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Health-related quality of life assessment for Hong Kong Chinese children with cancer

Key Messages

1. The direct measurement of quality of life in young children aged 30 to 72 months is feasible and valid.
2. An interactive storybook was developed to help inform young children with cancer of the medical procedures and consequences. The storybook had good construct, convergent, and criterion validity.

Introduction

Evaluation of health-related quality of life (QoL) in young children aged <5 years with cancer relies on proxy assessments by nurses or parents.[1-5] Both of which are subject to bias known as cross-informant variance.[6] Most children over 3 years old have the capacity to respond in a meaningful and reliable way, provided that they are assessed in an age-appropriate manner.[7] This would enable direct assessment of QoL in children. We therefore (1) developed an age-appropriate direct assessment of QoL for children aged 3 to 5 years with cancer, and (2) validated its use in children of southern Chinese cultural background aged 5 to 8 years, using an established QoL module specifically for cancer-related problems—the PedsQLCa.[8]

Methods

This study was conducted from January 2005 to December 2006. The development of the QoL assessment for children aged 3 to 5 years was based on an interactive 16-page storybook depicting the experiences of a gender-neutral cartoon bear going through a range of medical procedures and consequences typical to children having cancer. The child was asked to give two responses to each question on a 'smiley scale' and on an 'intensity thermometer', which broadly assess quality and intensity of the experience associated with the depicted scenarios. The storybook was developed over a 12-month period, and included detailed scrutiny and restructuring of each page's content. It took note of the ability of children to sustain the necessary attention and the ability of 3 to 5 years old to reliably link feeling states to several potential response formats, which were piloted and reviewed to produce the finalised storybook. On each page, one or more questions were asked regarding the experience depicted in each scenario, and up to two scores per question were produced: a five-point categorical scale indicating quality of experience (very good to very bad) and a three-point measurement of intensity (a little, somewhat, very much).

This instrument was then administered to newly recruited children in the target group (30 to 72 months old, with a diagnosis of cancer) attending one of five hospitals in Hong Kong and Shenzhen. Scores for all 26 questions were recorded on a pre-designed score sheet. Caretakers completed the PedsQLCa, whereas nurses concurrently completed both the PedsQLCa and several seven- and 10-point categorical scales measuring fatigue, pain (acute and chronic), general wellness, and eating. Clinical and sociodemographic data were also collected.

To validate the PedsQLCa, 135 children aged 60 to 108 months were recruited from five regional hospitals in the Pearl River Estuary region of southern China. A standard ethnographic translation-back-translation procedure was used to produce the Chinese version of the PedsQLCa. Eligible children completed the PedsQLCa after they and their parent/caretaker gave informed consent.

For analysis of PedsQLCa, individual scores for each page were recorded on a page-by-page basis and entered into a computer. The PedsQLCa produces separate module scores by summing scores for the eight modules (pain, nausea,

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treatment anxiety, worry, cognitive problems perceived physical appearance, and communication). The PedsQLCa avoids the problems of scaling by having no total score but just factor scores. Nonetheless, this makes the use of factor analysis inappropriate.

Correlations between concurrent nurse and caretaker assessments were calculated to determine the degree of observer concordance. Module scores by different assessors (caretaker vs nurse) were compared, and differences in children on and off active chemotherapy cycles to determine criterion validity were examined using the known groups approach.

For analysis of the storybook, higher scores indicate better QoL status. All scores were transformed to a range of 0 to 100. Two sets of data (feeling scores for different experiences [happy/unhappy]; intensity scores of pain, discomfort, nausea, alopecia, mucositis) were analysed separately. Each was subject to separate principal component analysis using oblique rotation. Factor and total scores were then calculated and correlated with caretaker and nurse PedsQLCa scores to determine convergent validity.

For the sub-set of children for whom both storybook and PedsQLCa assessments were available, correlations were performed to determine convergent validity. Responses completed in children who received active treatment within the past month were compared to those in children who had been treatment-free for at least 3 months to determine clinical (criterion) validity. Comparisons between children with cancer and those with thalassaemia were made to further examine clinical validity. Responses within children who, on both assessments, had been in remission for more than 3 months were used to assess test-retest reliability.

