Development and validation of the Children's Competence in Decision-Making Scale.

Abstract

Background/ Literature review

Measuring competence in children's ability to make decisions is laden with conceptual problems. A variety of competence measuring tools exist however, no scales were found that measured competence in children.

Aim

To develop, test and validate a competence measuring tool for children aged 8-12 years with long term conditions.

Design

A convergent sequential mixed methods validation design was used.

Methods

Four stages of questionnaire development were used following recommended procedures. The qualitative arm explored the experiences of children aged 8 to 12 years about being involved in decision making. This data was used to develop the tool which was then subject to psychometric testing.

Results

The result showed an overall alpha of 0.86. Additionally, the alpha 'if items deleted' analysis did not show considerable variation and did not have any value below 0.7.

Conclusion

The scale offers practitioners an ability to test the competence levels of children in order to decide the degree of involvement that children may want to have in the decision-making process. This in turn may help to plan care in a more effective way and may have an impact on adherence levels in self-management of illness.

Key words: decision-making, competence, validation, tool development, children's nursing

Introduction

Over the last thirty years, since publication of the United Nations Convention on the Rights of the Child (UNCRC 1989), there has been an increasing interest in children's rights to be involved in decisions about their care. More recently, the UN General Assembly on Children (2002) reemphasised the UNCRC (1989) statement that children have the right to participate in the decision-making process and the child is given the status of an active and competent participant. The legal stance is that involvement in the decision-making process is based on the assumption that the child has the cognitive ability necessary for this process (Griffith 2008). It appears that the main issue is that of competence, and whether the child possesses the ability to be involved in decisions about their care. There is a need to improve patient centred care when considering involvement in the decision-making process and attention must be given to how competent a child feels in being involved in this process.

Background/Literature

Measuring competence is laden with theoretical problems and although a variety of tools exist they and all differ in their focus and this may result in problems of inconsistency. A review of the literature revealed 22 scales. A number of these focussed on preferences for information and

involvement (Simon et al 2006, Degner et al 1997, Mazur and Hickman 1997, Bradley 1996, Thompson et al 1993, Beisecker and Beisecker 1990, Ende et al 1989, Cassileth et al 1980, Krantz et al 1980, Hollen 1994). Other tools evaluated health practitioners' communication, facilitation and support in the decision making process and the extent to which health practitioners involved patients (Sheilds 2005, Guimond et al 2003, Elwyn et al 2003, Braddock et al 1999, Kaplan et al 1996, Lerman et al 1990). Barry et al (1997) assessed education needs of men with prostatic hyperplasia and Brehaut et al (2003) and O'Connor (1995) looked at the impact of self- confidence and uncertainty in decision making in adults. Satisfaction was also assessed (Holmes-Rovner et al 1996).

One study assessed perceived competence in children (Harter 1982); however, this was not competence in decision making but in cognitive, social and physical domains. Only one study assessed decision making in children aged 14 to 18 (Hollen 1994), but this was primarily on healthy children and examined their information needs not their confidence in making decisions.

No recent studies were found that measured children's competence in the decision making process.

It is important that children are encouraged and enabled to make decisions within their capacity about their care but there are few tools to measure a child's competence to make decisions and therefore this needs to be addressed.

The aim of the study was to develop, test and validate a scale that measured competence in the decision-making process of children with long term conditions, called the Children's Competence in Decision-Making Scale (CCD-M).

Methods

Public and Patient Involvement

A group of 12 children offered advice on the study and assisted with the pre-testing phase. The group provided practical help on the development of the CCD-M Scale. Syntax and ordering of questions were changed and some questions, not deemed relevant, were removed and relevant questions were added following feedback from this group.

Design

A convergent sequential mixed methods validation design was used.

Sample and participants

An optimal sample size for a validation study should be 10 to 30 participants (Isaac and Michael 1995, Hill 1998, Julious 2005). Taking this into account 20 participants were selected for the pretesting stage and a different group of 20 participants for the test-retest stage.

Participants were recruited in two ways; from the out-patient departments in one Hospital in England and via online recruitment from adverts placed on charity websites. Inclusion criteria were; children aged between 8 and 12 years old with a diagnosis of either asthma or type 1 diabetes.

