfenstein & Young-Saleme, 2002), they may hesitate to report pain if they believe their opinions will be ignored. They may also hesitate to report their pain if they think their social activities will be restricted (Klopfenstein & Young-Saleme, 2002; Kyngäs, 2001). Developmental issues (e.g., needs for autonomy and control) could explain some of the unique barriers that adolescents have to managing pain.

However, barriers to pain management among adolescents with cancer have been neither systematically investigated nor linked to how they manage their pain. Because barriers may interfere with critical coping efforts, such as reporting pain and using analgesics, understanding adolescents' barriers has important implications for education directed at overcoming these barriers for adolescents and their families. To measure these barriers, a six-member pain management research team consisting of researchers from nursing and educational psychology and research assistants developed the Adolescent Barriers Questionnaire (ABQ). Content validity of the ABQ was previously examined through interviews with adolescents with cancer and with formal evaluation by panels of clinical experts and adolescents with cancer (Ameringer, et al., 2006).

The purposes of the present study were to (a) examine the internal consistency, test-retest reliability, and validity of the ABQ, and (b) describe barriers to pain management among adolescents with cancer. It was hypothesized that coping (reporting pain, using analgesics, and adequacy of analgesic use) would mediate the relationship between barriers and outcomes (pain severity, physical and psychosocial function).

Methods

Participants

Participants were adolescents recruited through a cancer survey center and from a pediatric oncology clinic, both located in the State of Wisconsin. Inclusion criteria were ages 12 to 17 years and diagnosed with cancer for at least one month. Exclusion criteria were known cognitive disabilities that would interfere with completing the surveys, as well as the participant's or the parent's inability to read and write in English. Among the 174 adolescents who were eligible, 47 were unable to be located and 41 refused to participate. Surveys were mailed to the 86 remaining adolescents who agreed to participate, with 60 (69.7%) returning the first survey (Time 1) and 51 returning both the first survey and the retest (Time 2). The group who returned surveys only at Time 1 (n = 9) was compared to the group who returned surveys at both Time 1 and Time 2 (n = 51) to determine if they differed on demographic or disease-related variables. The two groups did not differ significantly on any of these variables.

Measures

Barriers—Barriers were assessed with the ABQ, a self-report instrument consisting of 45 items and 11 subscales designed to measure the extent to which adolescents hold beliefs about reporting pain and using analgesics. Each subscale consists of three to six items. The 11 subscales are (a) concern about one's ability to monitor health-related changes in one's body, (b) desire to be a “good” patient, (c) fear of addiction, (d) concern about tolerance, (e) fatalistic beliefs that cancer-related pain is unavoidable, (f) concern about side effects, (g) concern about unwanted parental reactions, (h) concern about not being involved in treatment decisions, (i) concern about restriction of social activities, (j) concern about taking pain medications in public, and (k) fear of having undesirable tests. Examples of items are: “I may not be able to do things that are important to me if I take pain medications.” “My parents get very worried if I tell them I have pain.” “I may have to stay home if I tell about my pain.” We informed participants that we were interested in learning what they think about the treatment of pain, therefore there was no right or wrong answer. They were instructed to circle the number that comes closest to how much they agree with each statement, with response options from 0 (*do not agree at all*) to 5 (*agree very much*). Mean scores for each subscale and for the total scale were computed. Higher scores indicate stronger barriers. Participants reported that it took approximately 10 minutes to complete the ABQ.

Demographic and disease-related information—Participants were asked to provide such information as age, gender, ethnicity, cancer diagnosis, time since diagnosis, treatment status, and treatments received in the past month. Participants who reported experiencing pain in the past month were asked to identify the source and location of their pain and to list the analgesics they used for pain.

Coping Measures

Hesitancy to report pain and use analgesics—Six items were used to assess hesitation to report pain and use analgesics. Three items assess hesitancy to report pain to parents, doctors, or nurses, and three items assess hesitancy to use analgesics suggested by parents, doctors, or nurses. Response options range from 0 to 4, with verbal descriptors of *never*, *almost never*, *sometimes*, *often*, or *always*. An overall score was created by taking the mean of the six items. Higher scores indicate greater hesitation. These items are based on items used in previous studies to assess hesitancy (Lin & Ward, 1995; Ward & Gatwood, 1994). Internal consistency in the present study was 0.93.

