

Who helps and how?

*Examining the relationship between social support and the quality of life of adolescents with chronic illness*

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### Abstract

**Introduction.** Approximately 15% of adolescents in the United States suffer from one or more chronic conditions. And 50% of adolescents with chronic illness do not completely adhere to their treatment regimens, and many report decreased emotional wellbeing. While social support has been widely investigated as a factor related to improved quality of life (QoL) in adults with chronic illness, it is less understood in relation to the adolescent chronic illness population. Therefore, the purpose of this study was to understand how 4 forms of social support – nondirective emotional, nondirective instrumental, directive emotional, and directive instrumental – affect the physical, social emotional, and school QoL of adolescents with chronic illness. It was hypothesized that (1) nondirective emotional support from both parents and friends will have a positive relationship with physical, social, emotional, and school QoL; (2) adolescents will perceive greater nondirective and directive instrumental support from parents than from friends, and greater nondirective and directive emotional support from friends than from parents; (3) parental support will be positively associated with physical QoL; and (4) peer support will be positively associated with psychosocial (i.e. social, emotional, and school) QoL.

**Methods.** Data used in this study came from Robinson, Maslow, Wolbert, Sim, Bickford, Fisher, & Ferris's (2010) The Development of Character for Youth With Chronic Illness Study which utilized a 30-minute web-based questionnaire that was completed by 171 adolescent participants of Victory Junction Gang Camp, a camp for children and adolescents with chronic conditions. In the Robinson et al. (2010) study, quality of life was assessed with the PedsQL™ and social support was assessed with the Social Support for Adolescents Scale.

**Results.** There were no statistically significant relationships between type of social support from friends and quality of life. The only statistically significant finding was a positive relationship between nondirective emotional support from parents and emotional quality of life, when controlling for the covariates of age, race, gender, and physical disability.

**Conclusions.** Implications for research and clinical practice are discussed.

## **Introduction**

Over 15% of adolescents in the United States suffer from one or more chronic health conditions (The Data Resource Center for Child and Adolescent Health, 2012). Adolescents living with chronic illness must learn to manage the complexities of their illness while simultaneously completing crucial developmental tasks. Normal adolescent development is characterized by the tasks of establishing a personal identity, gaining independence from parents, making decisions about the future, developing a sexual identity, and maintaining a positive body image (Zebrack, Chesler, & Kaplan, 2010). The need to manage a chronic illness in addition to completing these developmental tasks places adolescents under a great amount of stress, which puts them at risk for negative outcomes, including emotional problems and treatment adherence challenges (Compas, Jaser, Dunn, & Rodriguez, 2012). For example, adolescents with chronic illness report decreased emotional wellbeing relative to their healthy peers, characterized by poor body image and fears about the future (Wolman, Resnick, Harris, & Blum, 1994). Additionally, several studies have shown that nearly 50% of adolescents with chronic illness do not completely adhere to their treatment regimens (Kyngäs, 2001).

## **Psychological Adjustment**

These negative emotional and physical outcomes fall under a broader umbrella of psychological adjustment problems. Stanton, Collins, and Sworowski (2001) identify five components of positive psychological adjustment to chronic illness: fully mastering illness-management tasks, preserving functional status, maintaining good quality of life, not having a psychological disorder, and maintaining low negative affect. A lack of any of these components can indicate adjustment problems. The evidence that adolescents with chronic illness report decreased emotional wellbeing and poorly adhere to treatment regimens indicates that they face

psychological adjustment challenges that can negatively affect their quality of life. Therefore, it is necessary to address these negative outcomes and determine ways to improve the quality of life of adolescents with chronic illness.

### **Improving Quality of Life**

There have been a number of different approaches studied to determine ways to improve quality of life of adolescents with chronic illness. Some studies have focused on understanding whether there is a relationship between chronic illness and psychopathology (Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980), and some have focused on understanding what impacts disease management ability and how that ability can be improved (Ingersoll, Orr, Herrold, & Golden, 1986). Some have focused on understanding whether effective coping could improve quality of life (Van De Ven, Engels, Sawyer, Otten, & Van Den Eijnden, 2007), and some have used the positive youth development framework to understand how to foster positive outcomes for adolescents with chronic illness (Maslow & Chung, 2013).

