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## Medical and Psychosocial Associates of Nonadherence in Adolescents With Cancer

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### Abstract

The current study examined adherence to medication regimens among adolescents with cancer by applying the Pediatric Self-Management Model. Adolescents and their parents reported on adherence to medication, reasons for nonadherence, and patient-, family-, and community-level psychosocial variables. Adolescent- and parent-reported adherence were significantly correlated, with about half of the sample reporting perfect adherence. The majority reported “just forgot” as the most common reason for missed medication. Patient-, family-, and community-level variables were examined as predictors of adherence. With regard to individual factors, adolescents who endorsed perfect adherence reported a greater proportion of future-orientated goals and spent fewer days in outpatient clinic visits. For family factors, adolescents who endorsed perfect adherence reported greater social support from their family and were more likely to have a second caregiver who they perceived as overprotective. The community-level variable (social support from friends) tested did not emerge as a predictor of adherence. The results of this study provide direction for intervention efforts to target adolescent goals and family support in order to increase adolescent adherence to cancer treatment regimens.

### Keywords

cancer; adherence; adolescence; psychosocial; future orientation

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One third to one half of adolescents with a chronic illness are believed to be nonadherent to their treatment regimen (Cromer & Tarnowski, 1989; Rapoff, 1999). In adolescents with cancer, objective laboratory assays and self-report data indicate that 38% to 50% are nonadherent to their oral medication regimen (Festa, Tamaroff, Chasalow, & Lanzkowsky, 1992; Kondryn, Edmondson, Hill, & Eden, 2009; Pai, Drotar, & Kodish, 2008; Smith, Rosen, Trueworthy, & Lowman, 1979; Tebbi et al., 1986). The consequences of

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nonadherence to cancer treatment are potentially life-threatening and include infection, treatment failure, relapse, and death (Kennard et al., 2004). Because of the grave consequences of nonadherence and lack of empirical investigation in this vulnerable population, adherence promotion has been identified as a critical element of clinical care for adolescents with cancer (Zebrack, Matthews-Bradshaw, & Siegel, 2010). Understanding the prevalence and associates of nonadherence in adolescents with cancer is needed to inform clinical guidelines and improve health outcomes for this vulnerable and underserved population. Therefore, the present article describes parent- and patient-reported adherence, reported reasons for nonadherence, and associates of adherence among adolescents with cancer.

Adherence to medication in adolescents with cancer is particularly challenging because of the nature of adolescent cancer and its treatment. Adolescents with cancer are generally diagnosed with higher risk cancers than younger children, which require longer and more debilitating treatment regimens (Bleyer et al., 2008; Wood & Lee, 2011). Treatment trials have revealed that adolescents with cancer are more likely to experience infection (Sung et al., 2009; Sung, Lange, Gerbing, Alonzo, & Feusner, 2007), osteonecrosis (Mattano, Sather, Trigg, & Nachman, 2000), and treatment-related death (Creutzig et al., 2004; Rubnitz et al., 2004) than younger children. In addition, protocols for adolescent cancer treatment frequently include chemotherapy and steroid medications, which can have severe and unpleasant side effects including hair loss, nausea, fatigue, gastrointestinal problems, mouth sores, mood changes, weight gain, and trouble sleeping (Love, Leventhal, Easterling, & Nerenz, 2006; Malbasa, Kodish, & Santacroce, 2007; Rapoff, McGrath, & Smith, 2006). Thus, medications may make the patient feel worse than the cancer itself and minimize motivation to adhere, especially for patients in remission who are not experiencing symptoms of their cancer and who are striving to return to normalcy (de Oliverira, Viana, Zani, & Romanha, 2004).

Normative developmental challenges of adolescence may further exacerbate adherence challenges for adolescents (Kondryn, Edmondson, Hill, & Eden, 2011; Malbasa et al., 2007). Adolescence is a time of forming close peer and romantic relationships, focusing on school achievement and aspiring career goals, establishing autonomy from parents, identity development, and setting and pursuing goals (Bandura, 2005; Holmbeck, 2002; Modi et al., 2009; Schwartz & Drotar, 2006; Schwartz & Parisi, 2013). Furthermore, adolescents may lack awareness of their health vulnerabilities (La Greca, Bearman, & Moore, 2002) and/or focus on a desire to be “normal” and avoid reminders of cancer (Zebrack & Isaacson, 2012).