Results

Instrument content

The storybook was compiled to match the aspects of the PedsQLCa in terms of the domains covered and then evolved to fit local clinical scenarios. The draft instrument comprised 16 pages, involving 25 questions, each addressing different aspects of the cancer experience. For each item, the first digit refers to the page, the second to the item number (up to five) on that page. These included anticipatory anxiety about hospital attendance (item 1.1) and medical procedures (item 1.2), feelings about going to the hospital (item 2), feelings when waiting for the consultation (item 3), feelings during the consultation (item 4), separation anxiety (item 5), anticipatory anxiety regarding blood draw (item 6), feeling and intensity of blood drawing (item 7), central venous line experience (item 8), lumbar puncture (item 9), anticipatory anxiety about medication (item 10), fever following medication (item 11.1), oral soreness (mucositis) following medication (item 11.2), nausea after medication (item 11.3), hair-loss after taking medication (item 11.4), nausea when presented with food (item 12, if yes then), nausea on smelling food (item 12.1), nausea-related food refusal (item 12.2), and lack of appetite (item 12.3), fever after chemotherapy (item 13.1), oral mucositis after chemotherapy (item 13.2), nausea after chemotherapy (item 13.3), hair loss after chemotherapy (item 13.4), fatigue after chemotherapy (item 13.5), activity level at home (item 14), post-treatment hair loss (item 15), embarrassment if any scarring is viewed (item 16).

Assessments

A total of 161 assessments (at different time points) were completed by children using the storybook for which there were concurrent caretaker assessments; 294 assessments

Table 1. Five-factor solution of observed variance following principal component analysis

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
7: Experience of blood drawing	0.766	-	-	-	-
9: Lumbar puncture	0.739	-	-	-	-
6: Anticipatory anxiety about blood drawing	0.738	-	-	-	-
8: Central venous line experience	0.556	-	-	-	-
5: Separation anxiety	0.475	-	-	-	-
10: Anticipation about medication	0.467	-	-	-	-
14: Hair loss after medication/chemotherapy	-	0.807	-	-	-
13.3: Nausea after medication/chemotherapy	-	0.795	-	-	-
13.5: Fatigue after medication/chemotherapy	-	0.669	-	-	-
13.2: Oral mucositis after medication/chemotherapy	-	0.606	-	-	-
12: Nausea on presentation of food	-	0.584	-	-	-
12.1: Nausea on smell of food	-	-	0.886	-	-
12.2: Nausea-related food refusal	-	-	0.815	-	-
12.3: Lack of appetite	-	-	0.809	-	-
4: Feelings during consultation	-	-	-	0.769	-
3: Waiting for consultation	-	-	-	0.674	-
1.1: Hospital attendance	-	-	-	0.543	-
16: Embarrassment over scars	-	-	-	0.494	-
1.2: Anticipation of medical procedures	-	-	-	0.492	-
2: Feelings about going to hospital	-	-	-	-	0.682
13.1: Fever after chemotherapy	-	-	-	-	0.669
14: Activity level at home	-	-	-	-	0.572

Table 2. Three-factor solution of intensity items following principal component analysis

Item	Factor 1	Factor 2	Factor 3
13.3.2: Intensity of nausea after medication/chemotherapy	0.795	-	-
13.4.2: Intensity of hair loss after chemotherapy	0.787	-	-
13.1.2: Intensity of fever after chemotherapy	0.733	-	-
13.2.2: Intensity of discomfort from mucositis after chemotherapy	0.724	-	-
13.5.2: Intensity of fatigue after chemotherapy	0.561	-	-
12.2.2: Intensity of food-related nausea/refusal after chemotherapy	-	0.939	-
12.1.1: Intensity of food smell–induced nausea	-	0.908	-
12.3.2: Intensity of appetite loss after chemotherapy	-	0.779	-
9.2: Intensity of discomfort about lumbar puncture	-	-	0.807
7.2: Intensity of discomfort about blood drawing	-	-	0.805
8.2: Intensity of discomfort about central venous line	-	-	0.754

were completed by children using the PedsQLCa, 187 of which also had concurrent caretaker assessments, whereas 48 assessments were completed by children using both assessments for which there were concurrent caretaker assessments. Only 30 nurse assessments were completed despite repeated efforts to improve the response rate.

