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An evaluation of two decision-making scales for children with life-limiting illnesses

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Abstract

Purpose—Annually, about 500,000 children are coping with life-limiting illnesses. Many of these children could benefit from pediatric palliative care which provides supportive services. These services can also aid parents in decision making. In order to measure the effect of pediatric palliative care programs on decision making, a valid and reliable tool must be identified. This study aims to validate the psychometric properties of the Decisional Conflict Scale (DCS) and the COMRADE instruments for children with life-limiting illnesses.

Methods—Analyses were conducted using survey data collected from 266 parents whose Medicaid enrolled children have life-limiting illnesses.

Results—Results of the analyses suggest that the DCS has better psychometric properties for measuring decision making within the population of children with life-limiting illnesses than the COMRADE.

Conclusion—Pediatric palliative care programs should use the DCS to measure the effectiveness of services aimed at supporting families with high levels of decisional conflict.

Keywords

decision-making; paediatrics; validation

Introduction

Each year in the United States about 500,000 children are coping with life-limiting illnesses.^{1–4} Evidence suggests that these children have unmet psychosocial and supportive

needs and there is a growing interest to address these needs by developing comprehensive programs.^{5–9} Experts from the American Academy of Paediatrics (AAP) and the Institute of Medicine (IOM) recently released reports calling for the integration of pediatric palliative care into ongoing medical management from the point of diagnosis to the end of life.^{10,11} To answer that call, a more appropriate model of integrated pediatric palliative care was developed. Since 2005, Florida and Colorado have developed and implemented this model of care for publicly insured children.¹²

Making a decision is one of the most important events encountered by parents of children with life-limiting illnesses who want to address their unmet needs through different treatment regimens or programs.^{13–15} It is common that children, parents and physicians must make decisions throughout the course of the children's illnesses. This is especially important given the fact that evidence-based medicine usually fails to identify one treatment as clearly superior because each of the alternatives is associated with benefits and risks.¹⁶ However, very few studies have investigated the process and outcomes of decision-making for children with life-limiting illnesses.

Promoting shared decision-making among patients, caregivers and doctors can better inform patients about the risks and benefits of health care interventions and offer them an opportunity to make an informed choice.¹⁷ Evidence suggests that compared to their counterparts, patients who engaged in shared decision-making are associated with greater patient–doctor communication and higher satisfaction with their doctors,^{18,19} improved adherence with treatment regimes^{20,21} and a greater sense of personal control and self-esteem.^{18,22} In addition, shared decision-making is associated with better quality of life or self-reported health status.^{23,24}

Shared decision-making models emphasise three major components: information exchange, deliberation and agreement about decisional control.²⁵ To date, many instruments have been developed to measure these different components.²⁶ Among these instruments, the Decisional Conflict Scale (DCS) has been used with a variety of populations including general cancer patients, breast cancer patients and patients at the end of life.^{27–29} The DCS focusses on decisional conflict associated with personal uncertainty in making a choice, perceptions of modifiable factors contributing to that uncertainty and the perception of the quality of the decision-making process and the decision made.³⁰ In contrast to the DCS, the Combined Outcome Measure for Risk Communication and Treatment Decision-Making Effectiveness (COMRADE) is a well-known instrument for measuring the degree of patients' involvement and participation in shared decision-making.³¹ This instrument emphasises the concepts of risk communication and decision-making effectiveness and was developed to be applied across a range of clinical conditions. Therefore, the DCS and the COMRADE measure both the process and outcomes of decision-making. Few studies exist that are focused on paediatric end of life decision-making,^{32–34} and none validate a decision-making tool.

Given the lack of appropriate instruments for measuring shared decision-making for parents of children who have life-limiting illnesses, the DCS and COMRADE appear to be useful alternatives. However, no information exists about their validity and reliability. The primary purpose of this study was to evaluate the psychometric properties of the DCS and COMRADE using a sample of parents whose children have life-limiting illnesses. The following psychometric properties were evaluated: construct validity, scale reliability, item-domain convergent and discriminant validity and known-groups validity. Information derived from this study will be crucial for recommending an instrument to monitor the effectiveness of pediatric palliative care programs in providing decision-making support.

