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Exploring views on satisfaction with life in young children with chronic illness: An innovative approach to the collection of self-report data from children under 11.

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Abstract

Objective: To explore young children's views on the impact of chronic illness on their life in order to inform future development of a patient based self-report health outcome measure.

We describe an approach to facilitating self-report views from young children with chronic illness.

Methods: A board game was designed in order to obtain qualitative data from 39 children with a range of chronic illness conditions and 38 healthy controls ranging in age from 3 to 11 years.

Results: The format was effective in engaging young children in a self-report process of determining satisfaction with life and identified 9 domains.

Conclusion: The board game enabled children aged 5 – 11 years with chronic illness to describe the effects of living with illness on home, family, friends, school and life in general. It generated direct, non-interpreted material from children who because of their age may have been considered unable or limited in being able to discuss and describe how they feel. Obtain this information for children aged 4 and under continues to be a challenge.

Key words: children; chronic illness; quality of life; focus groups.

Abbreviations: QOL – quality of life; WHO – World Health Organisation; SILCWORM-Satisfaction in Life with Children’s Own Report Measure; BPVS – British Picture Vocabulary Scale

Introduction

Quality of life (QOL) is an integrative construct of ‘physical and emotional well-being, level of independence, social relationships and their relationship to salient features of their environment’ (WHO QOL Group, 1995). Individuals attribute personal meaning to different areas of functioning however medical treatment will have an impact on health related QOL (Gill & Feinstein, 1994). Assessment of clinical interventions, clinical trials, and evaluation of illness outcomes and healthcare are strengthened by measures of impact on quality of life in addition to symptom based outcomes. The United States Food and Drug Administration (FDA) strongly encourage patient reported outcomes as a major component of clinical trials research and pharmaceutical trials (Food and Drug Administration (FDA), 2009).

Methodological Challenges to Instrument Development for Young Children

There are several challenges in determining a practical approach to obtain QOL information for young children. Language development, concrete thinking and developmental level will influence responses of young children to questions about their view of their quality of life (Christie, 2006). Young children have limitations in their ability to think about the future (Atance & O’Neill, 2001) which will influence their ability to think about how they would rate or give a value to their life in the future as opposed to how they rate it in the present. The ability to develop theories about oneself or other people and other experiences in the environment emerges in the first few years of life. This is both helped and constrained by biological endowment, current cognitive competencies, capacity, knowledge and opportunities provided by the environment. In addition, it is possible that perceptions of life,

and its reported quality, may be markedly different if a child has been ill for a substantial time, with the nature of the illness and treatment potentially also influencing perceptions. Young children may not find it easy to separate their own experience of the world from that of their caregiver(s) or may produce a response based not just on how they feel but on how they think they should feel (Lichtenberg, 1975).

Obtaining patient reported outcomes for young children is a challenge, since there are few QOL measures for young children that do not rely on adult proxy measures (Eiser & Morse, 2001; Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002). There are few generic tools designed specifically to assess child-reported QOL in young children with chronic illness (Eiser & Morse, 2001; Graham, Stevenson, & Flynn, 1997; Ravens-Sieberer et al., 2005; Ware & Sherbourne, 1992). Instruments to measure QOL in older children with chronic illness have been developed for specific illness conditions (e.g. Childhood Asthma Questionnaire, Quality of life in Children with Crohn's Disease, Diabetes Quality of Life for Youths, Quality of Life in Spina Bifida Questionnaire (Eiser & Morse, 2001). The PedsQOL (Varni, Seid, & Rode, 1999) is one of the most widely used child QOL measures and contains modules for diabetes, arthritis, cancer, cardiac disease, cerebral palsy and rheumatology. However none of these allow children younger than 5 to report on their own quality of life, relying on proxy parental report.

