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The Patient–Provider Relationship in Adolescent Oncology: An Exploratory Factor Analysis of a Thirteen Item Self-Report Measure

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ABSTRACT

Purpose: The patient–provider relationship has been understudied in adolescents with cancer. The current study describes an exploratory factor analysis of a patient–provider relationship self-report measure developed for use in adolescent oncology.

Methods: A self-report measure was included in an iPad/tablet survey delivered to 102 adolescent cancer patients (diagnosed between the ages of 10 and 20). Principal factor analysis with promax rotation and a three-factor structure was specified.

Results: The final solution identified three underlying dimensions of the patient–provider relationship– Supporting Independence (69.7% variance explained; Cronbach's α = .89), Family-Centered Communication (50.0% variance explained; Cronbach's α = .73), and Respectful Relationships (40.1% variance; Cronbach's α = .66).

Discussion: The current measure highlights the unique developmental place of adolescent cancer patients in their preference for aspects of both patient-centered and family-centered care. The current analysis begins to fill the need for adolescent-tailored measurement to assess the patient–provider relationship in this population.

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IMPLICATIONS AND CONTRIBUTION

The patient-provider relationship may provide an important scaffolding relationship for adolescent cancer patients, but valid measures to assess this relationship are lacking. The 13-item self-report measure was validated for adolescent cancer patients and identified three dimensions of the patientprovider relationship: Supporting Independence, Family-Centered Commu-Respectful nication, and Relationships.

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Adolescents are transitioning from the dependence of childhood to the independence of adulthood, and the patient-provider relationship may provide an important scaffolding relationship within the healthcare setting. Our ability to understand the best model for this relationship, however, is inhibited by a lack of tailored measurement for the adolescent healthcare setting. Adolescent cancer patients provide a valuable starting point to examine the patient-provider relationship because they feel out of place in the oncology setting and report many unmet needs [1]. The Institute of Medicine prioritized the patient-provider relationship as an important mechanism to increasing patient engagement, a process that may help alleviate some of adolescents' concerns [2]. However, the recommendations of the Institute of Medicine [2] do not consider variation in developmental stage, leaving adolescents and their providers with little guidance on how to structure the patient-provider relationship in order to foster patient engagement and improve quality of care.

Patient-centered care [3] and family-centered care [4] are successful patient—provider relationship models for use in adults and children, respectively. Even with several overlapping constructs, these two models do not provide a clear picture of the preferences of adolescent cancer patients who often present themselves as somewhere between children and adults [5]. Therefore, we detail the development and evaluation of a 14-item measure of the patient—provider relationship for use with adolescent cancer patients.

Methods

A sample of 102 adolescent cancer patients completed a modified patient-provider relationship measure as part of a larger study examining quality of care. We defined adolescent cancer patients as individuals in their second decade of life and diagnosed between the ages 10 and 20 to capture patients in the middle of adolescence as well as those transitioning in and out of this developmental stage [6]. Eligible participants were at least 3 months from diagnosis, and received treatment that included chemotherapy or radiation (Table 1). The research team approached 111 adolescents at two pediatric oncology clinics, and 102 completed informed consent and the survey during a scheduled clinic visit using an iPad/tablet (Participation Rate: 91.9%). Study methods received Institutional Review Board approval.

Ten items from the Give Youth a Voice questionnaire [7], a measure of teen-centered care, and four items from the Measure of Processes of Care [8], a measure of family-centered care, were modified to create one 14-item measure (Table 2). This modification is necessary because the adolescent development stage is characterized by constructs found in both patient-centered [3] and family-centered [4] care. Items similar across the two measures were combined into one item and re-worded, as appropriate, to elicit the adolescents' perspective. Response options were modified (from a 7-point scale: A lot, ++++, +++, Sometimes, ++, +, Never, and Does Not Apply to Me) based on feedback during pilot testing with four adolescents from a local K-8 school and the surrounding neighborhood (age range 10–17 years). Participants were asked to respond to the items using a 4-point scale: 1 = Never, 2 = Sometimes. 3 = Most of the time. 4 = All the time. Participants were also able to select "Does Not Apply to Me."

The measure was evaluated using principal axis factor analysis (PA), an analytic method that allows us to understand how the items are related to each other. The assumptions for PA and sample size were satisfied (Bartlett's Test of Sphericity: X^2 (91) = 606.01,

Table 1

Descriptive characteristics of adolescent cancer patients (N = 102)

Adolescent characteristic (N = 102)	N (%)
Highest grade in school completed	
5	11 (10.8)
6	2 (2.0)
7	7 (6.9)
8	10 (9.8)
9	16(15.7)
10	15 (14.7)
11	15 (14.7)
High school graduate	13 (12.7)
Some college courses	13 (12.7)
Patient's race/ethnicity	
American Indian/Alaska Native	2 (2.0)
Asian	4 (3.9)
Black or African American	8 (7.8)
Hispanic/Latino	27 (26.5)
White	61 (59.8)
Gender	
Male	61 (59.8)
Female	41 (40.2)
Primary cancer diagnosis	
Leukemia/Lymphoma	60 (58.8)
Central nervous system (CNS) Tumors	5 (4.9)
Bone tumors	21 (20.6)
Soft tissue and Kaposi sarcoma	8 (7.8)
Germ cell cancer	5 (4.9)
Other	2 (2.0)
Treatment	
Chemotherapy	100 (98.0)
Radiation	43 (42.2)
Surgery	54 (52.9)
Bone marrow transplant	8 (7.8)
Other (Oral medication)	1 (1.0)
Treatment status	(0)
Active treatment	57 (55.9)
Completed treatment	45 (44.0)
Recurrence status	20 (10 C)
Recurrence	20 (19.6)
No recurrence	82 (80.4)
Current age, M (SD)	15.63 (2.88)
Age at diagnosis, M (SD)	13.75 (3.12)

p < .001; Kaiser-Meyer-Olkin Measure of Sampling Adequacy: .85; Communalities > .30). Using listwise deletion, 97 participants were retained in the final model, and all analyses were conducted using StataSE 14 (College Station, TX).

Results

PA factor analysis with varimax rotation, both specifying and not specifying the number of underlying factors, was conducted but results suggested that factors were correlated (items loaded on more than one factor above the cutoff criteria of .4; results not shown). Therefore, the final solution utilized promax rotation to allow the factors to be correlated, specified a three-factor structure, and retained 13 items.

The proportion of the variance explained by the first factor was 69.7%, 50.0% for the second factor, and 40.1% for the third factor (Table 2). Table 2 also displays the factor loadings for the obliquely rotated factors. One item ("Allow you to answer questions") was eliminated because it did not meet the minimum criteria of a factor loading > .4. The final solution identified three factors (Cronbach's α : Supporting Independence = .89; Family-Centered Communication = .73; Respectful Relationships = .66; Overall Measure = .88). Supporting Independence assesses direct communication between

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