Children with other co-morbidities were excluded as the level and amount of decisions that they would be required to make would differ.

Tool development-Stage 1: Thematic generation

It was not possible to find a validated scale that measured competence in decision making and so a tool used in adults (the Decision and Self Efficacy Scale (O'Connor 1995)) was used as a framework and foundation for building the tool.

Twelve children were recruited who had either asthma or diabetes and had experience of the decision making process in the health care context. These children were recruited by approaching

support networks and through national UK charity websites. This group consisted of 50% that had asthma, 66% were female, all were White British ethnicity, ages ranged from 8 years to 11 years.

Data were collected through semi-structured interviews to explore the notion of competence and explore themes around how competence in the decision making process could be measured. No predetermined topic guide was introduced.

Four themes were evident from the analysis of the data, each representing differing aspects of competence and decision making:

- information acquisition (to have all the options available),
- information processing (to understand the context and outcomes of any decisions made),
- querying (either by being able to ask for more information or to ask for help in making the decision),
- exercising judgement (evaluating the options and the credibility of the source of information and acting on this by making a choice, or entrusting the decision making to someone else).

From the transcripts the following definition of competence was then developed, and this was the working definition used within this study.

Operational construct: Definition of competence.

Competence in the decision-making process in health care involves many relational and cognitive processes. Competence is therefore the ability to appropriately interpret information and produce a rational response within the context and in a way that is personally beneficial for that child.

Cognitive processes includes the themes developed above,

- information acquisition
- information processing
- querying
- exercising judgement

Decision-making competence also involves motivational factors relating to the capacity to voluntarily decide to avoid or to engage in the decision-making process, this is Decision Control (Mann et al 1989).

Stage 2: Scale development

A 21-item questionnaire with a 5-point Likert scale was developed. Construct validity was then tested by the PPI group who assessed whether the measure made sense. Face and content validity were tested and from these, changes were made to the sentence structure of some of the questions so that they could be more easily understood by children aged 8 to 12 years. It was important that the questionnaire was simple and easy to complete by the child and therefore each question was examined and adjusted so that it was developmentally appropriate. Initially there had been 21 items but in response to concerns expressed by the PPI group about the length of the questionnaire this was reduced to 14 in the final scale (Figure 1).

Stage 3 Pre-testing

To ensure that the tool was developmentally appropriate, and measured the construct of competence it was important to assess content validity and to ensure that the tool would yield the same results between different raters, inter-rater reliability was undertaken by the administration of

a pre-test questionnaire which was completed by 20 children. All were asked to comment on each question regarding its relevance on a 5-point Likert scale (1= not relevant, 5 = highly relevant). This enabled interclass correlations to be tested to measure the interrater reliability of ratings. The estimated reliability between children was 0.86 (95% C.I. =0.68 to 0.94, $p<0.001$). The average score for relevance was 4.6 out of a score of 5, showing that the tool was appropriate for the children and had high reliability.

Stage 4: Psychometric validation

The final scale was a 14-item 5-point Likert scale (0 (not confident) to 4 (very confident)) with 4 questions that related to information acquisition (Q1, Q2, Q6, Q7), 2 questions that related to information processing (Q3, Q8), 4 questions that related to querying (Q4, Q5, Q9, Q10) and 4 questions that related to exercising judgement (Q11, Q12, Q13, Q14). Although this was a 5-point

Likert scale, in an attempt to reduce central tendency related error, there was no neutral answer.

The researchers recognised that individual items may have a random measurement error, affecting reliability, and this can be minimised by use of a number of questions, as measurement error averages out when individual scores are summed, and this informed the development of the questionnaire.

Convergent, observation and discriminant validity were tested using Pearson's correlation coefficient, and the final version of the scale was delivered to a further (and different) 20 participants using a test –retest method. The scores were summed, divided by 14, and then multiplied by 25 so that all scores ranged from 0-100.

Cronbach's alpha, and 'α if item deleted' analysis were conducted. This was to check whether, changing the questions altered the overall rating of the tool.