Historically, assessment of young children's emotions, perceptions of social relationships, and future thinking has involved asking them to draw, complete stories or sentences, or describe pictures (Murray, 1943; Phillips, Smith & Broadhurst, 1973). These approaches require interpretation of the child's response by an adult. The psychometric validity, reliability and sensitivity of this approach has been challenged (Lilienfeld, Wood & Garb, 2000), since it is not clear whether it is the child's perception or the adults interpretation that

is being measured. The availability of a reliable, valid and responsive patient based outcome measure is important to an improved understanding of the impact of the illness in general. Generating the themes and questions in such a measure can be a challenge. For older children, semi-structured interviews or focus groups allow participants to use their own frame of reference to identify topics and they provide “safety in numbers”, allowing participants to raise personal and sensitive issues (Deyo & Patrick, 1989; Black et al., 1999). Focus groups are less amenable for use with children under 10 years of age (Porcellato, Dughill & Springett, 2002). The author DC has used a range of board games to communicate with younger children in clinical contexts. Material is presented in a game format that can be used to facilitate the understanding and disclosure of complex feelings experienced by children. A game format enables engagement with children about serious or difficult topics in a fun and playful way. It was decided to use this approach to explore young children’s views on their satisfaction with their quality of life (Streng & Stradmeijer, 2009; Hemmings 1991). This paper describes the development of a pilot data collection tool that will inform future development of a self report measure of satisfaction with life for children from 3 -11.

Methods

Participants

The study was approved by the Multi-Centre Research Ethics Centre (MREC) prior to study initiation. Young children (ages 3 -11) with a range of chronic illness conditions were recruited from three National Health Service (NHS) trusts in the North London area. Children were eligible to participate if they had been diagnosed with a chronic illness for more than six months. These included: irritable bowel disorder (IB); haemophilia (H); epilepsy (E); diabetes (D); juvenile idiopathic arthritis (JIA), sickle cell anaemia (SCA), nephrotic

syndrome (NS) and haematological malignancies. Children with acute or chronic psychiatric illnesses were not included.

An Information sheet for parents was given out to all families attending the hospital clinic by a play therapist. They were invited to contact the research team if they were willing to participate. A total of 39 children were recruited however three children had to be excluded as their medical condition was not noted on the data sheet. .

Controls were recruited from schools and nurseries in the geographical area covered by the three trusts. Children between the ages of 3-11 who were healthy with no known chronic illness were given information sheets by their class teachers. Parents were invited to return signed consent sheets if they were willing for their child to participate. A total of 38 children took part.

The British Picture Vocabulary Scale-II (Dunn, Dunn, Whetton and Burley, 1997) was given to each child to ensure they were within the normal range of ability for their age and would be able to understand verbal instructions given in the task. No children were excluded on the basis of this screening measure.

Children were invited to attend a session at the hospital (or in the school) in groups of 2 -3 in order to play the board game. Wherever possible parents were not present.

Table I. Demographic details for sample

	Cases	Controls
Gender (%)		
Male	57	62
Age (years)		
Mean Age	9	8
Range	3-11	3-11
Disorder (N%)		
Nephrotic syndrome	39 (51)	38 (49)
Diabetes	4 (10)	
SCA	8 (21)	
Haemophilia	11 (28)	
Epilepsy	3 (8)	
IBD	2 (5)	
	6 (15)	

JIA Unknown	2 (5) 3 (8)	
Ethnicity Caucasian	43%	85%
British Picture Vocabulary Scale II Standardised Score (mean = 100 SD = 15) Mean (SD)	98.56 (15.19)	104.86 (14.00)

Developing the Board Game questions

Currently available QoL measures were reviewed. These were combined with themes from focus group interviews previously completed by the author with adolescent meningitis survivors (Borg, Christie, Coen, Booy, & Viner, 2005). A semi-structured interview was then used to develop a series of questions that were reviewed by an expert group of psychologists and paediatricians. A series of potential themes and questions related to children's satisfaction with their life were agreed. The aim was to include questions that could be used flexibly and in an age appropriate manner in order to generate self-report statements that identified relevant domains and themes in their lives and to explore how a chronic medical condition impacted on these domains.