Methods

Sample

To validate the DCS and COMRADE instruments, we had to identify a sample of children that had life-limiting illnesses. Florida's guidelines for pediatric palliative care admission were used because at the time of this study, Colorado's guidelines had not been developed.³⁵ The reader is referred to Knapp *et al.*³⁵ for a list of diagnoses codes that are eligible for Florida's paediatric palliative care program. Administrative data were queried to identify children that had diagnoses which would make them eligible for the program. All children in the study were aged 1–18 years and enrolled in Medicaid. From the group of children with life-limiting illnesses, a primer letter was then sent to a random sample of 936 parents. Telephone surveys were conducted in English and Spanish between November 2007 and April 2008. Four hundred eighty-nine of the potential subjects had invalid contact information. Overall, 266 surveys were completed and the response rate was 54.4%. The University of Florida's Institutional Review Board approved this study.

Measures

The DCS consists of 16 items which measure five domains relevant to decision-making: uncertainty, informed feeling, values clarity, support and effective decision-making. The response categories for each item are 'strongly disagree', 'disagree', 'neither agree nor disagree', 'agree' and 'strongly agree'. The domain scores are calculated by summing item scores in a specific domain and then linearly transforming them to a 0–100 scale, with 0 for the lowest decision conflict and 100 for the highest.

The COMRADE consists of 20 items which measure two domains of decision-making: satisfaction with communication and confidence in decision. The response categories for each item are 'strongly disagree', 'disagree', 'neither agree nor disagree', 'agree' and 'strongly agree'. The domain scores are calculated using the algorithms of factor analysis provided by the developer, with 0 for the lowest effectiveness in shared decision-making and 100 the highest.

Information about parent's trust in their children's physicians and parent's personality traits were collected to validate the DCS and COMRADE. Prior evidence has shown a direct, significant relationship between trust in physician and patient confidence in participation and in decision-making.^{36–38} The Wake Forest Physician Trust Scale (WFPTS) was used to assess the extent to which the parent had confidence in the dependability, knowledge and reliability of the information provided by their children's physicians.^{39,40} The WFPTS is a 10-item unidimensional scale and the overall trust score was calculated by summing the score from each item, with 0 for the lowest physician trust to 100 the highest. A median split was created to classify parents who reported higher trust in their children's physicians (top 50th percentile) versus lower trust (bottom 50th percentile). After receiving permission from the instrument's authors, slight changes were made to the wording of the DCS, COMRADE and WFPTS to ensure that parents knew the questions were about their children's health care and not their own health care.

Parents' personality traits were collected for validating the DCS and COMRADE because evidence suggests that positive personality traits such as increased conscientiousness and openness to experiences are associated with preferences for an active role in decision-making.⁴¹ The Ten-Item Personality Inventory (TIPI) was used to measure parents' personality traits.²⁹ The TIPI is a 10-item scale measuring five personality traits, which are extraversion, agreeableness, conscientious, emotional stability and openness to experiences. For each item, the response categories are 'disagree strongly', 'disagree moderately', 'disagree a little', 'neither agree nor disagree', 'agree a little', 'agree moderately' and 'agree'.

strongly'. The domain score is calculated by summing scores of items in a specific domain, with a range from 1 (lowest level of personality trait) to 14 (highest). A median split was created to classify parents who have higher level of personality traits (top 50th percentile) versus lower level of personality traits (bottom 50th percentile). Demographic data including the children's age, gender, race/ethnicity and parents' education background were also collected.

Analyses

Descriptive analyses were performed to estimate the mean, median and standard deviation of the domain scores for both instruments. In addition to the descriptive analyses, the following psychometric analyses were conducted: scale reliability, construct validity, item-domain convergent/discriminant validity and known-group validity.⁴²

Scale reliability

To measure scale reliability, known as internal consistency, Cronbach's alpha coefficients were estimated to indicate the degree to which items of the same domain yield consistent results. Alpha coefficients above 0.7 were deemed acceptable for the purpose of group comparisons.⁴²

Construct validity

To measure construct validity, a confirmatory factor analysis was performed to examine how the constructs of the DCS and the COMRADE correspond to the scale structure as designed. The degree to which factorial structures of DCS and COMRADE can be well replicated in the population of children with life-limiting illnesses was tested. Two indicators were used to determine the goodness of model fit to the data: the comparative fit index (CFI) and root mean square error of approximation (RMSEA). Values of CFI > 0.9 and RMSEA < 0.06 were used to indicate a satisfactory goodness of fit.⁴²

Item-domain convergent/discriminant validity

Item-convergent and discriminant validity measures whether the designed items capture the concept the corresponding domains intend to measure. Pearson's correlation coefficient was used to examine item-domain convergent/discriminant validity. Specifically, convergent validity estimates the correlation between the score of a specific item with the score of the corresponding domain. Discriminant validity examines the correlation of the score of a specific item with the score of the other domains. To be satisfied with the convergent and discriminant validity, correlation coefficients larger for convergent validity as compared to discriminant validity should be observed.

