

A Qualitative Approach to Understanding Quality of Life in Pediatric Palliative Care

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Abstract

Helping pediatric patients achieve an optimal quality of life despite their serious illness is a hallmark for providing excellent pediatric palliative care. There is controversy regarding how to define pediatric Quality of Life (QoL) and how to assess this construct in children. Currently, there is no pediatric QoL instrumentation that has been standardized on population children with advanced disease. This qualitative study sought to determine what is quality of life from the perspective of pediatric patients with advanced disease. Twenty-nine pediatric patients (child mean age 14.7 years, range 9-21 years) participated in the current study. Through analysis, we identified three domains of QoL (physical, psychological, social) and a *lifestyle values* category. These results are important first steps for providing direction to future studies aimed at modifying QoL instruments in order to better understand the pediatric patient's illness experience and improve QoL when they are facing advanced disease.

Keywords: Quality of Life (QoL); Qualitative; Pediatric palliative care

Introduction

The World Health Organization (WHO) defines palliative care as an "approach that improves the quality of life of patients and their families facing life-threatening illness." This includes the "prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual." [1] When healthcare providers, together with families, decide which goals of care (whether curative or palliative) are of utmost importance in relation to the patient's disease course and individual and family values, the patient's perception of what is quality of life is at the forefront of this decision-making process. Thus, it is important for healthcare providers to have a clear sense of what is quality of life for their individual patients.

In pediatric patient populations, where children range in their cognitive and verbal skills and parents are often proxy-reporters and decision-makers for their children, it becomes even more challenging to assess the child's perception of what he/she considers to be quality of life. Pediatric Quality of Life (QoL) has been defined by others as a multidimensional construct that is a state of complete physical, mental, and social well-being for a child [2,3]; however, these definitions of QoL that are referring to the physical, psychological, and social domains of health are seen as distinct areas that are influenced by a person's beliefs, expectations, and perceptions of health [4]. Therefore, as much as possible, it is crucial to obtain the self-report of children in order to gain the most accurate assessment of their QoL. The controversy when defining "quality of life" lies in the fact that each of these domains can be measured objectively or subjectively. The objective measure is important in defining a patient's degree of health, while the subjective translates the objective assessment into the QoL experienced [5]. This explains how two people with the same health status may have very different perceptions of QoL.

Additional controversy rests among clinicians and researchers, alike, regarding not only how QoL is defined, but how to measure it. Criticisms about the assessment of pediatric QoL focus on the idea that parents and children share different views about the cause, etiology, treatment of the illness as well as differences in the interpretation of questions and adopt different time perspectives. These factors may alter the parent and child's ability to complete questionnaires and understand the language being used on these types of instruments.

Thus, time, context, and values can vary when QoL is being assessed across the same parent-child dyads, which could, in turn, result in different QoL scores on any given occasion [2]; therefore, it is important to continue to pursue obtaining QoL information from the pediatric patient directly in order to ensure his/her voices are heard accurately.

All previous pediatric QoL instrumentation have been standardized on patients with chronic illness (which may include patients with non-terminal illnesses) and/or life threatening illness [5-8], such as cancer, which may be curable if treated successfully. The term advanced disease, used here, refers to patients who have been diagnosed with a life threatening illness which has progressed and is not curable. To date, there is no measure of Pediatric QoL that has been standardized on a cohort of pediatric patients facing advanced illness. The objective of the current study is a first step in understanding what is QoL for pediatric patients with advanced disease from their own perspectives; a qualitative approach was used to uncover some of the principles described here.

Materials and Methods

The current study was derived from a larger mixed-methods study using both qualitative and quantitative research methodology to assess symptom communication in pediatric palliative care [9]. The current report is a secondary analysis of this larger dataset. Children's perceptions of their QoL were categorized and coded from interview narratives of their own experiences dealing with their illnesses. From our study interviews, pediatric patients with advanced disease acknowledged three main domains of QoL as being meaningful to their illness experiences. These main domains were categorized as physical, psychological, and social domains of quality of life. For the three domains of QoL identified here, we used the definitions provided

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by Spieth and Harris [10] to operationalize each category of QoL. An emerging, additional fourth domain was also identified in the pediatric interviews which we termed “lifestyle values.” It encompassed statements made by pediatric patients that were their “rules to live by” or values which helped them achieve an improved quality of life.