Few studies of adherence in adolescents with cancer have applied theoretical frameworks to guide their examinations. Landier et al. (2011) developed a model using grounded theory analysis of qualitative data to describe the process of adherence to oral chemotherapy in children and adolescents with leukemia. Their model emphasizes the role of the parent, in conjunction with the child, in taking responsibility for medication adherence. To be successful, the following must be present: recognition of life threat, ability to take control, and ability to manage adherence consistently (Landier et al., 2011). Our study is informed by this model in that we examine both parent and child perspectives on adherence and related associates, with the aim to better understand how adolescents can maintain adherence

long term. However, given our focus on associates of adherence, not the process of adherence, we applied a new theoretical model of pediatric self-management to guide investigation of influences on adherence among adolescents with cancer. The Pediatric Self-Management Model (Modi et al., 2012) applies a developmental–ecological framework by describing nonmodifiable and potentially modifiable patient, family, community, and health care system factors as influences on adherence. While the literature on adherence among adolescents with cancer has not explored community- and systems-level influences on adherence, studies have identified some patient- and family-related associates of nonadherence.

A few studies have identified patient-level nonmodifiable associates of adherence in adolescents with cancer such as treatment-related variables (see Butow et al., 2010; Pritchard, Butow, Stevens, & Duley, 2006, for review). However, findings on associations between treatment-related variables (ie, treatment modality, complexity, and duration; adverse impact on daily living) and adherence outcomes in pediatric cancer are mixed (Butow et al., 2010; Pritchard et al., 2006; Tamaroff, Festa, Adesman, & Walco, 1992). Studies with adolescents with cancer have reported forgetting to take medication as a leading reason for nonadherence (Hawwa et al., 2009; Landier et al., 2011; Mancini et al., 2012), which is also well documented in the broader adolescent chronic illness literature (La Greca & Mackey, 2009). Modifiable psychosocial patient-level associates, including higher depression and lower self-esteem, have also been found to relate to nonadherence in adolescents with cancer (Kennard et al., 2004; Malbasa et al., 2007; Tebbi et al., 1986). Adolescents with cancer who have less positive beliefs about medication efficacy and lower future orientation also tend to have higher rates of nonadherence (Landier et al., 2011; Tamaroff et al., 1992). There is also evidence from research on adolescents with asthma and adults attending physical rehabilitation that negative affect is positively related to nonadherence (Grindley, Zizzi, & Nasypany, 2008; van de Ven, Witteman, & Tiggelman, 2013). Furthermore, self-efficacy has been identified as one of the strongest psychosocial predictors of adherence in children and adolescents with a chronic illness (Clark & Dodge, 1999; De Civita & Dobkin, 2004).

On the family level, nonmodifiable factors such as lack of financial resources and living in a single parent home are related to nonadherence in adolescents with cancer (Landier et al., 2011; Mancini et al., 2012). Lower parental involvement, a potentially modifiable family-level factor, has been associated with nonadherence in adolescents with cancer (Malbasa et al., 2007). One potentially modifiable community-level associate is peer social support. Few studies have examined the effect of social support from friends on adolescent treatment adherence in chronic illness, and the existing literature is mixed, suggesting that further examination is warranted (Barker, Driscoll, Modi, Light, & Quittner, 2011; Bearman & La Greca, 2002). Other community-level and health care system-level associates of adherence identified in the Pediatric Self-Management Model have not been explored in studies of adolescents with cancer.

Despite these many findings, there is a need to expand this literature by studying the role of many associates of adherence in adolescents with cancer in a theoretical framework. Furthermore, prior research on adherence among adolescents with cancer is limited by lack

of empirical data, small sample sizes with single informants, homogenous samples, lack of racial and ethnic diversity, focus on leukemia, and atheoretical studies (De Civita & Dobkin, 2004; Landier et al., 2011; Modi et al., 2012; Pritchard et al., 2006; Windebank & Spinetta, 2008). Thus, the current study sought to examine parent- and patient-reported rates of and reasons for nonadherence in adolescents with cancer as well as demographic, treatment- and disease-related, and psychosocial associates of nonadherence within a theoretical framework in a diverse sample of adolescents with cancer. Specifically, we hypothesized that parent and adolescent report of adherence would be consistent (Tebbi et al., 1986) and that half of adolescents and their parents would report less than perfect adherence (Tebbi, 1993). In addition, adolescents were hypothesized to report forgetfulness as the most common reason for nonadherence (Mancini et al., 2012). We also applied the pediatric self-management framework (Modi et al., 2012) to examine nonmodifiable and potentially modifiable associates of nonadherence in adolescents with cancer. In accordance with this model, individual factors specific to the adolescent (nonmodifiable: older age, race/ethnicity, diagnosis, longer time since diagnosis, positive relapse status, greater intensity of treatment, treatment modality, greater number of days spent inpatient and outpatient; and modifiable: lower future orientation of goals, lower self-efficacy, less positive affect and more negative affect), family factors (nonmodifiable: lower household income, single parent; and modifiable: lower social support from family, less involved parents, lower family functioning), and modifiable community factors (lower social support from friends) were examined as associates of nonadherence in adolescents with cancer.