Adequacy of analgesic use—A modified form (Ward, et al., 1993) of the Pain Management Index (PMI) (Cleeland, 1993) was used to measure the adequacy of analgesic used. Based on the World Health Organization's “analgesic ladder,” the PMI compares the most potent level of analgesic used by a person to the person's self-reported level of pain. The index is constructed by first determining which of four levels of analgesic has been used: (0) no analgesic; (1) non-opioid (e.g., nonsteroidal anti-inflammatory or acetaminophen); (2) weak opioid (e.g., medications containing both nonopioids and opioids); and (3) strong opioid (e.g., morphine). Second, one determines the person's level of pain by using the worst pain item from the Brief Pain Inventory (BPI). The levels are the following: (0) worst pain rating of 0; (1) worst pain rating of 1-4; (2) worst pain rating of 5-6; and (3) worst pain rating of 7-10. The index is then calculated by subtracting the value of the pain level from the analgesic level. The index yields a two-category system (-3 to 3) where negative scores indicate inadequate analgesic use and scores of 0 or greater indicate use of an acceptably potent analgesic. Evidence of validity has been shown in previous studies with theoretically predicted relationships between the PMI and other variables (Ward, et al., 1993; Ward & Hernandez, 1994).

Outcome Measures

Pain severity—For the pain severity variable, a composite score of four items was used in the analysis. Three were intensity items from the BPI. Participants rated their worst pain during the last month, their least pain during the past month, and pain now. Response options range from 0 (*no pain*) to 10 (*pain as bad as I can imagine*). These items have been used extensively in cancer research and have been shown to be reliable and valid (Cleeland & Syrajala, 1992). The fourth item addressed the amount of time a participant had spent in moderate to severe pain during the past month. This was a modified item from the Total Quality Pain Management Program (Einhorn, 1994). Response options range from 0 to 4, with verbal descriptors of *always*, *almost always*, *often*, *sometimes*, and *never*. Validity has been supported through findings of moderate correlations between this item and the BPI and patient satisfaction with pain management (Gordon, Pellino, Schroeder, McConley, & Whitman, 1998). A pain severity composite score was created by first calculating and summing Z scores from the original scores for each of the four items, then computing a T-score (transformed standard score). The composite score has a possible range of 0 to 100, with higher scores indicating greater pain severity. In this study, the internal consistency for the composite score was 0.57.

Quality of life – physical function—Pain interference with physical function was assessed with the Functional Disability Inventory (FDI), a self-report instrument that measures the impact of pain on daily functioning (Walker & Greene, 1991). Respondents rate the difficulty they have in performing 15 activities. Response options range from 0 to 4, with verbal descriptors of *no trouble*, *a little trouble*, *some trouble*, *a lot of trouble*, and *impossible*. Scores for each item are summed to yield a total score that can range from 0 to 60. Higher scores reflect higher levels of functional disability. The FDI has been used with adolescents with chronic pain (Walker & Heflinger,1998). Construct validity was supported with significant correlations to pain severity and depressive symptoms (Claar & Walker, 2006). Internal consistency has been excellent, with alphas ranging from 0.90 to 0.94 (Garber, Van Slyke, & Walker, 1998; Walker & Green, 1991). In the present study, the internal consistency was 0.93.

Quality of life – psychosocial function—Psychosocial function (social, emotional, school function) was assessed with 15 items from the Pediatric Quality of Life Inventory ™ 4.0 (PedsQL™) (Varni, Seid, & Kurtin, 2001). Response options range from 0 to 4, with verbal descriptors of *never*, *almost never*, *sometimes*, *often*, and *always*. Items are reverse scored and linearly transformed to a 0 to 100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). Mean scores for the total scale were used in the analysis. Higher scores indicate better health-related psychosocial quality of life. Adequate internal consistency has been shown (alpha = .83) (Varni, Seid, & Kurtin, 2001). Construct validity was supported with distinguishing between healthy children versus children with cancer (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). Internal consistency in the present study was 0.94.