The positive youth development framework is a relatively newer approach and is especially notable because of its long-term outlook. It emphasizes the importance of improving quality of life such that positive outcomes are maintained through adulthood as well. According to the positive youth development framework, positive outcomes include greater self-care, academic achievement, positive interpersonal relationships and overall wellbeing. These outcomes are accomplished by helping adolescents to develop competence, confidence, character, social connection, and compassion (Maslow & Chung, 2013).

Social support from parents and friends is a factor that has received much attention for its demonstrated association with greater social connection, self-esteem, and overall wellbeing for

adults with chronic illness (Patel, Peterson, & Kimmel, 2005). However, the impact of social support on the adolescent age group has received less attention.

### **The Relationship Between Social Support and Quality of Life**

Evidence suggests that the source and type of social support matters for adolescents with chronic illness. For example, in the case of adolescents with diabetes, family was found to be the primary source of support for the technical aspects of disease management, such as insulin administration and blood glucose testing. However, family and friends supported exercise and feelings equally (O'Dell, 1997).

Regarding the differential impact of type of social support, existing studies indicate that adolescents with chronic illness perceive certain forms of social support from parents and friends to be positive, while other forms of support from family and friends are perceived as negative (Graetz, Shute, & Sawyer, 2000). This uneven impact of social support highlights the importance differentiating between source and type of social support when investigating quality of life outcomes for adolescents with chronic illness.

In the case of adults with chronic illness, two sets of terms have been used to distinguish forms of social support that affect quality of life: nondirective versus directive support and emotional versus instrumental support. A study by Fisher, La Greca, Greco, Arfken, and Schneiderman (1997) was one of the first to define forms of support that differentially impact health and quality of life outcomes for adults with chronic illness. The study investigated the impact of social support on adults with diabetes. They defined nondirective support as that which cooperates with the recipient and accepts the recipient's feelings without passing judgment (e.g. "What can I do to help you take your medicine?" and "How are you doing?"). They defined directive support as that which takes responsibility of the recipient's tasks and directs the

recipient's feelings (e.g. "You need to take your medicine, so I brought it over for you" and "You should feel proud of yourself"). Nondirective support was found to be associated with good disease management in adults with diabetes, as measured by hemoglobin A1c level (a measure of the amount of blood glucose bound to hemoglobin). A lower hemoglobin A1c level, including levels between six and eight percent, indicated good disease management. Directive support was found to be counterproductive to disease management because it was associated with increased depressed mood, and depressed mood was associated with poor disease management (hemoglobin A1c above ten percent) (Fisher, La Greca, Greco, Arfken, & Schneiderman, 1997).

Following that study, Penninx, van Tilburg, Boeke, Deeg, Kriegsman, & van Eijk (1998) published a study defining two additional forms of social support relevant to adults with chronic illness. Emotional support was defined as that which provides empathy, reassurance, and encouragement (e.g. "You are doing a great job monitoring your blood sugar") - and was found to be associated with an improvement in depressive symptoms in adults with chronic illness. Instrumental support was defined as that which provides physical assistance (e.g. "I will take you to your doctor's appointment") and was associated with increased depressive symptoms in adults with chronic illness.

Although the impacts of directive versus nondirective and emotional versus instrumental support have been distinguished in studies with adults, the impact of the combination of these forms of support from parents and friends on adolescents with chronic illness has not yet been investigated. Additionally, in following the positive youth development model, strong interpersonal relationships are key to quality of life, so it is important to understand how the source and form of social support might affect quality of life for adolescents with chronic illness.

### **The Current Study**

This study addressed two research questions: (1) are physical and psychosocial dimensions of the quality of life of adolescents with chronic illness related to four types of perceived social support: nondirective emotional, nondirective instrumental, directive emotional, and directive instrumental support; (2) do adolescents perceive different levels of parental and peer support across the four dimensions of support, and (3) do the relationships between quality of life and social support differ for support from friends and from parents.

