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Perceptions of Communication, Family Adaptability, and Cohesion: A Comparison of Adolescents Newly Diagnosed with Cancer and their Parents

Celeste R. Phillips-Salimi, Ph.D., R.N.,

Indiana University, School of Nursing, Indianapolis

Sheri L. Robb, Ph.D., MT-BC,

Indiana University, School of Nursing, Indianapolis

Patrick O. Monahan, Ph.D.,

Indiana University, Division of Biostatistics, Indianapolis

Amy Dossey, B.S.N., R.N., and

St. Vincent Hospital, Department of Neurology, Indianapolis

Joan E. Haase, Ph.D., R.N.

Indiana University, School of Nursing, Indianapolis

Abstract

Purpose—Describe and compare adolescent and parent perspectives on communication, family adaptability and cohesion, as well as relationships among these variables, during the first month of the adolescent's cancer diagnosis.

Methods—Seventy 70 adolescent-parent dyads were enrolled as part of a larger multi-site study. Adolescents ranged in age from 11–19 and 61% were males. Parents were predominately mothers (83%). Dyads were predominately non-Hispanic Caucasian (63%). Measures included the Parent-Adolescent Communication Scale and the Family Adaptability and Cohesion Evaluation Scale (FACES II). Paired *t* tests, Pearson correlations, intra-class correlation coefficients, and multiple linear regression analyses were completed.

Results—Adolescent scores on communication, family adaptability, and cohesion were significantly lower than parent scores. The inter-dyadic agreement between adolescents and parents was low. Communication, family adaptability, and cohesion were examined separately for adolescents and for parents, significant relationships were found. Both adolescent- and parent-perceived communication was significantly associated with family adaptability and cohesion outcomes.

Conclusions—Differences were found in adolescent and parent perceptions of communication, family adaptability, and cohesion. When both adolescents and parents had better perceived communication, it was associated with better perceived family adaptability and cohesion. Results

suggest the development of interventions to enhance adolescent-parent communication could help foster better family adaptability and cohesion which may ultimately impact their psychological adjustment. In addition, understanding the degree to which adolescents and parents disagree on their perceptions, including the results that parents generally have more favorable perceptions, may be a useful starting point when developing interventions.

Keywords

adolescents; cancer; adolescent-parent communication; family adaptability; family cohesion

INTRODUCTION

When adolescents are diagnosed with cancer and begin cancer treatment, both they and their parents experience an increase in stress which can hinder their communication with each other.¹⁻³ Even under the best circumstances, adolescents and their parents often struggle to communicate. Adolescence is a unique, but challenging developmental period that requires parents to make adjustments in their communication in order to support the adolescent's identity formation and role-taking ability – a process referred to as individuation.⁴⁻⁶ When an adolescent receives a diagnosis of cancer and undergoes treatment, the process of individuation is challenged by their uncertainty about the future, interruptions in social activities, and increased dependence on their parents.^{7,8} Parents report trying to manage the situation by taking charge and avoiding emotionally difficult discussion about the cancer in an effort to minimize their adolescent's distress.^{3,9} However, parents' decisions to avoid open communication may be misguided as open and honest communication about the cancer has been shown not to increase distress in children/adolescents with cancer.^{1,9-11} If communication difficulties persist between adolescents and their parents, it could negatively impact the family's adaptability and cohesion during cancer treatment, ultimately leading to negative psychological consequences, such as post-traumatic distress symptoms, in both the adolescent and parents.^{12,13}

According to Olson's Circumplex Model of Marital and Family Systems,¹⁴ effective, open communication facilitates the way in which families adapt and remain cohesive during developmental and situational stresses. Family adaptability refers to the families' ability to change in its leadership, role relationships, and relationship rules. Family cohesion is the emotional bond between family members. Olson and colleagues characterize optimal family functioning as a balance on both adaptability and cohesion. They propose that families who exhibit balanced family adaptability and cohesion have higher levels of positive communication. This relationship has been supported in studies with healthy and ill adolescents and/or their parents.¹⁵⁻²¹