Procedure

The institution's review board for the protection of human subjects granted approval for the study. Two approaches to recruitment were used. In one approach, advanced practice nurses asked parents of adolescents who were treated in the clinic if they (the parents) wished to be contacted by the researchers to learn about the study. In the other approach, recruiters from the University of Wisconsin Survey Research Center sent opt-in letters of invitation to parents whose adolescents were listed in the Wisconsin Cancer Reporting System (WCRS). Two weeks after the initial letter was mailed, the recruiters attempted to telephone parents who had not returned the letter. A second invitation letter was sent to parents who could not be contacted by telephone. Lastly, 2 weeks after the second invitation was sent, parents received a reminder postcard asking them to please respond to the invitation letter. For parents who opted into learning more about the study, the recruiters passed contact information to the researcher.

With both of the recruitment approaches, the researcher telephoned interested parents and explained the study, then, with parental permission, explained the study to the adolescent. At this time, parent consent and adolescent assent forms were verbally reviewed with the families, as were instructions for completing the surveys. Participants were then mailed the first packet that contained the survey (Time 1), the parent-consent-for-minors form, the assent form, a cover letter with instructions, and a pre-paid addressed envelope to return the survey and forms. The adolescents were asked to complete the survey on their own, except for the demographic and disease-related information and the medications they used for pain—parents could help them complete these items. At Time 1, all participants were instructed to complete the ABQ and the demographic and disease-related items. Only participants who reported having cancer-related pain in the past month were instructed to also complete the coping and outcome measures in the survey. To examine stability of the ABQ, participants were asked to complete the ABQ again (Time 2), approximately 2 weeks after Time 1. For their time and effort, participants were reimbursed five dollars for each returned survey, for a maximum of ten dollars.

Results

Sample

The mean age of the adolescents was 14.77 years (*SD* 1.86, range 12–17 years). See Table 1 for sample characteristics. The majority of the adolescents were Caucasian (90%) and female (53.3%). The mean length of time diagnosed with cancer was 30.52 months (*SD* 14.91, range 2–60 months). Leukemia was the most common cancer diagnosis (35%), followed by lymphoma (21.7%), and bone tumors (13.3%). The majority (70%) reported they had finished treatment for their cancer. Most of the participants (88.3%) received care at pediatric oncology clinics.

Twenty-two (36.7%) reported experiencing cancer-related pain within the past month. Pain was most frequently attributed to treatments and procedures (36.4%). The most frequently reported types of pain were headache (59.1%) and backache (31.8%). These adolescents experienced moderate to severe pain with a mean (*SD*) worst pain of 6.55 (2.77); but, 16 (72.3%) were under-medicated for their pain as indicated by negative PMI scores. A significantly greater percentage of participants with pain were in active treatment (61.1%) compared to the percentage with pain who were off treatment (26.2%; $p = .02$, Fisher's exact test).

Reliability

Reliability of the ABQ was evaluated with internal consistency and test-retest reliability. Total and subscale internal consistencies were examined by Cronbach's alpha. Items were considered for deletion if they reduced the internal consistency of the scale's total and subscale scores. Internal consistency (Cronbach's alpha) of the ABQ total scale at Time 1 was 0.91 and at Time 2 was 0.94 (see Table 2). Alphas for the subscales at Time 1 ranged from 0.54 to 0.89 and at Time 2 ranged from 0.63 to 0.93. Based on the item analysis, no item reduced the internal consistency of both the total and subscale scores enough to eliminate it at this early stage of instrument development. For test-retest reliability, the association (Pearson correlation) between Time 1 and Time 2 ABQ total scores was r = 0.82. The correlations between Time 1 and Time 2 subscale scores were adequate (r = 0.63 – 0.90), except for the Fatalism subscale (r = 0.46).