Known-groups validity

Known-groups validity was used to examine the extent to which the instruments discriminate between external groups that are significantly associated with decision-making. Both scales should be sensitive enough to detect underlined differences between parents with higher and lower trust in their children's physician and between parents with higher and lower levels of a personality trait.

Mplus version 5.1 was used to perform construct validity and STATA version 10.0 was used to perform the remaining analyses.

Results

Sample characteristics

Table 1 shows the characteristics of the sample. Fifty-five percent of the respondent's children were male and the majority of respondent's had graduated from high school (35%) or had some college (43%). Race/ethnicity of the respondents was as follows: white, non-Hispanic, 41%; black, non-Hispanic, 24%; and Hispanic, 30%. Most respondents were married (49%). Although not shown in Table 1, mean age of respondents was 43 years old (standard deviation = 11.5) and mean age of the respondent's children was 12 years old (standard deviation = 5.5).

Domain scores

Table 2 shows the distribution of DCS and COMRADE domain scores. For the DCS, the mean scores of all domains were skewed to the right, implying a greater proportion of participants reported less decisional conflict. For the COMRADE, the mean scores of the two domains were skewed to the left, implying that a greater proportion of participants reported higher satisfaction with risk communication and confidence in decision-making.

Scale reliability

As shown in Table 3, Cronbach's alpha coefficients suggest that both the DCS and the COMRADE demonstrated acceptable internal consistency reliability (>0.84 for the DCS and >0.93 for the COMRADE).

Item-domain convergent/discriminant validity

Table 3 also shows item-domain convergent/discriminant validity. For the DCS, the Pearson's correlation coefficients suggest that convergent/discriminant validity was satisfied for the domain of informed feeling and was marginally satisfied for the domains of values such as clarity, support and effective decision. By contrast, item-domain convergent/discriminant validity was not supported for the domain of uncertainty (0.66–0.80 and 0.60–0.82, respectively).

For the COMRADE, Pearson's correlations suggest that convergent/discriminant validity was not supported for the domain of risk communication (0.59–0.85 vs 0.57–0.75, respectively). However, item-domain convergent/discriminant validity was satisfied for the confidence in decision-making domain (0.74–0.85 vs 0.57–0.77, respectively).

Construct validity

Although not shown in the tables, findings from confirmatory factor analysis suggest that construct validity was more acceptable for the DCS as compared to the COMRADE. For the DCS, the CFI was 0.96, which is an acceptable level of fit. However, the RMSEA was 0.20, which did not meet the acceptable level of fit (<0.06). For the COMRADE, findings from the confirmatory factor analyses suggest that the data failed to replicate the hypothesized two-factor structure of the COMRADE. The CFI was 0.79, which is less than the acceptable level. The RMSEA of 0.59 also did not meet the acceptable level. The results suggest that the constructs of the COMRADE do not correspond to the anticipated scale structure.

Known-groups validity

Tables 4 and 5 show the known-groups validity of the DCS and the COMRADE associated with trust and personality. In general, known-groups validity of the DCS is superior to the COMRADE. Using trust in physician as the known groups, parents who reported more trust with their children's physicians were more likely to report less decisional conflicts than

parents who reported less trust ($P < 0.001$) across all domains of the DCS. Likewise, using personality traits as the known groups, parents who reported higher levels of four of the personality traits (more agreeable, more conscientiousness, emotional stability and openness to experiences) were more likely to report less decision conflicts as measured by the DCS than parents who had lower levels of the same personality trait ($P < 0.05$).

Comparatively, the COMRADE showed mixed results for the known-groups validity. Using trust in physician, parents who reported more trust with their children's physician were more likely to report better risk communication and higher confidence in their decision than parents who reported less communication ($P < 0.001$). Using personality traits, results showed that the confidence in decision-making domain was significantly associated with agreeableness ($P < 0.1$), conscientiousness, emotional stability and openness to experiences ($P < 0.01$). However, the risk communication domain was not significantly associated with any of the personality traits ($P > 0.05$).