## Methods

The current study is a secondary analysis of data from a broader study on goals and adjustment of adolescents with cancer collected between March 2007 and April 2009. The institutional review board of the large Mid- Atlantic children's hospital where the study took place approved all procedures.

## Participants

Participants were 103 adolescents with cancer and a parent/guardian. Adolescents were eligible if currently receiving treatment for cancer for at least 1 month (not palliative), aged 13 to 19 years during the study, fluent in English, without cognitive impairment as determined by their parent or provider, physically capable of completing questionnaires, and had a parent/guardian willing to participate. Of the 133 families approached for participation in the study, 123 agreed to participate, and 103 completed the relevant measures for the current analyses. Reasons for refusal were too much work (n = 2), child too ill (n = 1), parent refusal (n = 4), cognitive impairment (n = 1), or no reason specified (n = 2). See Table 1 for a description of the sample, including demographics and disease-related information.

## Procedure

Potential adolescents with cancer were invited to participate in the original study during inpatient hospitalization (n = 65) or outpatient clinic visits (n = 38). Participants recruited on the inpatient floor did not differ from those recruited in clinic by reported perfect versus

nonperfect adherence. Adolescents and parents provided consent or assent (below 18 years old), and then completed a packet of psychosocial questionnaires at home or in the hospital. Adolescents were compensated with \$25 for time and effort on completion of measures.

## Measures

### Individual Factors

**Demographics:** Parents provided data regarding the child's gender, current age, race and ethnicity, parent marital status, and annual household income.

**Disease- and treatment-related variables:** Review of electronic medical records was conducted by a trained research assistant to identify diagnosis (categorized as leukemias, lymphomas, solid tumors, or brain tumors), time since diagnosis, number of days spent inpatient and outpatient, relapse status (yes/no), and treatment modality (categorized as surgery, chemotherapy, radiation, transplant). *The Intensity of Treatment Rating 2.0* (ITR-2; Werba et al., 2007) is a validated system for rating pediatric cancer treatment intensity on a 4-point Likerttype scale (1 = *least*, 2 = *moderately*, 3 = *very*, 4 = *most*), with higher scores indicating more intense treatment. Two independent pediatric oncology providers reviewed patient medical records and completed the ITR-2. A small number of discrepancies were resolved by a third pediatric oncology provider who referred back to the medical charts as needed. "Least" and "moderately" intense scores were collapsed due to few ratings of "least" intense.

**Health-Related Hindrance Inventory:** Adolescents completed the Health-Related Hindrance Inventory (HRHI; Schwartz & Drotar, 2009; Schwartz & Parisi, 2013) which instructs respondents to list their self-identified goals and select up to 10 of their "most important" goals. While the main focus of the HRHI is to assess hindrance of personal goals, that data were not used for the current study; only the code of future orientation (yes/no) of goals was used. Following procedures described in Schwartz and Parisi (2013), 2 independent coders coded the adolescent goals. Goals coded as future-oriented represented aspirations and plans beyond high school, adolescence, or cancer treatment (eg, do well on SATs, apply for college, start a family). Goals were not considered future-oriented if it could be achieved during adolescence and did not have clear future-oriented implications (eg, get a job). Agreement between the raters was 98% and all discrepancies were easily resolved.

**Cowen Self-Efficacy Scale:** Adolescents completed the Cowen Self-Efficacy Scale (Cowen et al., 1991) on which they rated their ability to handle 20 situations on a 5-point scale, with higher scores indicating greater perceived self-efficacy. Internal consistency was good ( $\alpha = .89$ ).

**Positive and Negative Affect Scale:** Adolescents rated how much they experienced 20 feelings in the past week on the Positive and Negative Affect Scale (PANAS; Watson, Clark, & Tellegen, 1988) which forms 2 subscales: Positive and Negative Affect, which both had good internal consistencies ( $\alpha = .88$  and  $\alpha = .90$ , respectively). Ratings are made via a 5-point scale with higher scores corresponding to higher affect.

## Family Factors

**Perceived social support from family:** Adolescents' perceptions of social support from their family was assessed using the Perceived Social Support from Family Scale (Procidano & Heller, 1983). A total score is calculated, with higher values indicating more support. This measure had good internal consistency ( $\alpha = .86$ ).

**Parental Bonding Instrument:** Adolescents and parents completed the Parental Bonding Instrument (PBI) which consists of 2 subscales: Overprotection and Caring (Parker, Tupling, & Brown, 1979). Parents rated their own parenting, and adolescents completed the PBI for their primary and secondary caregiver, if applicable. A total score is calculated with higher Caring scores indicating more warmth and understanding, and higher Overprotection scores indicating more perceived control and intrusiveness. Internal consistency was good for both subscales and reporters with Cronbach's  $\alpha$ s ranging from .79 to .89.