Communication, family adaptability, and family cohesion have been identified as important family factors that can facilitate optimal adjustment in adolescents diagnosed with cancer and their parents.^{22,23} Previous research has focused on examining these variables among adolescent cancer survivors and their parents (i.e. those who completed cancer treatment at least 3 months or more at the time of participation). Two studies have found that adolescent cancer survivors' positive perceptions of communication, family adaptability, and cohesion

are associated with positive post-treatment adjustment and higher quality of life.^{24,25} In contrast, poor perceptions family adaptability and cohesion have been associated with post-traumatic stress symptoms experienced by adolescent cancer survivors and their parents.^{26,27} Despite this evidence, however, no studies have directly examined adolescent-parent communication and its relationship to family adaptability and cohesion during cancer treatment. Since we know these variables contribute to optimal adjustment post-treatment, it is even more important to understand how adolescents and parents perceive these variables during the early phases of treatment. Such information would contribute to our understanding of adolescent and parent perspectives about regarding these important family variables at the time of the adolescent's cancer diagnosis. This information could also help researchers develop interventions to improve communication and family functioning during cancer treatment, ultimately fostering early positive adjustment adolescents with cancer and their parents.

The purpose of this study was to describe and compare adolescent and parent perspectives on adolescent-parent communication, family adaptability, and family cohesion, as well as the relationship among these variables, within the first month of the adolescent's cancer diagnosis. Because adolescent-parent communication is likely to influence family adaptability and cohesion, we used regression models to evaluate the association between communication and adolescent and parent perceptions of family adaptability and cohesion, while adjusting for the effects of age and gender of both the adolescent and parent. We controlled for age because the age range of our sample of adolescents and parents is fairly wide which reflect a range of developmental and life situations differences. We controlled gender because males and females may vary in their perceptions of these family variables. Although the variables are all measured at one point, for brevity we refer to the family functioning (adaptability and cohesion) variables as "outcomes" because they are dependent variables in our models.

Research Questions

- 1 To what extent do adolescents and parents agree on their perceptions of communication, family adaptability, and family cohesion within the first month of the adolescent's cancer diagnosis?

After adjusting for the influences of age and gender of adolescents and parents:

- 2 To what extent is adolescent-perceived communication with their parent associated with four outcomes (adolescent-perceived family adaptability, adolescent-perceived family cohesion, parent-perceived family adaptability, and parent-perceived family cohesion)?
- 3 To what extent is parent-perceived communication with the adolescent associated with the four outcomes?
- 4 To what extent is the agreement between adolescent- and parent-perceived communication associated with the four outcomes?

MATERIALS AND METHODS

Participants

Data were generated from a larger study that evaluated the Resilience in Illness Model, previously referred to as the Adolescent Resilience Model.^{22,28} The sample was accrued from four cancer centers across the United States between 1997 and 2004. Human subjects approval was obtained the Institutional Review Board at all study sites prior to data collection. Eligibility criteria for the adolescent included: (1) newly diagnosed with a childhood/adolescent cancer (i.e., diagnosed with cancer in the past month); (2) between the ages of 11–19; and (3) able to read and speak English. There were no restrictions on the type or stage of cancer; however, adolescents who had cancer with central nervous system involvement were excluded. If an adolescent wanted to participate, one of their parents was also approached. Parents had to be able to read and speak English in order to participate. Newly diagnosed adolescents ($n = 74$) and one of their parents ($n = 73$) were consecutively enrolled in the larger study.

For this secondary analysis, data from the larger study were used to identify matching adolescent-parent dyads. When identifying adolescent-parent dyads, three adolescents were excluded because they did not have a parent who completed the measures. Additionally, two adolescents had both a mother and father complete the instruments; because this study had a lower number of fathers than mothers, the mother's data was dropped to increase the percentage of fathers in the dataset. We also excluded one adolescent-parent dyad from the analysis because the participant too young (10 years old) to be classified as an adolescent. Thus, a total of 70 AYA-parent dyads provided data that were used for this secondary analysis.