Based on existing literature indicating that directive support is counterproductive to disease management for adults with chronic illness (Fisher, La Greca, Greco, Arfken, & Schneiderman, 1997) and that instrumental support is associated with an increase in depressive symptoms for adults with chronic illness (Penninx, van Tilburg, Boeke, Deeg, Kriegsman, & van Eijk, 1998), it is hypothesized that (1) nondirective emotional support from both parents and friends will have a positive relationship with physical, social, emotional, and school. Additionally, some studies suggest that parents provide more instrumental support, while friends provide more emotional support (Idalski Carcone, Ellis, Weisz, & Naar-King, 2011). Therefore, it is hypothesized that (2) adolescents will perceive greater nondirective and directive instrumental support from parents than from friends, and greater nondirective and directive emotional support from friends than from parents.

Previous research with adolescents with chronic illness also indicates a differential impact of support from parents and friends - specifically that support from parents is associated with better disease management than support from peers, while support from peers is associated with better emotional wellbeing than support from parents (La Greca, Auslander, Greco, Spetter, Fisher, & Santiago, 1995). Therefore, it is hypothesized that: (3) parental support will be

positively associated with physical quality of life and (4) peer support will be positively associated with psychosocial (i.e. social, emotional, and school) quality of life.

## **Methods**

### **Participants**

This study used data collected from 171 adolescents with chronic illness who were attending Victory Junction Gang Camp, a camp for children and adolescents with chronic conditions, as part of The Development of Character for Youth With Chronic Illness Study (Robinson et al., 2010). The average age of participants was 15.3 years old. The sample was ethnically diverse: 57.05% of participants were white, 33.53% were African American, 4.71% were Hispanic, and 4.71% were of other ethnic backgrounds; and 54.12% were male and 45.88% were female. The majority of participants had parents who were highly educated, with 36.83% of participants' parents having attended some college and 43.06% having attended college plus a graduate program. Participants had a range of chronic conditions, including rheumatoid arthritis, diabetes, sickle cell disease, inflammatory bowel disease, neurological disorders, cardiovascular disorders, cancer, cystic fibrosis, or muscular dystrophy.

### **Measures**

Data was collected in the Robinson et al. (2010) study via a 30-minute web-based questionnaire. The Duke Health Institutional Review Board approved the study. Participants were recruited via email invitations that were sent to all of the parents of registered campers prior to the beginning of camp. The invitations asked both parents and adolescents to give consent and for the adolescents to participate in the study, which involved completing the study questionnaire one week before they attended camp. Completion of the questionnaire did not affect the camper's ability to attend camp and staff members at the camp were blinded to camper

participation. Some demographic and descriptive information was collected as part of the questionnaire and other demographics, including age, sex, and medical conditions were collected from the camp charts.

**Assessment of quality of life and social support.** The questionnaire assessed quality of life using the PedsQL™ and social support with the Social Support for Adolescents Scale. The PedsQL™ is a twenty-three-item questionnaire that includes physical (eight items), emotional (five items), social (five items), and school functioning (five items) scales to measure physical, emotional, social, and school quality of life. Responses to the questionnaire use a five-item Likert scale, with each response being a rating from zero to four. Scores from the emotional, social, and school quality of life scales are summed. That sum is then divided by the number of items answered across those three scales, yielding a psychosocial quality of life score. The physical functioning scale score is the score for physical quality of life. Overall quality of life is calculated as the sum of all questionnaire items divided by the number of items answered. Utilization of psychosocial and overall quality of life scores versus the physical, social, emotional, and school quality of life component scores varies in existing literature. For the purposes of the current study, the focus was the physical, emotional, social, and school quality of life scores.

The Social Support for Adolescents Scale is a seventeen-item questionnaire that was adapted from the Social Support Inventory, which has been validated for use in adults. The scale was validated in a study from 2011 of 135 adolescents with chronic illness participating in a summer camp. An exploratory factor analysis yielded four factors from the Social Support for Adolescents Scale: nondirective emotional, directive emotional, nondirective instrumental, and directive instrumental. In the current study, participants completed the Social Support for

Adolescents Scale twice – once in response to support received from parents and once in response to support received from friends.