**Family Assessment Device:** Adolescents and parents completed the 12-item General Functioning subscale of the Family Assessment Device (Epstein, Baldwin, & Bishop, 1983). Adolescent- ( $\alpha = .85$ ) and parent-report ( $\alpha = .88$ ) had good internal consistencies.

## Community Factors

**Perceived social support from friends:** Adolescents' completed the Friends version of the Perceived Social Support scale to assess their perceptions of social support from their friends (Procidano & Heller, 1983). A total score is calculated, with higher values indicating more support. This measure had good internal consistency ( $\alpha = .84$ ).

## Adherence

**Medical Adherence Measure:** Adolescents and parents responded to 2 items from the widely used and validated Medical Adherence Measure (Zelikovsky & Schast, 2008). Patient adherence was rated on a 10-point scale (1 = *never*; 10 = *always take medication*). Respondents were asked to consider all their medication when responding to these questions. Though the Medical Adherence Measure was developed as a clinical interview, for the purposes of the current study, participants responded to these items in a questionnaire format. This measure has been used as a pencil-and-paper measure in other studies (Silverio & Cheung, 2014). Because of a ceiling effect, ratings were dichotomized as perfect adherence (rating of 10) or less than perfect adherence (rating less than 10). All adolescents and parents (including those who rated their adherence as a 10) also selected reasons for nonadherence from a list of 12 reasons. Respondents had the option to choose "do not miss/NA" or to write in a reason other than the 12 provided.

## Data Analytic Plan

Descriptive statistics were conducted on disease, demographic, and adherence parameters. To determine if adolescent and parent reports of adolescents' adherence to their medication regimen were consistent, a bivariate correlation was conducted. Frequencies and percentages were calculated to describe the reasons for nonadherence in the sample. *t* Tests (for continuous variables) and  $\chi^2$  analyses (for dichotomous variables) were conducted to

compare adolescents reporting less than perfect adherence to those reporting perfect adherence on individual-, family-, and community-level variables. A binary logistic regression was used to test a multivariate model of significant associates of reporting nonperfect adherence. The significance level was set at  $P < .05$ . We conducted a sensitivity power analysis and found that given the  $\alpha$  threshold for significance ( $\alpha = .05$ ) and sample size of 99 for the logistic regression, we had 80% power to detect effects lower than an odds ratio of 0.44 and greater than an odds ratio of 2.27 (Faul, Erdfelder, Lang, & Buchner, 2007).

## Results

### Prevalence of Nonadherence

Adolescent and parent report of adolescent adherence was found to be consistent ( $r = .33$ ,  $P = .001$ ). For both adolescents and their parents, the mode rating was a 10 (“always takes his/her medication”) with approximately half of the respondents in each group endorsing perfect adherence (adolescents:  $n = 44$ , 42.72%; parents:  $n = 55$ , 53.39%). Parents’ average rating of adherence (mean [M] = 9.08, standard deviation [SD] = 1.47, range = 3–10) was slightly higher than adolescents’ rating (M = 8.72, SD = 1.87, Range = 0–10).

### Reasons for Nonadherence

All adolescents and parents reported on barriers to adherence. For adolescents (37.9%;  $n = 39$ ) and parents (22.3%;  $n = 23$ ), the most frequently endorsed barrier to medication adherence was “just forgot.” See Table 2 for information regarding the frequency of other barriers to adherence.

### Differences Between Adolescents With Self-Reported Perfect and Nonperfect Adherence

Because of the high ratings of adherence, the adolescents were dichotomized into 2 groups for further analyses: those who endorsed perfect adherence and those who endorsed less than perfect adherence. Adolescents who reported nonperfect adherence were compared with those who reported perfect adherence on individual-, family-, and community-level factors (Table 1).

**Individual Factors**—No differences were observed between the groups on demographic variables (ie, adolescent gender, age, race/ethnicity). Analyses were also conducted to determine if there were differences between the groups on disease- and treatment-related variables (ie, treatment intensity, treatment modality, relapse status, time since diagnosis, number days spent inpatient and outpatient). Patients did not differ by perfect or nonperfect adherence on number of days spent inpatient. However, adolescents who reported nonperfect adherence tended to have spent more days in outpatient clinic visits since their diagnosis ( $t[100] = -2.12$ ,  $P = .04$ ). A trend for significance was observed for relapse status,  $\chi^2(1, N = 102) = 3.53$ ,  $P = .06$ , such that those adolescents who had relapsed were more likely to endorse nonperfect adherence. No other differences were observed between the groups on disease characteristics.