Recruitment

A clinical nurse specialist or social worker who worked in the pediatric oncology setting initially approached eligible participants to ascertain interest in participation. If an eligible participant was interested in learning more about the study, a member of the research team provided a more detailed explanation of the study and data collection procedures. After the research team member answered the family's questions about the study, written informed consent/assent was obtained.

Data Collection Procedures

After informed consent/assent was obtained, the adolescent and one of their parents were each asked to separately complete a booklet of questionnaires that included the instruments used in this analysis. The adolescent's booklet included more questionnaires than the parent booklet. Completion of the booklet took approximately 45 to 75 minutes for the adolescent and 10 to 15 minutes for the parent. Because the adolescent booklet took more time to complete, a monetary incentive of \$10.00 was given to the adolescents after they completed the booklet. The adolescent and parent was asked to complete the booklet while they were in the hospital or clinic. However, if an adolescent was unable to finish the booklet during the hospital stay or clinic visit, they were given the opportunity to take the booklet home and return it by mail, using a study-provided stamped and addressed envelope. For participants

who completed the booklet in the hospital/clinic setting, a data collector was available to answer questions about format or meanings of words. For participants who took the booklets home, arrangements were made for a follow-up phone call to answer questions.

Measures

Adolescent-parent communication was measured using the Parent-Adolescent Communication Scale (PACS).²⁹ This 20-item instrument measures adolescent and parent perceptions of the quality of communication they have with one another on a 5-point Likert scale. Adolescents and parents filled out separate instruments. Adolescents completed a separate instrument for both their mother and for their father. In this secondary analysis, however, we only used data that corresponded to the gender of the parent who participated in the study. So in other words, if the adolescent-parent dyad consisted of a father, then the adolescent's perception of their communication with their father was used. Parents filled out the instrument about their communication with their adolescent. Higher scores represent better adolescent-parent communication. The reported alpha coefficient for this instrument is .88 and was .83 in this study.²⁹

Family adaptability and cohesion were measured using the Family Adaptability and Cohesion Evaluation Scales (FACES-II).³⁰ This instrument contains 30 items on a 5-point Likert scale that measures respondents' perceptions of family adaptability (14 items) and cohesion (16 items). Higher scores indicate greater family adaptability and cohesion. The reliability and construct validity of this instrument has been well established.³⁰ In this study, alpha coefficients were .90 (adaptability) and .78 (cohesion) for the adolescent and .89 (adaptability) and .84 (cohesion) for parents.

Covariates used were age and gender for both the adolescent and parent. Ages of the adolescent and parent were reported as continuous variables and gender was coded as: 0 = male, 1 = female.

Analysis

Descriptive statistics were used to describe demographics of the respondents. Before answering the research questions using models adjusted for covariates (adolescent and parent age and gender), we used Pearson correlations to evaluate the associations between variables. Paired *t* tests were performed to evaluate the extent of mean differences between adolescents and parents regarding their perceptions of adolescent-parent communication, family adaptability, and family cohesion. The degree of agreement between adolescent and parents was assessed with the intra-class correlation coefficient (ICC) computed using the agreement version of the index from the two-way random effects model.

Multiple linear regression analyses were employed to examine the extent to which adolescent perceptions of communication with parent, and parent perceptions of communication with the adolescent, respectively, were associated with each of the four outcomes, after adjusting for adolescent and parent age and gender. Additional linear regression analyses were conducted to examine the extent to which the agreement between adolescent and parent perceptions of communication with each other was associated with the

four outcome variables. Agreement on communication was measured as absolute agreement computed as the absolute value of the difference score between the adolescent and parent.