Discussion

This study investigated the psychometric properties of two instruments within a population of children who were eligible for an integrated pediatric palliative care program. Compared to extant studies, the uniqueness of this study is the use of different psychometric approaches such as confirmatory factor analysis for testing construct validity and testing known-groups validity.

Our findings support the construct validity of the DCS, which essentially emphasises decisional conflict (e.g. uncertainty in making a choice, factors contributing to the uncertainty and the perception of effective decision-making). In contrast, construct validity of the COMRADE, which focuses on satisfaction with risk communication and affective outcomes of treatment decision-making, was not supported.

One possible interpretation is that compared to the DCS, the COMRADE was developed for a general practice setting with its myriad of clinical decision-making situations. The construct of risk communication and affective outcomes associated with decision-making as measured by the COMRADE is likely different from that of general practice patients. Studies of parents of children with cancer show that parents prefer to be responsible for their children's medical decisions and they want to be active participants and collaborators.^{13, 43, 44}

Evidence of known-groups validity provides other information to support the superiority of the DCS to the COMRADE. Our study found greater discrimination by the DCS than the COMRADE for personality known-groups. This finding confirms the extant literature which shows that people with different personality traits may have a different approach in managing decisional conflict as measured by the DCS. For example, people with a higher level of agreeableness are more trustful, compliant and modest, personality characteristics that are linked to higher informed feeling and lower uncertainty in decision-making process.^{45–47} The DCS was also able to discriminate between different levels of physician trust. Although the WFPTS has not been validated in a paediatric setting, we did test to see if there were any significant differences in physician trust across children with different illness severities and none were found.

Most of the extant end of life decision-making research focuses on adults.⁴⁸ These studies focus on a variety of end-of-life decisions, such as do not resuscitate orders, discussion of survival length, the use of artificial nutrition and fluids, location of death and the use of pain medication and symptom control.^{49–55} In contrast, a lesser number of palliative care studies are focused on decision-making in the pediatric population.^{32–34} The majority of these

studies is from the provider's rather than patients' perspective to describe clinical experience, clinical barriers and clinical recommendations for decision-making in the context of pediatric palliative care.⁵⁶⁻⁶⁰

Results from this study provide integrated pediatric palliative care programs with an additional outcome (effectiveness of decision-making), beyond mortality and survival length, to measure programmatic effectiveness. This is crucial for publicly funded paediatric palliative care programs which are required to meet specific criteria related to effectiveness. Although publicly funded pediatric palliative care programs are in their infancy in the U.S., recent proposed legislation (House Resolution 6931) would require all Medicaid eligible children to receive hospice services earlier than the last 6 months of life.⁶¹ Consequently, our study results could have immediate and far reaching impacts on states as they seek guidance on how to measure programmatic benefits.

Several study limitations merit attention. First, the response rate for the survey was 54.4%. Although this response rate is consistent with other surveys conducted with Medicaid eligible populations,⁶² there may be inherent differences between responders and non-responders. Second, Medicaid eligible children tend to have high utilization of health care services and lower health outcomes,⁶³ both of which could affect their parents' decision-making experiences. Further testing should be conducted to determine if the DCS is valid with a broader socioeconomic group in the U.S. or abroad. Third, the DCS items are not predicated by a screener that asks if a decision was recently made. Further testing could be conducted with a group of parents who recently made a decision versus those who did not. Fourth, instrument validation is a dynamic process.⁴² Future research should longitudinally validate the DCS. In addition, the instrument should be re-validated if significant policy changes alter the eligibility, scope, frequency or duration of services offered by publicly-funded pediatric palliative care programs.

Despite these limitations, our findings are the first to provide evidence on the psychometric properties of any decision-making instrument within a population of children who are eligible for pediatric palliative care. Our study compares two decision-making scales within a heterogeneous sample and recommends the DCS. The ability to measure outcomes in a valid and reliable manner should provide the paediatric palliative care community with useful information that can be used to advocate for additional programs or expansion of existing programs so that more children and families can receive palliative care.