Statistical analysis

An analysis of data normality was conducted using the Kolmorgorov–Smirnov test. Inter-observer reliability through the intra-class correlation coefficient (ICC) for each indicator as well as the overall instrument was tested using Chronbach's alpha values >0.8. Additionally, 'α if item deleted' analysis was conducted. All analyses were performed using the statistical package SPSS version 24 (IBM SPSS Statistics for Windows, Version 24.0).

Ethical Considerations

The study was approved by the Research Ethics Committee of the Health Research Authority 2016. All participants provided informed written consent.

Results

The result of Cronbach's alpha of the overall scale was 0.86 which shows good internal validity. Additionally, as seen in Table 1, showing the means as well as Cronbach alpha scores, 'if items deleted' does not show considerable variation. No substantial increase in alpha could be achieved if any single item is to be deleted from the scale. The alpha 'if items deleted' scores do not have any value below 0.7, in fact all are very close to the average value of 0.86, showing excellent internal validity throughout and no substantial increase in α could be achieved.

A full correlation matrix (Table 2) is presented to demonstrate convergent and discriminant validity.

To test the internal consistency of the subscales, Cronbach's alpha was conducted using the summative scores. As seen in Table 3 the subscale scores of alpha show good overall consistency.

Additionally, no substantial increase in the alpha value is achievable by deleting any single subscale item (table 3, no value below 0.7), which shows that all subscale items have good internal consistency.

Retest

After two weeks a retest of the scale was performed on the same participants and the Cronbach Alpha test was repeated to measure the internal consistency. To test the reliability of the tool, a correlation was conducted between the summative scores of the scales tested at the two time frames.

The Shapiro-Wilk test was conducted and the data were found to be normally distributed (p=0.93 for test 1, p= 0.41 for test 2), as the p value was greater than 0.05, therefore the choice of test to correlate the two scores was Pearson's correlation.

The overall scale results show *r*= 0.87 which indicates a very strong correlation and the p value of <0.001 is statistically significant, which demonstrates that the scale has a good reliability score. The

Test-retest scores of the subscales can be found in table 4. All subscales show strong positive correlation with significant p values showing that the scale is reliable in the test retest ability, apart from the subscale of information processing domain which shows weak correlation and the correlation is not statistically significant (r=0.36, p=0.1).

The internal consistency of the scales as per Cronbach alpha test is good, as seen by the Cronbach alpha scores of 0.86 (Test 1) and 0.91 (Test 2 (re-test)). All the items have good internal consistency as there are no scores lower that 0.7 if any individual items are deleted.

A Cohen's kappa coefficient was used to compare the tool against the gold standard, which was the Gillick competence framework. The Kappa value of the level of agreement between the two tools is low (*k*= -0.05) and the significance is greater than 0.05 (p=0.79), suggesting that there is a poor level of agreement between the two tools.

Discussion

The purpose of the study was to develop and validate a tool to assess the level of competence a child has in the decision-making process. The results demonstrated that the Children's Competence in Decision-Making Scale was valid and reliable in measuring children's competence levels in this process. However, in order to confirm these results it would be valuable to conduct further studies in different contextual settings with confirmatory factor techniques.

The CCD-M scale offers the possibility of evaluating children's competence in the decision-making process about decisions that affect their health and management of their health states. This may have a positive impact on health care by increasing a more patient centred practice. Involvement therefore can be specifically tailored to the children's needs and this in turn may impact on the self-management part of the treatment, increasing adherence to treatment. Currently, involvement in decision-making has either been tokenistic or has been too complex for the child to cope with, and this has been linked with dissatisfaction of the service offered.

The tool has been developed with and internationally standardised language and therefore the possibility of reduced performance is low, however it would be worthwhile to retest the reliability of the instrument should it be translated.

As there was also a lack of a gold standard measurement the Gillick competence framework was used. It was found that there was a poor level of agreement between the tool and the Gillick framework. However, this may be because the two scales have different categories. It is worthwhile to mention that a scale measuring psychosocial or psychological measures, including Gillick, is

considered more relevant if it provides other more extensive responses rather than yes or no. Also the age ranges tested for each tool were different and thus there is limited value in comparing of constructs that have different measurements.

Limitations

With regard to inter-observer reliability, as this is a self-report scale, it was not possible to test this.