Analyses were conducted to determine differences between adolescents who reported perfect adherence and those who reported nonperfect adherence on individual-level psychosocial variables (ie, future orientation of goals, self-efficacy, affect). No significant differences were observed between the groups on self-efficacy or positive or negative affect. There was a significant difference between groups for future-orientation ( $t[101] = 2.39, P = .02$ ), such that adolescents who reported perfect adherence had a greater proportion of future-oriented goals ( $M = 0.34, SD = 0.28$ ) than those who reported nonperfect adherence ( $M = 0.22, SD = 0.24$ ).

**Family Factors**—With regard to family factors, results revealed a significant difference between the groups on family social support ( $t[101] = 2.33, P = .02$ ), such that those adolescents who endorsed perfect adherence to their medication ( $M = 16.30, SD = 4.25$ ) reported more social support from their family than those who were nonadherent ( $M = 14.31, SD = 4.31$ ). There was a significant difference between groups on parental overprotection by their secondary caregiver,  $t(99) = 2.19, P = .04$ , such that those adolescents who endorsed perfect adherence to their medication ( $M = 12.60, SD = 7.27$ ) perceived their secondary caregivers as more overprotective than those adolescents who were nonadherent ( $M = 9.71, SD = 5.99$ ).<sup>1</sup> No differences were observed between the groups on income, parent education, parent marital status, perceived caring from primary or secondary caregivers, overprotection from the primary caregiver, and family functioning.

**Community Factors**—There was no significant difference between adolescents with perfect versus nonperfect adherence on perceived social support from friends.

### Binary Logistic Regression Model of Significant Associates of Perfect Adherence

A binary logistic regression model was created using the significant patient- and family-level associates of perfect adherence as predictors (see Table 3). Though relapse status was only marginally significant ( $P < .10$ ), it was included in the regression due to theoretical rationale for its association with nonadherence (Kondryn et al., 2011). Days spent in outpatient clinic visits, relapse status, social support from family, overprotection by a secondary caregiver, and percentage of future-oriented goals were entered as predictors in a multivariate model of self-reported perfect adherence in adolescents with cancer. The overall model was significant ( $\chi^2[5, n = 99] = 20.95, P = .001$ ) and according to McFadden's  $R^2$ , explained 15.52% of the variance in adherence. Adolescents who reported nonperfect adherence had less family support, less overprotectiveness from their secondary caregiver, and fewer future-oriented goals than adolescents who reported perfect adherence. Number of days in outpatient clinic visits and relapse status did not significantly predict nonadherence.

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<sup>1</sup>The majority of adolescents identified mothers as their primary caregiver ( $n = 86, 88\%$ ) and fathers as their secondary caregiver ( $n = 77, 76\%$ ). Fathers ( $n = 13, 13\%$ ), grandmothers ( $n = 1, 1\%$ ), and aunts ( $n = 1, 1\%$ ) were also nominated as primary caregivers. Some adolescents identified mothers ( $n = 13, 13\%$ ), step-fathers ( $n = 4, 4\%$ ), grandmothers ( $n = 2, 2\%$ ), aunts ( $n = 2, 2\%$ ), or uncles ( $n = 1, 1\%$ ) as their secondary caregivers.



## Discussion

The current study described rates of parent- and adolescent-reported adherence to medication regimens, reported reasons for nonadherence, and is the first study to our knowledge to apply the Pediatric Self-Management model to associates of adherence in adolescents with cancer (Modi et al., 2012). Consistent with our hypotheses, parent- and adolescent-report of the adolescent's adherence were moderately correlated, indicating overall consistency of ratings. Approximately half of parents and adolescents reported perfect adherence to medication regimens, with parents reporting slightly better adherence than their teens. These rates of nonadherence are consistent with other examinations of adolescents with cancer (Lansky, Smith, Cairns, & Cairns, 1983; Smith et al., 1979; Tebbi et al., 1986), including objective laboratory assays of medication adherence (Festa et al., 1992), suggesting that a 1-item question regarding adherence may be a sufficient screener for nonadherence in this population. In accordance with our hypothesis, "just forgot" was the most commonly endorsed reason for nonadherence among both adolescents and their parents. The second most common reason for nonadherence reported by adolescents was "am not home." This finding is consistent with the extant literature regarding barriers to adherence in adolescents with cancer, as forgetfulness is a commonly cited barrier (Mancini et al., 2012).