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Table 1

Sample characteristics

Characteristics	Number of observations (%)
Child's gender	
Male	147 (55.3%)
Female	119 (44.7%)
Parent's education background	
Below high school	59 (22.2%)
High school or GED	93 (35.0%)
Some college	59 (22.2%)
Associate degree or above	55 (20.7%)
Parent's race/ethnicity	
Hispanic	79 (29.7%)
White/non-hispanic	110 (41.4%)
Black/non-hispanic	65 (24.4%)
Other	12 (4.5%)
Parent's marital status	
Married/common law	129 (48.5%)
Divorced/separated	64 (24.1%)
Single	67 (25.2%)
Widowed	6 (2.3%)

Table 2

Distribution of domain scores

Domain scores	Mean	Median	SD	Range	Floor effect (%)	Ceiling effect (%)
Comrade						
Risk communication	66.91	65.00	10.57	27.88–82.58	40.00	40.00
Confidence in decision	68.14	66.32	9.40	27.71–84.20	38.00	38.00
DCS						
Informed feeling	22.28	25.00	18.87	0–83.33	25.95	0.38
Values clarity	20.72	25.00	17.38	0–83.33	27.48	0.38
Support	20.77	25.00	17.78	0–83.33	26.05	0.38
Uncertainty	23.74	25.00	17.96	0–83.33	20.93	1.16
Effective decision	18.65	25.00	14.21	0–75.0	26.44	1.15

Table 3

Reliability and item-domain convergent/discriminant validity

Domain scores	Reliability (Cronbach's alpha)	Convergent validity	Discriminant validity
Comrade			
Risk communication	0.94	0.59–0.85	0.57–0.75
Confidence in decision	0.96	0.74–0.85	0.57–0.77
DCS			
Informed feeling	0.92	0.81–0.86	0.66–0.80
Values clarity	0.88	0.76–0.79	0.65–0.80
Support	0.86	0.71–0.79	0.56–0.78
Uncertainty	0.85	0.66–0.80	0.60–0.82
Effective decision	0.90	0.72–0.84	0.55–0.75

Table 4

Known-groups validity of the DCS scale

Known-groups	Domain			
	Informed feeling	Values clarity	Support	Uncertainty
Effective decision				
Wake forest physician trust scale				
<i>Trust</i>				
High	14.00	12.74	12.98	15.36
Low	29.56	27.59	27.61	31.14
F-ratio	52.48***	57.45***	52.72***	61.32***
94.88***				
Ten-item personality inventory (TIPI)				
<i>Personality trait</i>				
Extraversion				
High	22.38	18.79	19.37	23.07
Low	22.00	22.31	22.23	24.54
F-ratio	0.02	2.33	1.46	0.37
0.89				
Agreeableness				
High	19.67	18.66	18.75	21.56
Low	25.47	23.75	24.05	26.51
F-ratio	5.95*	5.07*	5.06*	4.33*
9.43**				
Conscientiousness				
High	18.06	16.83	15.24	18.81
Low	25.06	23.51	24.49	27.46
F-ratio	8.42**	9.00**	17.57***	14.19***
12.78***				
Emotional stability				
High	20.00	17.93	18.60	20.09
Low	24.94	23.77	23.31	27.33
F-ratio	4.47*	7.4**	4.54*	10.52**
6.08*				
Openness to experiences				
High	18.84	17.72	17.63	20.83
Low	24.88	22.92	24.44	26.35
F-ratio	6.74*	5.95*	9.26**	5.82*
7.22**				

* $P < 0.1$;
 ** $P < 0.01$;
 *** $P < 0.001$.

Table 5

Known-groups validity of the COMRADE scale

Known groups	Domain	
	Risk communication	Confidence in decision
Wake forest physician trust scale		
<i>Trust</i>		
High	71.93	73.41
Low	62.40	63.58
F-ratio	62.67 ***	98.32 ***
Ten-item personality inventory (TIPI)		
<i>Personality trait</i>		
Extraversion		
High	66.42	68.22
Low	67.51	68.02
F-ratio	0.55	0.03
Agreeableness		
High	67.29	69.53
Low	66.48	66.53
F-ratio	0.31	4.89 *
Conscientiousness		
High	68.24	70.30
Low	66.11	66.49
F-ratio	2.33	10.07 **
Emotional stability		
High	67.79	69.55
Low	66.20	66.46
F-ratio	1.40	7.13 **
Openness to experiences		
High	67.64	69.75
Low	66.12	66.46
F-ratio	1.15	7.31 **

* $P < 0.1$;** $P < 0.01$;*** $P < 0.001$.