### **Analysis Plan**

Multiple imputations were used before performing any analyses, in order to account for missing responses in the questionnaire data set. Multiple imputations replace missing values with a set of plausible values (five sets of values in the case of the current study) that account for the uncertainty of the correct value to impute (Rubin, 1987). This increased the number of participants with complete responses for the quality of life and social support measures of interest from an initial 161 to a final 171.

The Development of Character for Youth With Chronic Illness Study (Robinson et al., 2010) adopted a non-categorical approach to chronic illness in which quality of life was investigated across all types of chronic illness rather than by specific illness type. The first step of analysis in the current study was to determine if quality of life differed by illness type, based on the presence or absence of physical disability, indicated by a response of “yes” to the question “Do you have a physical disability?” in the demographics section of the questionnaire.

Two sets of analyses were then undertaken to investigate the relationship between social support and quality of life. First, mean differences in the four dimensions of social support from parents and friends were compared. Second, multiple regression analyses were run to analyze the relationship between the four forms of social support from parents and friends and physical, social, emotional, and school quality of life controlling for age, race, gender, and physical disability.

### **Results**

Comparison of the means of physical, social, emotional, and school quality of life

indicated that there was a significant mean difference in the physical and overall quality of life between adolescents with chronic illness who also have a physical disability (N = 36) and those who do not have a physical disability (N = 135) (Figure 1, Table 1). Therefore, in the subsequent regression analysis, physical disability was included as a covariate.

**Figure 1**

*Mean Quality of Life for Those With and Without Physical Disability*

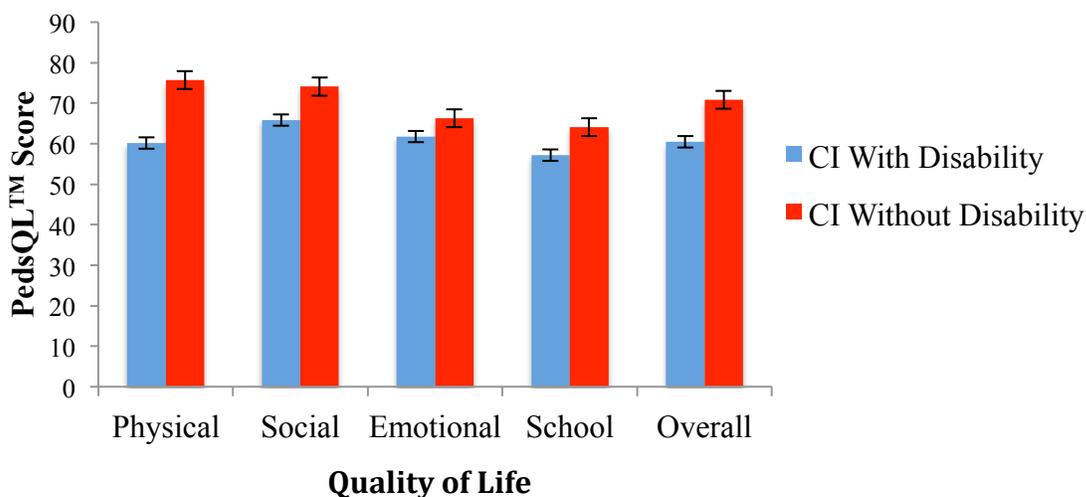


Table 1

*Quality of Life for Those With and Without Physical Disability*

	<u>Physical QoL</u>	<u>Social QoL</u>	<u>Emotional QoL</u>	<u>School QoL</u>	<u>Overall QoL</u>
With Physical Disability	60.16	65.87	61.81	57.15	60.41
Without Physical Disability	75.70	74.08	66.29	64.07	70.82
Difference Between Means	F = 10.88 Std. Err. = 5.09 DF = 30.10 p = 0.0025	F = 2.90 Std. Err. = 5.08 DF = 30.30 p = 0.099	F = 1.09 Std. Err. = 4.48 DF = 69.40 p = 0.30	F = 2.25 Std. Err. = 4.58 DF = 23.70 p = 0.14	F = 7.75 Std. Err. = 3.73 DF = 26.70 p = 0.0097

Comparison of the means of the adolescent’s report of support provided by parents and friends indicated there was not a significant difference in the amount of nondirective emotional support, directive emotional support, or nondirective instrumental support provided by parents and friends. However, parents were perceived to provide significantly more directive instrumental support than friends (Figure 2, Table 2).