Results provide empirical evidence in support of the Pediatric Self-Management Model's emphasis on the roles of nonmodifiable and modifiable individual-, family-, and community-level factors in adherence (Modi et al., 2012). With regard to modifiable individual-level factors, future orientation of adolescents' goals emerged as a significant predictor of adherence in the model. Adolescents with a higher proportion of future-oriented goals were more likely to report perfect adherence (Tamaroff et al., 1992). It may be that those who are more future-oriented also have a greater understanding of the consequences of nonadherence to their regimen than those adolescents with fewer future-oriented goals. It may also be that these adolescents prioritize pursuit of long-term rewards over short-term rewards by looking forward to and have greater hope for their futures (Berg, Rapoff, Snyder, & Belmont, 2007), which may cause them to be more adherent to their regimen. Those adolescents who are less adherent may feel a sense of foreshortened future which makes them more likely to pursue short-term rewards (eg, avoid unpleasant side effects of medication) and, therefore, less likely to adhere (Landier et al., 2011).

In addition to adolescents' future orientation, the current findings suggest that modifiable family-level characteristics, including social support from family and protection from a second caregiver, also play an important role in adherence among adolescents with cancer. Adolescents with a second caregiver whom they perceived to be overprotective endorsed better adherence. Examination of the means of the overprotection subscale (see Table 1) suggest that the secondary caregivers are actually less overprotective than the primary caregivers, and the means in this sample are similar to published means (Parker, 1983). Therefore, while as a whole the second caregivers in the sample are not overly protective, they are exhibiting a level of protectiveness and presumably involvement that seems to help facilitate adherence. Protective secondary caregivers may serve as a second person reminding adolescents about medication and to whom the adolescents are accountable with

regard to medication adherence. Adolescents with cancer desire parental involvement with regard to adhering to their medication regimens (Malbasa et al., 2007), and it may be more adaptive for them to have caregivers who are more protective of them and their treatment, rather than allowing them to be autonomous. In addition, even though adolescence is a time in which individuals begin to develop deeper peer relationships, results indicate that social support from family promotes adherence to the medical regimen, but social support from friends was not found to be related. Unlike other adolescents with less controlled regimens like diabetes (La Greca et al., 1995), adolescents with cancer may spend more time with their caregivers than with their peers, making family support that much more important to adherence behaviors. Furthermore, research has demonstrated that adolescents with cancer do not discuss treatment adherence with their peers in an attempt to maintain a sense of normalcy with others their age (Malbasa et al., 2007).

Two nonmodifiable, treatment-related, individual-level factors also emerged as possible associates of adherence in adolescents with cancer. Though only marginally significant, adolescents who had relapsed were more likely to be nonadherent than those adolescents who had not relapsed. This is particularly concerning because nonadherence to medication could lead to relapse (Lilleyman & Lennard, 1996). Additionally, adolescents who have relapsed are at a higher risk of mortality (Nguyen et al., 2008) and should be particularly diligent to adhere to their medical regimen. Results also provide preliminary evidence that adolescents with cancer whose protocol involves more outpatient clinic visits and less inpatient stays may have more opportunities for nonadherence; however, this should be interpreted with caution because days spent as an outpatient did not emerge as a significant predictor of adherence in the model. These 2 treatment-related factors warrant further investigation to understand how they interact with modifiable factors to influence adolescent adherence.

This study has several strengths relative to the existing literature on adherence in pediatric cancer. First, this study exclusively examined adolescents with pediatric cancer who are at a unique developmental stage and are likely to be at greater risk for nonadherence than children and adults (Butow et al., 2010). Second, we examined a heterogeneous group of adolescents on treatment for cancer including a diversity of ethnic backgrounds and diagnoses. Of the studies that have been conducted, most have examined this issue in children and adolescents with leukemia and lymphoma, which limits generalizability to other cancers (Butow et al., 2010). Third, our study uses a model of pediatric adherence as a framework for examining cancer treatment adherence in adolescents (Modi et al., 2012).

The results of the current examination should be considered in light of several limitations. First, there were no biological measures of treatment adherence to corroborate patient and parent report. It may be that reported rates of adolescent adherence are higher than actual rates of treatment adherence due to social desirability. However, prior studies on adolescents with cancer have demonstrated that objective and self-report data on adherence are highly consistent (Kennard et al., 2004; Pai et al., 2008; Tebbi, 1993; Tebbi et al., 1986). Also, due to restricted range and high rates of perfect adherence, adolescent adherence was dichotomized for the analyses. It may be that those adolescents who reported an adherence rating of 9 out of 10 are more similar to adolescents who rated their adherence as a 10 than