A cross sectional design was used and therefore the responsiveness of the instrument was not tested. Sample size was small and not diverse as it consisted of only White British participants, therefore the content validity may be affected. There was also a lack of a gold standard that could be used as a benchmark and although the Gillick competence framework was used to compare against, it had limitations such as it provides a binary outcome and was developed for a different age range.

Conclusion

The results of this study showed that the tool was found to be a valid and reliable measure of the construct of competence in the decision-making process. Information processing subscale had weak correlation, potentially because only two items explored this theme. Although this could be further developed and refined it can be used as an assessment tool for children and can contribute information to support decision-making and patient centred care.

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Figure 1. Children's Competence in Decision-Making Scale

Please show how confident you feel for each statement from 0 (not confident at all) to 4 (very confident) by circling the number. I feel confident that:					
1. I can get all the information about any problems and side effects	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
2. I can get all the information I need to make a choice	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
3. I can get understand the information enough to make a choice	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
4. I can ask questions without feeling silly	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
5. I can ask for help to decide on the best choice for me	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
6. I am confident that I can tell staff if I am worried about any choice	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
7. I am confident that I can tell the person that cares for me if I am worried about any choice	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
8. I can have as much time as I want to make my decision	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
9. I can let the staff know what I think is best for me	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
10. I can let the person that cares for me know what I think is best for me	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
11. I can make a decision without pressure from staff	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
12. I can make a decision without pressure from the person that cares for me	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
13. I can make the right decision for me	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4
14. The decision I make will not cause me to be ill	Not confident 0	A little bit confident 1	Confident 2	Quite confident 3	Very Confident 4

Table 1. Means and alpha scores for individual items

Item	Mean	S.D.	Scale mean if item deleted	α if item deleted
Q1.	2.60	1.046	32.40	.857
Q2.	2.35	.813	32.65	.853
Q3.	2.25	1.164	32.75	.843
Q4.	2.30	1.525	32.70	.850
Q5.	2.50	1.318	32.50	.854
Q6.	2.00	1.124	33.00	.849
Q7.	3.35	.813	31.65	.860
Q8.	2.05	1.317	32.95	.845
Q9.	2.40	1.353	32.60	.835
Q10.	3.20	.894	31.80	.845
Q11.	2.35	1.182	32.65	.848
Q12.	2.70	1.261	32.30	.832
Q13.	2.65	.988	32.35	.861
Q14.	2.30	1.418	32.70	.853

Table 2 Inter item correlation matrix

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14
Q1	1.00													
Q2	.24	1.00												
Q3	.17	.24	1.00											
Q4	.18	.04	.40	1.00										
Q5	.61	.32	.33	.16	1.00									
Q6	.27	.46	.36	.21	.28	1.00								
Q7	-.07	.12	.24	.04	.42	.11	1.00							
Q8	.13	.47	.27	.25	.32	.53	.10	1.00						
Q9	.42	.25	.37	.68	.35	.24	.30	.43	1.00					
Q10	.43	.40	.45	.11	.62	.21	.55	.57	.54	1.00				
Q11	.25	.19	.54	.58	-.12	.32	-.19	.26	.57	.13	1.00			
Q12	.26	.42	.66	.62	.25	.41	.26	.33	.72	.43	.75	1.00		
Q13	-.04	-.10	.49	.11	.22	.09	.55	.01	.23	.44	.02	.25	1.00	
Q14	-.09	-.41	.27	.35	-.03	.49	-.09	.78	.29	.19	.44	.46	-.07	1.00

Table 3 Means and alpha scores for subscales

Subscale	Mean	S.D.	Scale mean if item deleted	α	α if item deleted
Information acquisition	2.47	0.60	7.20	0.69	0.86
Information processing	2.15	0.99	7.62	0.46	0.79
Querying	2.55	0.89	7.22	0.72	0.81
Exercising judgement	2.50	0.86	7.27	0.66	0.82

Table 4 Test re-test scores of the subscales

Item	*r*	Sig
Overall score	0.87	<0.001
Information acquisition	0.7	<0.001
Information processing	0.36	0.1
Querying	0.8	<0.001
Exercising judgement	0.7	<0.001