RESULTS

Demographics

Sample demographics are as follows. Adolescents ranged in age from 11–19 ($M=14.8$, $SD=1.7$) and 61.4% were male. Parents ranged in age from 31–55 ($M=41.9$, $SD=6.3$), and 82.9% were female. Although most (63%) of the participants were non-Hispanic Caucasian, other ethnic groups were fairly well represented: Hispanic (11%), Asian (6%), Native American (6%), African American (4%), other (3%).

Preliminary Correlations for Research Questions

Correlations were examined to describe the bivariate strength of relationships between communication and each of the four outcomes: adolescent- and parent-perceived family adaptability and adolescent- and parent-perceived family cohesion (see Table 1). These correlations indicate that adolescent and parent-perceived communication was significantly associated with the outcomes, for both the adolescent and parent, which indicates that perceived communication may play an important role in outcomes. Furthermore, the outcome variables of family adaptability and family cohesion were highly correlated, as expected; nevertheless, substantial variance in one of the outcomes is not explained by the other outcome, supporting the notion that the outcomes are unique constructs deserving to be studied in separate models, as we did here.

All correlations in Table 1, Parts A and B were significant at the $p<0.01$ level. The correlations on the diagonal of Table 1, Part C provide an approximate examination of the agreement between the adolescent and parent for each construct, although agreement was assessed more formally with the ICC below in research question 1. The off-diagonal correlations demonstrated significant associations between adolescents and parents in regards to the constructs, These bivariate relationships are explored more rigorously below in research questions 2 and 3, for which models were used to adjust for potentially confounding covariates of age and gender of the adolescent and parent reporting their perceptions.

Research Question 1

Means and standard deviations of adolescent and parent responses are displayed in Table 2. Adolescents indicated lower mean scores on perceptions of family adaptability ($p=0.001$), family cohesion ($p=0.001$), and adolescent-parent communication ($p<0.001$) than their parents. Effect sizes ranged from 0.40–0.57. To determine the extent of agreement between the adolescent-parent dyads' perceptions of family adaptability, cohesion, and communication, ICCs were estimated. Adolescents and parents showed their highest agreement on perceptions regarding family cohesion ($ICC=.517$) and their lowest agreement on perceptions about communication with each other ($ICC=.310$).

Research Question 2

Table 3 displays the regression models, with adolescent-perceived communication with their parent as the main independent variable. Results indicated that after adjusting for demographic variables (age and gender of adolescent and parent): (1) Poorer adolescent-perceived communication with the parent was significantly ($p<0.001$) associated with lower adolescent-perceived family adaptability. (2) Poorer adolescent-perceived communication with parent was significantly ($p<0.001$) associated with lower adolescent-perceived family cohesion. (3) Poorer adolescent-perceived communication with the parent was significantly ($p=0.007$) associated with lower parent-perceived family adaptability. (4) Poorer adolescent-perceived communication with the parent was significantly ($p<0.001$) associated with lower parent-perceived family cohesion. In each regression model, there was a significant increase in the total variance explained in demographics only model to the model with communication and demographics as shown in Table 3.

Research Question 3

Table 4 displays the regression models, with parent-perceived communication with their adolescent as the main independent variable. Results indicated that after adjusting for demographic variables (age and gender of adolescent and parent): (1) Poorer parent-perceived communication with the adolescent was significantly ($p=0.003$) associated with lower adolescent-perceived family adaptability. (2) Poorer parent-perceived communication with adolescent was significantly ($p=0.005$) associated with lower adolescent-perceived family cohesion. (3) Poorer parent-perceived communication with adolescent was significantly ($p=0.002$) associated with lower parent-perceived family adaptability. (4) Poorer parent-perceived communication with adolescent was significantly ($p<0.001$) associated with lower parent-perceived family cohesion. In each regression model, there was a significant increase in the total variance explained in demographics only model to the model with communication and demographics as shown in Table 4.