those who rated adherence as a 3. We also did not assess for type of treatment regimen in the sample. Because the sample is heterogeneous with regard to cancer diagnosis and time since diagnosis, it may be that some adolescents have treatment regimens which are highly controlled by the staff at the hospital (ie, intravenous chemotherapy treatments) whereas other adolescents and their families are responsible for the entirety of their treatment regimen (ie, oral chemotherapy or oral antibiotics). It would be important to address this in future research in order to assess whether there are differences in adherence by treatment regimen. The sensitivity power analysis indicated that we may not have had an adequate sample size to detect the effects of days in outpatient clinic visits and relapse status. As such, future studies should continue to examine the impact of these illness factors on adherence in adolescents with cancer. Finally, we acknowledge that our study did not test all components of the Pediatric Self-Management Model (Modi et al., 2012), nor were we comprehensive in testing all levels of this framework. It is likely that the community and health care system have important contributions to adolescent adherence that we are unable to measure in our study. As such, future studies should include these systems to understand their contribution to adherence in adolescents with cancer.

### Clinical Implications

The current study has important implications for improving adherence to medication regimens for adolescents with cancer. Adolescent adherence to cancer treatment regimens should be carefully assessed by the medical team, and barriers should be identified by both adolescents and their caregivers. Notably, those barriers that were endorsed most frequently by the adolescents and their parents can be addressed through behavioral interventions and simple changes on the part of the family and medical team. Forgetfulness and not being home can be addressed by setting alarms, placing notes in frequented places around the house, using pill boxes to organize medication and to allow the adolescent to take the medication with him/her, as well as scheduling activities around administration times. In addition, an emerging literature on mobile health initiatives have demonstrated that text-message reminders for medication administration significantly improve adherence among pediatric patients with other chronic illnesses (eg, Franklin, Waller, Pagliari, & Greene, 2006).

Regarding other barriers to nonadherence, including the taste of medicines, difficulty swallowing, and unpleasant side effects, open communication with the medical team is imperative (Butow et al., 2010). There may be options to change the dosing, method of administration, and frequency of supportive medications. Although there may be less flexibility in other medications, such as life-saving chemotherapy, awareness by the medical team of adherence difficulties could result in additional supportive care (eg, referrals to pediatric psychology) to optimize adherence.

The current findings also suggest modifiable individual- and family-level targets of intervention. Promoting future orientation among adolescents by integrating adherence into their repertoire of goals may be an avenue for future intervention research (Schwartz & Drotar, 2006; Schwartz & Parisi, 2013). Cognitive-behavioral interventions may also help adolescents to develop greater future orientation and, in turn, improve adherence. Our results

suggest that caregivers, specifically secondary caregivers, must remain involved in the adolescent's medical care to optimize adherence. Communication between adolescents and their parents regarding nonadherence should be explored in future research, as it may help parents to monitor barriers to the adolescent's adherence and to help the adolescent develop solutions to these barriers. Our findings provide support for family interventions to enhance adherence in children and adolescents with chronic illnesses, such as behavioral family systems therapy (Wysocki et al., 2006), which targets family communication and problem solving and applies these skills to medical regimen adherence behaviors. Thus, extensions of this study should examine familial communication as a mechanism of promoting adherence among adolescents with cancer.

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**Table 1**

Individual-, Family-, and Community-Level Sample Characteristics.

Variable	Total Sample (n = 103), n (%)	Adolescent-Reported Perfect Adherence (n = 44), n (%)	Adolescent-Reported Nonperfect Adherence (n = 59), n (%)	P
Individual factors				
Male gender	58 (56)	26 (59)	32 (54)	NS <sup>a</sup>
Age, mean (SD), Range	15.77 (1.77), 13–19	15.70 (1.64), 13–18	15.81 (1.87), 13–19	NS
Ethnicity/race				
Non-Hispanic White	70 (68)	29 (66)	41 (70)	NS
African American/Black	15 (15)	5 (11)	10 (17)	
Asian	3 (3)	2 (5)	1 (2)	
More than 1 race	3 (3)	2 (5)	1 (2)	
Hispanic	12 (12)	6 (14)	6 (10)	
Income <sup>b</sup>				
<\$9 999	23 (22)	12 (27)	11 (19)	NS
\$40 000–79 999	31 (30)	10 (23)	21 (36)	
\$80 000–99 999	9 (9)	4 (9)	5 (9)	
\$100 000+	31 (30)	14 (32)	17 (29)	
Diagnosis				
Leukemia	30 (29)	15 (34)	15 (25)	NS
Lymphoma	20 (19)	7 (16)	13 (22)	
Solid tumor	42 (41)	16 (36)	26 (44)	
Brain tumor	11 (11)	6 (13)	5 (9)	
Months since diagnosis, mean (SD), range	20.91 (38.70), 1.00–193.22	15.09 (37.38), 1.00–193.22	25.26 (39.41), 1.00–175.38	NS
Relapse (yes)	29 (28)	8 (19)	21 (36)	.06
Days inpatient, mean (SD), range	37.65 (38.78), 0.00–200.00	37.07 (40.54), 0.00–196.00	38.08 (37.76), 0.00–200.00	NS
Days outpatient, mean (SD), range	21.29 (24.06), 0.00–118.00	15.75 (20.94), 0.00–111.00	25.50 (25.56), 0.00–118.00	.04
Treatment intensity				
Least or moderately	21 (20)	10 (23)	11 (19)	NS
Very	45 (44)	20 (46)	25 (42)	
Most	37 (36)	14 (32)	23 (39)	
Treatment modality				
Surgery	30 (29)	13 (30)	17 (29)	NS
Chemotherapy	99 (96)	41 (93)	58 (98)	
Radiation	40 (39)	18 (41)	22 (37)	
Bone marrow transplant	10 (10)	3 (7)	7 (12)	
Future orientation of goals, mean (SD), range	0.27 (0.26)	0.34 (0.28)	0.22 (0.24)	.02
Self-efficacy, mean (SD), range	69.59 (11.94)	70.18 (12.10)	69.15 (11.91)	NS
Positive affect, mean (SD), range	30.02 (8.73)	29.12 (8.58)	30.69 (8.85)	NS
Negative affect, mean (SD), range	21.43 (8.52)	20.93 (7.28)	21.81 (9.38)	NS
<b>Family factors</b>				