An initial set of 64 questions and statements were developed. These were divided into four categories relevant to both healthy controls and children with chronic illness. For children with chronic illness a fifth category of supplementary disease-specific questions were asked in order to invite the child to talk about the illness in relation to everyday life. The four categories were;

(1) Home and Family (e.g., *What is the best/worst thing about being at home with your family, what do you like doing the most with your mum/dad*).

(2) School and Friends (e.g., *One thing I like/don't like about school is...., what games do you like to play with your friends?*).

(3) Feelings and Worries (e.g. *I feel happy when..., I am pleased when..., I feel scared when...,*).

(4) Neutral (e.g. *I am the world's greatest..., The worst time of the day for me is ..., The best thing that happened this year is...*).

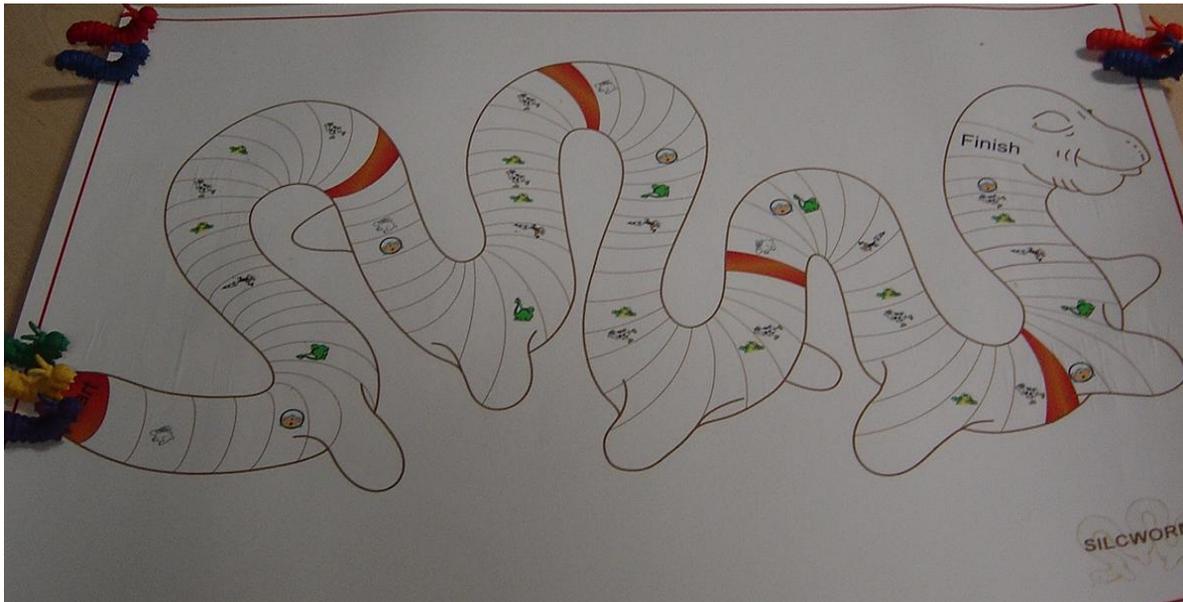
(5) Chronic illness questions (e.g. *what do you/don't you like about coming to the hospital? ,When I go to bed the worst/best thing about my illness is.....*).

The vocabulary used in writing the questions was designed to be appropriate and readily understandable for all the children taking part..

Procedure

The project title “Satisfaction In Life for Children With Own Report Measures” (SILCWORM) inspired the design of the game layout. This was a large worm divided into segments (see Figure 1). Large plastic ‘silkworms’ were used as game pieces. Each of the 64 questions/statements was written on a card with a cartoon character representing the category on the back of the card. These category cards were placed in piles on the board. The cartoon character appeared in different segments all along the worm’s body. The game was piloted with four children of different ages and small modifications were made before the final format was decided upon. Questions that weren’t answered were rewritten or abandoned and the method of delivery was refined to ensure maximum responses.