Describing Barriers

Descriptive statistics were computed to describe barriers. Group differences on barriers scores between participants with pain versus without pain were examined with *t*-tests and Fisher's exact tests. Regression analysis was used to examine whether demographic and disease-related variables predicted barriers. The mean (*SD*) ABQ total score at Time 1 was 1.62 (0.74) (see Table 2) and the median was 1.58. The subscales with the highest means were the concern about restriction of social activities, the fear of undesirable diagnostic tests, the concern about the ability to monitor symptoms, and the concern about becoming tolerant to analgesics. At Time 2, the mean (*SD*) ABQ total score was 1.67 (0.81) and the median was 1.58. At Time 2, the subscales with the highest means were the concern about restriction of social activities, the fear of unpleasant diagnostic tests, the concern about becoming tolerant to analgesics, and the concern about addiction.

Next examined was whether barriers scores varied by age, gender, or disease-related variables using data from Time 1. Separate multiple regression tests were used for these analyses, with the variables of interest entered in the first step, and the interaction entered in the second step. First, the relationships between Barriers, age, and gender were examined. Neither ABQ total nor subscale scores were significantly associated with age or gender. In addition, there were no significant interaction effects. Next, the relationships between barriers and each of the disease-related variables, and interactions between gender and each of the disease-related variables, were examined. Age was a control factor. The disease-related variables were cancer-related pain, non-cancer pain, other health problems, type of clinic, previous use of prescription analgesics, length of time diagnosed with cancer (dichotomized into ≤ 2 years and > 2 years), and treatment status. Barriers did not significantly differ on any of these variables. No interaction effects were found between gender and any of the disease-related variables.

Construct Validity

Table 3 shows the descriptive statistics on the model variables. Zero-order correlations among model variables are displayed in Table 4. For the adolescents who reported pain (n = 22), the ABQ total mean (*SD*) was 1.81 (0.81). The mean (*SD*) Hesitation score was 0.97 (1.02). Pain interfered with physical function to a moderate degree, with a mean (*SD*) FDI score of 26.22 (14.54). Based on the PMI, only 6 participants were categorized as adequately medicated; none was female. Yet, pain severity did not significantly differ between males and females.

To examine the construct validity of the ABQ, the theoretical relationships in the conceptual model were tested using data from the subset of participants who reported pain in the past month (n = 22; 36.7%). It was expected that coping would mediate the relationship between barriers and the outcomes, such that, the hypothesized path was that barriers would influence hesitation to report pain and use analgesics (first mediator), which, in turn, would affect analgesic use (second mediator), which would subsequently influence outcomes. Three separate tests of mediation were conducted, one for each of the outcomes (pain severity, physical function, and psychosocial function).

The present study used the test of mediation proposed by Cohen and Cohen (1983) and supported by MacKinnon, Lockwood, Hoffman, West, and Sheets (2002). This procedure requires testing a path between the independent variable and the mediator, followed by testing the path between the mediator and the outcome and partialling the independent variable. Because each of these tests is needed to establish the mediating effects, the test of each path was assigned a Type I error rate of alpha = .05, two-tailed. The initial plan was to test the mediating effect of coping (Hesitation and PMI) on the relationship between barriers (ABQ) and each of the outcomes (pain severity composite, FDI, PedsQL™), controlling for age and gender. Surprisingly, no females were categorized by the PMI as using an acceptably potent analgesic. In other words, based upon the PMI, all the females were categorized as under-medicated (see Table 5). Because no females were categorized as adequately medicated, the PMI variable was excluded in the tests of mediation. The statistical procedure used was analysis of covariance.

The tests of mediation showed that the first path between Hesitation and Barriers, controlling for age and gender, was significant: B = .46, t[19] =2.15, p=.046, η^2 = .204. But, the paths between Hesitation and each of the three outcome variables, controlling for Barriers, age, and gender, were not significant. Barriers was significantly correlated with Hesitation, but Hesitation did not mediate the relationships between Barriers and any of the three outcomes.

Discussion

The ABQ appears to be a reliable measure of adolescent barriers. The alphas for the total scale were adequate at both Time 1 and Time 2. Six of the subscales had somewhat low alphas at Time 1, but all of these subscales except one had acceptable alphas at Time 2. With respect to the stability of the ABQ, the correlation between Time 1 and Time 2 ABQ total scores was high and, other than the Fatalism subscale, the correlations between the subscales at Time 1 and Time 2 were substantial. These findings suggest that the ABQ is a stable measure over a 2-week period.