**Figure 2**

*Means of the Forms of Social Support from Parents and Friends*

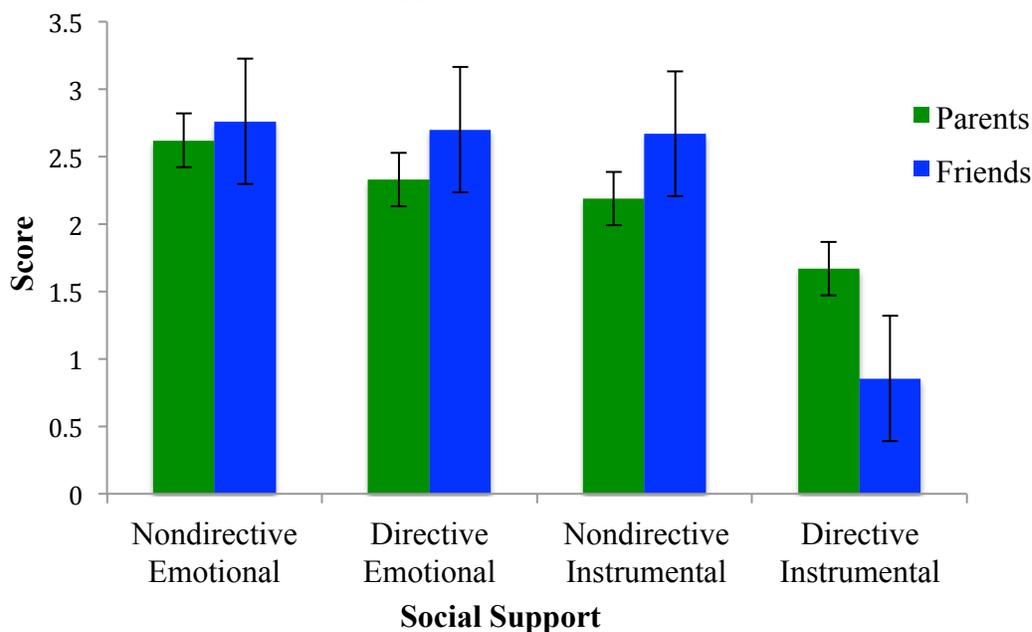


Table 2

*Social Support from Parents and Friends*

	<u>Nondirective Emotional Support</u>	<u>Directive Emotional Support</u>	<u>Nondirective Instrumental Support</u>	<u>Directive Instrumental Support</u>
Parents	2.62	2.33	2.19	1.67
Friends	2.76	2.70	2.67	0.86
Difference Between Means	F = 0.53 Std. Err. = 0.129 DF = 9.4 p = 0.48	F = 2.11 Std. Err. = 0.17 DF = 6.6 p = 0.19	F = 5.44 Std. Err. = 0.18 DF = 5.1 p = 0.066	F = 7.87 Std. Err. = 0.16 DF = 7.7 p = 0.02

Multiple regression analyses were conducted to evaluate the relationship between each of the four forms of social support from parents and each of the four forms of social support from friends in relation to physical, social, emotional, and school quality of life, controlling for age, race, gender, and physical disability [a total of 40 regressions]. Only one significant relationship was found: nondirective emotional support from parents had a statistically significant relationship with emotional quality of life ( $\beta=4.42$ ,  $p=0.02$ ) (Table 3). An interaction effect between physical disability and social support was tested for but was not found to be significant.