Figure I. Design of the game layout inspired by the project title ‘SILCWORM’



Each child was asked to throw a pair of large foam dice, pick the card relevant to the square they landed on and then answer a category question before they could move along the board. Depending on the question asked, the researcher would ask probe questions and encourage the other children in the group to give their answers to the same question. The researcher kept track of the questions asked and either speeded up or slowed down the rate of progress to make sure that as many of the 64 questions as possible were answered in each game. A parallel board for the controls was created that did not include the hospital specific question character. Children coloured in segments of a ‘worm’ on a card as they answered the questions. The completed card was used as a reward certificate for the child to take away at the end of the game. The game took about an hour to complete and answers to the questions were tape-recorded and transcribed verbatim.

Following the pilot phase it was decided that children aged 3 and 4 years would be seen individually. During the subsequent data collection period it was noted that children aged four and under struggled to answer the questions. Half way through the data collection period the board game questions were rewritten to make a story book. This was used to cue

answers to the same questions used in the game. This was used with a small number of the remaining four-year-olds in the sample.

Analysis

Each group or individual game was tape recorded and transcribed verbatim. Transcripts were analysed using Interpretative Phenomenological Analysis (IPA). The advantages of IPA lie in its ability to capture in detail lived experience by focusing on the uniqueness of an individual's thoughts and perceptions (Smith & Osborn, 2008). Furthermore, by taking a bottom-up inductive approach prior assumptions can be avoided when trying to investigate a new area.

The transcript from each game was read several times by a research psychologist. The text was closely inspected on a sentence-by-sentence basis. Comments, insights and possible interpretations were documented. Answers that were felt to be 'silly' or 'jokey' were rejected. Emerging themes and key words that captured the essence of the paragraph were also identified. Connections between the emerging themes were noted and allocated as either subordinate or core themes. This process was repeated for each transcript until no new themes emerged. For each theme identifiers were noted to ensure that specific examples of the themes could be identified within the different transcripts. For a more detailed description of the process see Smith & Osborn pp (2008).

The transcripts of the games were also reviewed and coded by a second psychologist who followed the same process as above to arrive at core themes and contributory sub-themes. All comments received equal weighting without distinguishing between potential subgroups (e.g. gender, illness status) or reporting the number of subjects contributing to each theme.

For 'non-illness' responses there were no differences in the themes generated by the cases and controls. Nine themes were identified: family, school, peers, physical status, psychological status, daily routine, coping and control, medical treatment and understanding and disclosure of condition. Only quotes from the children with chronic illness - including illness and non illness specific responses - illustrating each theme are presented here. Data from the controls will be presented in a further paper.

Family

Children talked about their siblings, wanting to spend time with their families and the differences between their mums and dads in relation to parenting roles.

"I like to go to my grandma's house and visit my cousin and my aunty and my granddad. I like to go with him to my baby cousin's house with my mum and my dad and brothers and my sister"

"I wish mummy and Daddy weren't so busy. Because mummy does the housework and I want mummy and daddy like to read a story and sit with me"

School

Children talked about achievement, motivation and missing school

"I don't like coming here (the hospital) because I want to learn about Maths, English Science and Art at School"

"The worst thing about having sickle cell is I don't get to go, sometimes I don't go to school"

Feelings & Worries

Peers were spoken about in relation to positive and negative interactions as well as children comparing themselves to others,

“I feel upset when people are being nasty to me and they make me upset”

“I feel happy when I am not sick and I get to play with my friends a lot”

Physical Status

Physical status reflected thoughts about diet, pain and physical vulnerability

“The worst thing about diabetes is sometimes it makes me not eat food very much. Not all of it. It stops me eating chips and sandwiches. I only have one sandwich and... I can't have meat, I can't drink sugary drinks and I can't have things when I am high and have to listen to my mum about my diabetes. When I can't have sugary drinks and I can't have something when I am high and when I feel sick, I don't feel sick”

“Sometimes they take out so much blood out and I don't like looking at it when they put it in, it kind of hurts but after (last words inaudible)”

“I feel brave when I am with an adult”

Psychological Status

Children spoke about feeling isolated, anxious or worried, not wanting to be ill or different to others

“When I feel lonely was when my mum told me to lie on my bed and I felt very sick”

“I'm worried about low sugars”

“Like they normally play with me differently to what they do other children”

“Because I didn't want to have Diabetes..... And I was this close to dying”

Daily Routine

Children talked about how illness interfered with their daily routine

“When I’m running, it feels like I am going to throw up, so I just have to sit down and everyone is waiting for me and it’s not fair on everyone because they really to play”

Coping

Different coping strategies and trying to control what was happening in their daily lives were commented on.