Construct validity of the ABQ was supported by the significant correlation between Barriers and Coping. However, this study's hypotheses regarding the model—that coping would mediate the relationship between barriers and outcomes—were only partially supported. The relationship between barriers and coping was significant, but coping did not function as mediator between barriers and outcomes. Given the small sample size of participants reporting pain, further research on these relationships is warranted.

All the adolescents in the present study reported some barriers. Findings are consistent with past research on adolescent pain management—adolescents have some of the same barriers to pain management as adults. In addition, they have barriers that are related to being an adolescent, such as concerns about restriction of social activities and unwanted parental reactions. In fact, the barrier subscale with the highest mean score was Social Activities.

It was not surprising that the concern about the restriction of social activities was foremost among adolescents. Across studies, adolescents with cancer and other chronic illnesses have consistently remarked that a particularly distressing aspect of their diseases is the restriction of social activities (Claflin & Barbarin,1991; Enskar, Carlsson, Golsater, & Hamrin, 1997;

Hockenberry-Eaton & Minick, 1994; Walters & Williamson, 1999; Woodgate, 2005). Why are adolescents worried that their activities will be restricted? Most probably because adolescents with chronic illnesses have reported that they feel their parents tend to be overprotective (Blum, Resnick, Nelson, & St Germaine, 1991; Enskar, 1997; Hokkanen, Eriksson, Ahonen, & Salantera, 2004) and that providers may restrict their activities if they report pain (Ameringer, et al., 2006). Restricting activities can be detrimental for adolescents because it has been linked to feelings of sadness, of isolation, and of being different (Claflin & Barbarin, 1991; Enskar, et al., 1997; Hockenberry-Eaton & Minick, 1994; Walters & Williamson, 1999; Woodgate, 2005). In addition, activity restriction has been associated with depression (Walters & Williamson, 1999).

In the current study, concerns about using analgesics in public had an unexpectedly low mean score. In a previous study examining the content validity of the ABQ, the Pain Medications in Public subscale was rated by both adolescents with cancer and clinical experts as very relevant to adolescents with cancer (Ameringer, et al., 2006). In addition, adolescents with chronic pain have reported that they are less likely to discuss their pain with their peers because they are embarrassed to admit pain (Hunfeld, et al., 2002) and that they are more likely to experience rejection by peers compared to adolescents without chronic pain (Merlijn, 2003).

In the present study, barriers did not vary by gender, age, or disease-related variables. It was anticipated that older adolescents would have higher barrier scores on the Treatment Decisions subscale because older adolescents expect to have increasingly more control over decisions that affect their daily lives. Contrary to expectations, adolescents of all ages reported similar concerns about not being involved in treatment decisions. Similar barriers scores across ages could be due to parents and providers already increasingly involving the older adolescents in medical decisions. Interestingly, adolescents have expressed a desire to be involved in treatment decisions, but the degree to which they want to be involved may vary from adolescent to adolescent. In a previous study involving adolescents with cancer, half of the participants reported they preferred decisions be made collectively with their physician, their parents, and themselves, but the other half reported they preferred that their physicians make the decisions (Dunsmore & Quine, 1995). Frank and ongoing discussions with adolescents with cancer are needed to determine what they wish their role to be in the decision-making process and whether, over time, they want to adjust their role. Changes in their development and physical condition may affect the degree to which they want to be involved in treatment decisions.

Adolescents in the current study did not differ on other disease-related variables with respect to ABQ scores. No differences were found between the ABQ scores and length of time the adolescents were diagnosed with cancer. This finding, particularly regarding fatalistic beliefs, is contrary to findings by Ljungman and colleagues (2000) in which adolescents' beliefs that pain can be successfully managed decrease over time. Too few studies examining beliefs about cancer pain among adolescents have been conducted to draw any meaningful conclusions, but even the limited number of findings suggests a need for further examination of adolescents' beliefs.