The storybook generates two dimensions of responses: feelings (positive or negative, in a five-point scale) and intensity of feeling (mild, medium, severe in a three-point scale). These two sets of dimensions were treated independently in the first instance in order to determine if the factor structure of the instrument was both coherent and approximated to the PedsQL factor structure.

The five-factor solution accounted for 55.25% of the observed variance (Table 1). The five factors were: procedural and separation anxiety (procedures) [6 items, 17.68% of variance], symptoms (symptoms) [5 items, 12.15%], nausea (3 items, 11.34%), treatment anxiety (treatment) [5 items, 7.37%], and at home (home) [3 items, 6.71%]. The 11 intensity items were subject to obliquely rotated principal component analysis which yielded a Kaiser-Meyer-Olkin measure of 0.629 and a significant Bartlett's test score. A three-factor solution accounted for 64.9% of the observed variance. The three factors were symptom intensity (5 items, 26.39%), nausea intensity (3 items, 20.75%), and invasive procedure intensity (3 items, 17.78%) [Table 2].

Discussion

Treatment decision making difficulties and outcome expectancies strongly predicted postoperative and outcome psychological morbidity after adjustment for disposition and coping efficacy, consultations, mediated by treatment decision making–related factors can exacerbate baseline distress, in turn mediating adjustment one month postoperatively.

Physical symptom distress, accounting for most variance in outcome CHQ12, was itself predicted by active treatment and baseline CHQ12.

Table 3. Factor structure (pattern matrix) of storybook

Factor structure	Active treatment (scores)		P value
	On (n=10)	Off (n=61)	
Procedural and separation anxiety	51.10	54.66	>0.05
Symptoms	13.48	19.65	>0.05
Nausea	20.23	2.80	0.004
Treatment anxiety	29.74	40.40	>0.05
Home	31.92	40.23	>0.05
Symptom intensity	87.5	78.06	>0.05
Nausea intensity	80.83	96.94	0.011
Procedure intensity	79.17	55.47	0.042

Chemotherapy paradoxically enhanced physical symptom distress, but lowered follow-up psychological morbidity. Chinese women may feel that they are receiving additional treatment thereby gaining reassurance from chemotherapy while experiencing the side-effects.[1,7] So symptoms are worse, but worry is less. We did not find similar reports on western patients.

Comparisons between storybook and PedsQLCa

A subset of 30 children aged 60 to 71 months completed both the storybook and the PedsQLCa. Correlations (*r*) were moderate (range, <0.01-0.10) for conceptually unrelated items and up to 0.357 for more strongly related items. Associations showed conceptual (nausea: nausea; anxiety-anxiety) correspondence and consistency (both feeling and intensity scores loaded on the same PedsQLCa module). Factor 4 (treatment anxiety) in particular correlated with a number of dimensions including worry, appearance, communications, treatment, and procedural anxiety, whereas procedural/separation anxiety correlated with PedsQLCa pain, treatment anxiety, and perceived appearance. Storybook nausea correlated with PedsQLCa nausea, cognitive difficulties, and perceived appearance, whereas storybook procedural intensity correlated with PedsQLCa pain, procedural anxiety, worry, perceived appearance, and cognitive difficulties.

Comparisons between child-completed storybook and proxy caretaker- and nurse-completed PedsQLCa

We examined if the child-completed storybook scores

corresponded more closely with those of the caretaker proxy scores on the PedsQLCa for younger children (under 72 months of age). These correlations showed similar patterns, but were weaker than those in children who self-completed both instruments. Correspondence was greatest for nausea and least for anxiety and procedural intensity.

Discriminant/criterion validity (known groups approach)

To explore if the storybook were able to discriminate between children who had higher or lower QoL, we compared scores in children who were on and off active treatment. Storybook scores in nausea feeling, symptom intensity, and procedural intensity were differentiated between the two groups (Table 3). All other scores indicated better QoL among the off-treatment group.

Conclusion

The storybook had a valid factor structure within its two key dimensions of feeling and intensity, suggestive of good construct validity, whereas the correlations with the PedsQLCa indicated good convergent validity. All factor scores, particularly both feeling and intensity nausea factors, significantly differentiated between children on and off treatment, suggesting that the instrument had effective criterion validity. Further development in this area is warranted.

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