Table 3

*Multiple Regression Results*

	Emotional Quality of Life	
	Coef.	$p> t $
Nondirective Emotional Support - Parents	4.42	0.026
Age	-0.219	0.87
Gender	0.408	0.92
Race		
Black	-2.00	0.66
Hispanic	-6.08	0.53
Other	-4.78	0.63
Physical Disability	-5.71	0.226
R <sup>2</sup> of the Model		0.095
Adjusted R <sup>2</sup> of the Model		0.050

### Discussion

These results indicate that the physical and overall quality of life of adolescents with chronic illness who also have a physical disability is poorer than that of adolescents with chronic illness who do not have a physical disability. This finding was consistent with previous evidence that the presence of physical disability is associated with a decreased quality of life for individuals with chronic illness (Livingston, Rosenbaum, Russell, & Palisano, 2007).

The difference in physical and overall quality of life between adolescents with chronic illness who have a physical disability and those who do not brings into question whether future research should take a within-illness approach rather than an across-illness approach. Since physical disability affects quality of life outcomes, it is possible that a within-illness approach may lead to clearer findings regarding the relationship between social support and quality of life.

Furthermore, current studies investigating the quality of life outcomes of adolescents with chronic illness tend to assess quality of life using the broader categories of physical, psychosocial, and overall quality of life. However, it would be advantageous to examine quality of life by including the psychosocial subcategories of social, emotional, and school quality of life. In this way, it might be possible to distinguish relationships that might otherwise be masked, such as the relationship between nondirective emotional support from parents and emotional quality of life that was found.

The results also indicate that the only significant difference in perceived support from parents and friends is that parents provide more directive instrumental support than friends. There is no difference in the amount of nondirective emotional, directive emotional, or nondirective emotional support provided by parents and friends. This finding does not fully support the second hypothesis that stated adolescents will perceive greater nondirective and directive instrumental support from parents and greater nondirective and directive emotional support from friends.

The finding that parents provide more directive instrumental support than friends makes sense in the context of existing literature that indicates support from parents is associated with better disease management than support from peers (La Greca, Auslander, Greco, Spetter, Fisher, & Santiago, 1995). However, further research is needed to understand whether the positive

effect of support from parents on disease management is due to the amount of support provided, or rather the method in which it is provided.

Regression analyses yielded only one significant result: nondirective emotional support from parents is positively related to emotional quality of life. The lack of additional significant findings indicates that the first hypothesis, stating nondirective emotional support from both parents and friends will have a positive relationship with physical, social, emotional, and school quality of life, is not fully supported. This also indicates that the third and fourth hypotheses, stating that parental support will be positively associated with physical quality of life and that peer support will be positively associated with psychosocial (i.e. social, emotional, and school) quality of life, are not supported.

When considering the single significant result that nondirective emotional support is positively related emotional quality of life, it is evident that only 10% of variance in emotional quality of life is accounted for by nondirective support, age, race, gender, and physical disability combined. That indicates that 90% of the variance in quality of life is due to other factors. The research literature indicates that coping skills may also affect the quality of life of adolescents with chronic illness (Penninx, van Tilburg, Boeke, Deeg, Kriegsman, & van Eijk, 1998); therefore, coping skills could be a variable of interest in future research.

### **Limitations**

There are several limitations to these findings. First, there is great variation in the characteristics of illnesses represented in the sample. Some illnesses have more debilitating characteristics and some occur in very specific individuals. For example, Muscular Dystrophy has a strong disability component and occurs primarily in males. It is unclear how the variety of illness characteristics may affect the relationship between social support and quality of life.

Additionally, the sample size of 171 is relatively small and therefore may not have been large enough to display the relationships of interest. The use of multiple imputations to complete some of the missing data may also have affected the visibility of significant results. Finally, the number of regressions completed may mean that a significant result was due to chance, rather than the existence of a relationship between social support and quality of life.

### **Future Directions**

This study provides evidence that adolescents with chronic illness who also have a physical disability face poorer physical quality of life than those without a physical disability. Therefore, research and interventions related to improving the quality of life of adolescents with chronic illness should focus on this disadvantaged group. Interventions should not focus solely on fostering social support in order to enhance quality of life, and rather they should include additional resources, such as methods of coping.

Finally, given that nondirective emotional support from parents is positively related to emotional quality of life, future studies should focus on looking more closely at specific forms of social support and their relationship with psychological constructs, such as depression and self-esteem, since it is possible support is more related to emotional wellbeing than quality of life.

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