Most surprising was the high percentage of adolescents in the current study who were categorized as under-medicated and, even more so, that none of the females was categorized as using adequate analgesics. Several factors could potentially explain these findings. One is that the PMI is problematic because it is a rough estimate of analgesic use; dosing is not assessed. Another is that the participants did not accurately recall their worst pain, potentially overestimating their pain. Data on recall accuracy are inconsistent. Previous study findings suggest that the percentage of persons recalling pain accurately range from

29% to 83%, while percentages of those who overestimate their pain range from 38% to 40% and percentages of those who underestimate range from 24% to 31% (Lander, Hodgins, & Fowler-Kerry, 1992; van den Brink, Bandell-Hoekstra, & Abu-Saad, 2001; Zonneveld, McGrath, Reid, & Sorbi, 1997). Another possibility is that participants in the present study did not accurately report their medications despite their parents' help with completing the list. However, if the categorizations were accurate, then why were so many participants classified as under-medicated? It could be that providers may be hesitant to prescribe opioids to adolescents because of the concern about the risky behaviors of adolescents, such as illegal drug use, or that providers prescribe the correct medications but adolescents refuse to use them. Further investigation is warranted to examine the adequacy of analgesics used by adolescents with cancer.

The present study had several limitations. First, the sample size was small, which was partly due to challenges in obtaining current contact information for potential participants. The WCRS, which was used to enlist participants, lists only adolescents' names; parents' names are unknown. Thus, if the last name of the adolescent is different from the parent's last name, locating current contact information for the adolescent is nearly impossible. Another study limitation was the lack of racial and ethnic diversity in the sample, a situation that resulted from the relative homogeneity of Wisconsin, where the adolescents were recruited. Our narrow operationalization of coping is another limitation. Coping is often viewed as a broad range of cognitive and behavioral activities. In contrast, we focused on only two behaviors that are directly relevant to the problem at hand, reporting pain and using analgesics. Future work could benefit from studying both these two particular behaviors as well as a measure that more broadly addresses a wide range of cognitive and behavioral activities. Finally, the rather low internal consistency (.57) of the pain composite is a limitation in this study.

In summary, initial psychometric testing of the ABQ shows adequate reliability and validity; however, as with any new instrument, further psychometric testing is needed. Clearly, as demonstrated in findings from this study and previous investigations, adolescents with cancer hold beliefs that can interfere with pain management. All of the adolescents in the present study reported some barriers. Higher barrier scores were significantly correlated with adolescents' hesitation to use analgesics and report pain. These correlations neither exclude alternative explanations nor specify causation, but they do point to the importance of further examination of adolescents' barriers to pain management.

In addition, past research findings suggest that parents of adolescents with cancer exhibit their own barriers to their child's pain management (Lehr & BeVier, 2003; Pederson, Parran, & Harbaugh, 2002; Zisk, Grey, MacLaren, Kain, 2007), but it is unclear whether parents' barriers influence adolescents' barriers and, consequently, their pain management. In fact, several experimental studies have been conducted to educate parents regarding pain management and to improve attitudes towards analgesics (Chambers, Reid, McGrath & Finley, 1997; Greenberg, Billett, Zahurak, & Yaster, 1999; Huth, Broom, Mussatto, & Morgan, 2003); however, none of these studies considered the adolescents' knowledge and attitudes or examined the influence of parents' attitudes on the adolescents' coping behaviors. Because adolescents with cancer expect to be and are involved in treatment decisions, their knowledge and attitudes regarding pain management must be considered in the study and subsequent use of interventions. Therefore, in addition to the need for ongoing investigation of adolescent barriers, further understanding of parents' barriers and their effects on adolescents' attitudes and coping behaviors is needed.