Variable	Total Sample (n = 103), n (%)	Adolescent-Reported Perfect Adherence (n = 44), n (%)	Adolescent-Reported Nonperfect Adherence (n = 59), n (%)	P
Single parent	29 (28)	16 (36)	13 (22)	NS
Family functioning, mean (SD), range	1.88 (0.43)	1.86 (0.44)	1.90 (0.43)	NS
Social support from family, mean (SD), range	15.16 (4.37)	16.30 (4.25)	14.31 (4.31)	.02
Parent caring, mean (SD), range				
Primary caregiver	29.95 (13.29)	29.44 (6.30)	30.32 (5.56)	NS
Secondary caregiver	27.00 (7.53)	26.32 (8.42)	27.70 (6.83)	NS
Parent overprotection, mean (SD), range				
Primary caregiver	13.29 (6.54)	13.61 (6.03)	13.05 (6.93)	NS
Secondary caregiver	10.94 (6.69)	12.60 (7.27)	9.71 (5.99)	.03
<b>Community factors</b>				
Social support from friends, mean (SD), range	15.03 (4.03)	15.18 (4.05)	14.92 (4.05)	NS

<sup>a</sup> NS = not significant at  $P < .05$ .

<sup>b</sup> Nine participants did not indicate income.

**Table 2**

## Barriers to Adherence.

Reasons for Not Taking Medication	Number of Times Endorsed <sup>a</sup>	
	Adolescent, n (%)	Parent, n (%)
Just forget	39 (37.9)	23 (22.3)
Am not home	12 (11.7)	5 (4.9)
Hard to swallow pills	11 (10.7)	6 (5.8)
Hate the taste	10 (9.7)	7 (6.8)
Am not feeling well	7 (6.8)	5 (4.9)
Don't like side effects	4 (3.9)	4 (3.9)
Interferes with activity	4 (3.9)	1 (1.0)
Don't think it necessary	3 (2.9)	1 (1.0)
Refuse/defiant	3 (2.9)	4 (3.9)
Ran out/didn't fill	2 (1.9)	1 (1.0)
Can't afford	2 (1.9)	1 (1.0)
Other	2 (1.9)	1 (1.0)

<sup>a</sup>More than one barrier could be endorsed by participants.

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**Table 3****Binary Logistic Regression Predicting Nonperfect Adherence<sup>a</sup>.**

<b>Predictor</b>	<b><math>\beta</math></b>	<b>SE</b>	<b>Wald</b>	<b>OR [95% CI]</b>	<b>P</b>
Days in outpatient clinic visits	0.02	0.01	1.34	1.02 [0.99–1.04]	NS <sup>b</sup>
Relapse status	0.35	0.62	0.31	1.41 [0.42–4.81]	NS
Family social support	-0.14	0.06	5.44	0.87 [0.78–0.98]	.02
Secondary parent overprotection	-0.07	0.04	4.26	0.93 [0.87–1.00]	.04
Future-oriented goals	-2.13	0.90	5.53	0.12 [0.02–0.70]	.02
Constant	3.47	1.13	9.34	32.04	.00

Abbreviations: OR, odds ratio; CI, confidence interval.

<sup>a</sup> Adolescent report of adherence was used: 0 = perfect adherence; 1 = nonperfect adherence.

<sup>b</sup> NS = not significant at  $P < .05$ .