“Because it calms me down when I am angry with my brother”

“Kind of hard to cop, Because you’ve got to control it, Erm, I just try to forget about it”

Medical treatment

Responses that were about medical treatment referred to going to hospital and relationships with health care professionals

“Umm, when I feel ill... I just wish that I couldn’t, I don’t have to have blood tests and I don’t have to keep going back and forth doing stuff and having tablets and all that”

“The doctors are always just laughing. You get to talk a lot. And it is a different building to other hospitals and places. People are friendly”

Disclosure

The final theme on understanding and disclosure of condition reflected different levels of knowledge about how to manage the illness and understanding the impact of the present and future as well as concerns about who and when to tell.

“Erm, sometimes because err I’m sick and sometimes I need to get some medicine”

“They don’t know that I have sickle cell but they know I get really sick”

“Because if I tell them, I think they are going to treat me different”

Discussion

We describe a novel approach to communicating with young children about their thoughts, feelings and beliefs about their life and the impact of chronic illness. The use of a board game emerged as engaging, enjoyable, and enabling for children. This allowed open and free-flowing dialogue about their perspectives on a wide range of aspects of their lives. All the children told us they enjoyed playing the game. Although the game format created an opportunity for the children to give what might be thought to be silly answers we were struck by how seriously children took the opportunity to talk about their lives. In this paper we have described how the game was used to collect self-report views and generate themes from young children with chronic illness and healthy controls.

A key strength of the study is that statements made by the children were taken at face value with the themes being derived empirically from the data. The approach elicited material directly from children although we acknowledge that there is an interpretive component involved in any qualitative analysis. By asking children to tell us about their thoughts and feelings we were able to include children who were unable to write this down. The board game format permitted a bottom up approach for developing the themes by starting with the views of the children. The vocabulary used in writing the questions was developmentally appropriate and all participating children had receptive vocabulary within normal limits for their age.

Changing the format to the story book did not increase the accessibility of the material for children under five years old. It remains a challenge to identify ways that the views of children under the age of 5 can be understood. Using a board game enabled children with chronic illness to talk about the implications of illness for home, family, friends, school and life in general. The children expressed and demonstrated substantial enjoyment playing the game, and joined in with enthusiasm. They were happy with the examiner controlling the rate

of play. In a clinical setting it would be possible for the person administering the game to participate however we found that the young people enjoyed talking to each other about their responses and did not seem to need the additional input from the examiner. The format of the game created a safe environment enabling them to talk freely about thoughts, feelings and behaviours that were part of their everyday life. Accordingly, the game approach was demonstrated as a fun way to generate direct, non-interpreted material from children who because of their age may be considered unable or limited in being able to discuss and describe how things are for them.

The 9 themes that were identified by the children included the 3 themes that are in the PedsQoL (physical, emotional, and school functioning). However using the game format we describe an additional 6 themes (family, feeling & worries, daily routine, coping, medical treatment and disclosure). The next stage will be to remove repetitive or unnecessary questions using both qualitative analysis and statistical modelling to confirm the independence of the themes and create a smaller question set that would enable the board game to be used in a clinical setting. In addition the themes and responses that have been collected will be examined statistically to see if the 9 themes should be used as part of a simple to administer questionnaire that will enable exploration of satisfaction of life in a larger population of children with chronic illness. The authors are exploring a range of media solutions that will retain the game aspect whilst ensuring a more practical and pragmatic delivery option.

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