Research Question 4

Models were estimated for which adolescent and parent absolute difference scores on perceived communication were the primary independent variable (not shown in tables). These absolute difference scores provided the degree of agreement (i.e., lower scores) or disagreement (i.e., higher scores). Equal scores for adolescents and parents would result in an absolute difference score of 0, which represents perfect agreement. Maximally disparate scores for adolescent and parent would result in an absolute agreement difference score equal to the maximum score of the original scale (e.g., communication has a maximum score of 100), which represents perfect disagreement. The amount of disagreement between the adolescent and parent in regard to perceived communication with one another showed: (1) a significant association with adolescent-perceived family cohesion ($p=0.003$); (2) a marginal association with adolescent-perceived family adaptability ($p=0.084$); and (3) non-significant associations with parent perceptions of family cohesion ($p=0.586$) and adaptability ($p=0.659$).

DISCUSSION

Results demonstrate that adolescents and their parents had significantly different perceptions of communication, family adaptability, and cohesion within the first month of the adolescent's cancer diagnosis; with adolescents perceiving these variables to be significantly poorer than their parents. These findings are consistent with other studies.^{15,17,20,21,31}

Although differences in these perceptions are similar to non-cancer adolescents and their parents, it is likely these differences could be problematic for the family as the adolescent with cancer progresses through treatment. Given that adolescent cancer survivors perceptions of family adaptability and cohesion have been found to be strongly related to post-treatment psychological adjustment,^{24–26} development of interventions to strengthen these factors during treatment would likely have a positive impact on adjustment during treatment and survivorship. In order to develop such interventions, we need a better understanding of how adolescent and parent perceptions of these variables may change over time. Longitudinal data may indicate how these perceptions relate to the long-term health outcomes of adolescents with cancer and their parents, so we recommend that future research focus more explicitly on monitoring adolescent and parent perceptions of these variables from diagnosis through long-term survival.

In this study, adolescents and parents had low to moderate levels of agreement in their perceptions of communication, family adaptability, and cohesion. In regards to adolescent-parent communication, our sample's level of agreement was lower than the level of agreement found in a study of non-cancer adolescents and their parents; but slightly higher for family adaptability and cohesion.¹⁵ The lower level of agreement in perceptions of adolescent-parent communication is particularly concerning because communication has been established as a key factor related to optimal family adaptability and cohesion,¹⁵ and is also associated with resilience and quality of life outcomes of adolescents with cancer.²² Communication was also significantly associated with all four outcome variables (i.e., adolescent-perceived family adaptability, adolescent-perceived family cohesion, parent-perceived family adaptability, and parent-perceived family cohesion). For example, as adolescent scores for communication decreased, both adolescent and parent scores for family adaptability and cohesion decreased. The same was true when parent-perceived communication was the main independent variable. Developing interventions to help improve adolescent and parent perceptions of their communication with one another is likely to foster a greater sense of family adaptability and cohesion, which may ultimately influence the positive adjustment, resilience, and quality of life of adolescents with cancer.^{22,24,25}

The results of this study extends previous research by providing evidence of adolescent and parent perceptions of communication, family adaptability, and cohesion within the context of the adolescent's cancer diagnosis. Few studies have examined the influence of individual family members' perceived communication on their own or on another family members' perceived family adaptability and cohesion as we did here;^{14,15} thus, our results extend the knowledge in this area and support the importance of fostering better communication within families.¹⁵ Our findings also support the need for a dyadic approach to adolescent and parent-directed communication interventions to help strengthen communication, family adaptability, and cohesion to facilitate positive behavioral health outcomes.

Lastly, the extent of agreement between adolescent- and parent-perceived communication was only associated with the adolescent's perceived outcomes. Thus, the degree of agreement on perceived communication may affect adolescent outcomes more than parent outcomes; however, an experimental design would be needed to examine the causal effects.

The study is not without limitations. First, data from this study, gathered between 1994 and 2004, are not very current. While it is not likely that changes in treatment would alter adolescent and parent perceptions of family around the time of diagnosis, it is possible. Second, no conclusions can be made about the long-term impact of the differences in adolescent and parent perceptions found in this study because the analysis was cross-sectional. Third, parent data were only gathered from one available parent; including both parents in future research studies would provide a better description of the variables. Despite these limitations, this study provides novel information about adolescent-parent communication, family adaptability, and cohesion during the early phases the cancer diagnosis for adolescents and their parents.