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Table 1

Demographic and Disease-related Characteristics of Study Sample (N = 60)

Characteristics	***M***	***SD***	***n***	**%**
Age (Range: 12-17 years old)	14.77	1.86		
Length of time with cancer (Range: 2-60 months)	30.52	14.91		
Gender				
Female			32	53.3
Male			28	46.7
Race				
American Indian/Alaskan Native			1	1.7
African-American			2	3.3
Caucasian			54	90.0
Asian			2	3.3
Other			1	1.7
Cancer diagnosis[a]				
Leukemia			21	35.0
Lymphoma			13	21.7
Central Nervous System tumor			6	10.0
Bone tumor			8	13.3
Soft tissue tumor			4	6.7
Germ cell tumor			1	1.7
Carcinoma			4	6.7
Other			1	1.7
Active treatment				
Yes			18	30.0
No			42	70.0
Type of clinic[a]				
Pediatric			53	88.3
Adult			4	6.7
Other health problems				
Yes			9	15.0
No			51	85.0
Taken prescription medications for cancer pain				
Yes			50	83.3
No			10	16.7
Pain in past month				
Yes			22	36.7
No			38	63.3

[a] Percent will not sum to 100 due to missing data.

Table 2
Descriptive Statistics on the Adolescent Barriers Questionnaire

Subscale	Mean[a]	*SD*	Alpha	T1-T2[b]
Time 1 (*n* = 60)				
Monitor	1.84	1.19	.54	.63**
Good patient	0.99	1.01	.62	.78**
Addiction	1.78	1.56	.89	.90**
Tolerance	1.79	1.36	.78	.72**
Fatalism	1.38	0.95	.61	.46**
Side effects	1.70	1.13	.67	.83**
Parent reactions	1.28	0.90	.64	.76**
Treatment decisions	1.44	1.32	.88	.78**
Social activities	2.53	1.20	.71	.83**
Pain medications in public	0.74	0.93	.68	.74**
Undesirable tests	2.05	1.32	.86	.73**
Total	1.62	0.74	.91	.82**
Time 2 (*n* = 51)				
Monitor	1.76	1.25	.70	
Good patient	1.10	1.14	.73	
Addiction	1.82	1.68	.96	
Tolerance	1.94	1.48	.91	
Fatalism	1.50	1.16	.77	
Side effects	1.66	1.20	.78	
Parent reactions	1.35	0.93	.63	
Treatment decisions	1.29	1.20	.90	
Social activities	2.51	1.29	.86	
Pain medications in public	0.64	1.01	.88	
Undesirable tests	2.43	1.49	.93	
Total	1.67	0.81	.94	

[a] Range for Adolescent Barriers Questionnaire scales is 0-5.

[b] Correlation between Time 1 and Time 2 scores.

** $p < .01$.

Table 3
Descriptive Statistics on Major Study Variables (n = 22)

Variable (range)	***M***	***SD***	**Observed Range**
ABQ Total (0-5)	1.81	0.81	.19-3.09
Pain Severity Composite Score items			
Worst pain (0-10)	6.55	2.77	1-10
Least pain (0-10)	0.77	1.06	0-3
Pain now (0-10)	1.86	2.10	0-6
Frequency of moderate-severe pain (0-4)	1.23	0.75	0-3
Transformed Pain Severity Composite Score	50	10	29.85-65.73
Hesitation Total (0-4)	0.97	1.02	0-3.67
FDI Total (0-60)	26.22	14.54	0-51
PedsQL™ (0-100)	64.55	22.24	5-100

Note. ABQ = Adolescent Barriers Questionnaire. FDI = Functional Disability Inventory. PedsQL™ = Pediatric Quality of Life Inventory™.

Table 4

Zero Order Correlations among Model Variables (n = 22)

	ABQ	Hesitation	Pain	FDI	PedsQL™
Beliefs (ABQ Total)	—	.47	.48	.64	-.61
Coping (Hesitation)		—	.17	.39	-.27
Pain severity (Pain composite)			—	.56	-.48
Physical function (FDI)				—	-.56

Note. ABQ = Adolescent Barriers Questionnaire. FDI = Functional Disability Inventory. PedsQL™ = Pediatric Quality of Life Inventory™.

Table 5
Number of Adolescents Using Acceptable versus Unacceptable Analgesics by Gender (n = 22)

	PMI Category	
Gender	**Acceptable**	**Not Acceptable**
Females	0	12
Males	6	4

Note. PMI = Pain Management Index.