CONCLUSION

Our findings indicate that newly diagnosed adolescent cancer patients and their parents differ in their perceptions of communication, family adaptability, and cohesion during the first month of the adolescent's cancer diagnosis. Since perceived communication was associated with all four outcome variables of adolescent and parent perceived family adaptability and cohesion, developing interventions to enhance adolescent-parent communication holds promise to impact adolescent and parent perceptions of family adaptability and cohesion. Additionally, understanding the degree to which adolescents and parents disagree on their perceptions, including the results that parents generally have more favorable perceptions, may be a useful starting point when developing interventions.

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Table 1

Pearson Correlations

<u>Part A. Adolescent with Cancer Perceptions</u>			
	<u>Family Adaptability</u>	<u>Family Cohesion</u>	
Family Cohesion	.713 **	–	
Communication with Parent	.463 **	.657 **	
<u>Part B. Parent Perceptions</u>			
	<u>Family Adaptability</u>	<u>Family Cohesion</u>	
Family Cohesion	.740 **	–	
Communication with Adolescent	.335 **	.422 **	
<u>Part C. Adolescent and Parent perceptions</u>			
	<u>Parent Perceptions</u>		
<u>Adolescent Perceptions</u>	<u>Family Adaptability</u>	<u>Family Cohesion</u>	<u>Communication with Adolescent</u>
Family Adaptability	.420 **	.368 **	.286 *
Family Cohesion	.392 **	.517 **	.217 *
Communication with Parent	.302 *	.338 **	.310 *

*
 $p < 0.05$;

**
 $p < 0.01$

Table 2

Comparison between Adolescent with Cancer and Parent Perspectives

	Adolescent		Parent		Effect Size	<i>p</i>	Intra-Class Correlation coefficient	<i>p</i>
	M (SD)	M (SD)	M (SD)	M (SD)				
Family Adaptability	47.74 (7.78)	51.23 (7.93)	0.44	.001	.420	<.001		
Family Cohesion	57.84 (10.71)	61.87 (9.66)	0.40	.001	.517	<.001		
AYA-Parent Communication	71.63 (11.70)	78.13 (11.04)	0.57	<.001	.310	.004		

Table 3

Regression Models with Adolescent-Perceived Communication as Main Independent Variable

	Model with demographics only	Model with demographics and communication	
	R Square	R Square	Adolescent-Perceived Communication with Parent <i>B¹/p-value</i>
Adolescent-Perceived Family Adaptability	.140	.365	.486/<.001
Adolescent-Perceived Family Cohesion	.104	.537	.674/<.001
Parent-Perceived Family Adaptability	.052	.156	.330/.007
Parent-Perceived Family Cohesion	.117	.266	.396/.001

I standardized regression coefficient shown. The p-value for communication is from the partial t-test of the significance of communication adjusted for demographic variables, and is equivalent to the test of whether the increase in R Square from the demographic only model to the model with communication and demographics is significant. Demographics were: gender and age of adolescent, and gender and age of parent.

Table 4

Regression Models with Parent-Perceived Communication as Main Independent Variable

	Model with demographics only	Model with demographics and communication	
	R Square	R Square	Parent-Perceived Communication with Adolescent B^1/p -value
Adolescent-Perceived Family Adaptability	.140	.251	.338/.003
Adolescent-Perceived Family Cohesion	.104	.208	.328/.005
Parent-Perceived Family Adaptability	.052	.182	.365/.002
Parent-Perceived Family Cohesion	.117	.296	.429/<.001

¹ standardized regression coefficient shown. The p-value for communication is from the partial t-test of the significance of communication adjusted for demographic variables, and is equivalent to the test of whether the increase in R Square from the demographic only model to the model with communication and demographics is significant. Demographics were: gender and age of adolescent, and gender and age of parent.