Pediatric healthcare professionals (two psychologists and one doctoral level nurse) interviewed parents and their children, ages 9-21 years, with advanced diseases (operationalized in this study as having a less than 20% chance of survival beyond 3 years). Exclusion criteria included children and parents who were unable to speak English fluently enough to participate and parents who were not mentally competent. For this qualitative study, children were recruited from all subspecialty divisions at one children’s hospital, the hematology/oncology division of another children’s hospital, and at an in-home children’s hospice. Institutional Review Board approval for the study protocol was granted from each of the three institutions where participants were recruited. Potential participants were identified from referrals by health care providers affiliated with these institutions. The current report examines the interviews of 29 pediatric patients (child mean age 14.7 years, range 9-21 years). Data saturation was used to determine sample size.

The semi-structured interviews provided an opportunity for participants to tell their personal narratives while also ensuring that they responded to particular questions regarding symptom communication (see Table 2 for interview prompts). The interviewers asked children to share what it has been like for them to be sick. This broad prompt allowed children to tell their stories in their own words without interruption, and allowed them to freely describe what was important in their life while facing a serious illness. Children were interviewed without their parent(s) present.

Qualitative Data Analysis

All interviews were audiotaped and videotaped. They were then transcribed verbatim, with at least one individual performing a reliability check on each transcript and correcting any errors of transcription. The grounded theory approach used to perform the qualitative analyses used here is described in Hsiao, Evan and Zeltzer, 2007 [11].

A preliminary codebook with operational definitions for each code related to QoL was generated to promote consistency between coders and help eliminate individual coder bias. Blocks of texts ranged in size from a single sentence to several lines. Using this preliminary codebook, a random subsample of interviews was separately coded by two research assistants trained in qualitative content analysis. Where differences occurred, the two coders met with the project coordinator and appropriate adjustments were made to the set of codes, such as adding a new code or refining a code definition. Inter-rater reliability was determined by comparing the coded interviews for consistency in the manner in which codes were applied to the same narrative. Reliability between both coders was 0.91, which is considered to be high. The focus of the current study is on all codes concerning QoL.

Results

Of the 29 children who participated, seventeen (59%) participating patients were female and 12 male (41%); 59% were Caucasian, 31% Hispanic, and 3% Asian. Response rate for invited subjects for this qualitative study was 57%. Reasons for not participating consisted of “being too busy to participate” (7 families), “not a good time” (4 families), did not return phone calls (3 families), and child passed away before the meeting time was rescheduled (1 family). All enrolled

subjects completed the study. One family’s demographic information was missing. The demographic characteristics of the patients are shown in Table 1.

The average child interview was 17.8 pages. The five children who were under 12 years of age had relatively shorter interview transcripts (average 10.2 pages, range 5-18 pages). In addition, the two younger children with the shortest transcripts (5 and 6 pages each) had cognitive deficits, which made communication difficult. Length of the child transcript did not vary by child’s diagnosis or gender. Given that the interview elicited narratives, differences in lengths of interview may reflect differences in individual communication styles.

Table 3 shows the main domains of QoL identified by children with advanced diseases and the frequency in which these themes were mentioned.

Physical Quality of Life was defined as the ability to perform age appropriate daily activities including self-care, mobility, physical activity as well as leisure activities in relation to the child’s subjective perception of QoL. Children often cited physical limitations as the one aspect of being sick that bothered them the most. One of the most common problems children associated with these limitations was the inability to do activities that were important to them, such as sports, walking, eating their favorite foods, and taking care of themselves/being self-sufficient, etc. The inability to be a “normal” child, or what the child perceived as normal, was a major cause of the problem. Often, children stated that the inability to participate in such activities and be “normal” served as a source of stress and frustration in the child’s life. Specifically, they hated the stress of relying on others, feeling

Variable	Number (%)	Mean (SD)	Range
Dyads	29		
Child Characteristics			
Gender	12 (41%)		
Male	17 (59%)		
Female			
Age (years)		14.7 (3.90)	9-21
Education/ grade		8.39(3.43)	3-13
Ethnicity	17 (58.6%)		
Caucasian	1(3.4%)		
Asian/Pacific Is.	9(31.0%)		
Hispanic	1(3.4%)		
Other	1(3.4%)		
Missing Values			
Birthplace:	26(89.7%)		
USA	1 (3.4%)		
Other	2 (6.9%)		
Missing Values			
Religion	23 (79.1%)		
Christian	1(3.4%)		
Jewish	3 (10.3%)		
None	2 (6.9%)		
Missing Values			
Medical Grouping:	14 (48.3%)		
Cardiology	13 (44.8%)		
Oncology	1 (3.4%)		
GI	1 (3.4%)		
Missing Values			
Disease Stage	2 (6.9%)		
Post-BMT	11 (37.9%)		
Multiple Relapse	4 (13.8%)		
End Stage	3 (10.3%)		
Pre-transplant	3 (10.3%)		
Post-transplant	4 (13.8%)		
Congenital Heart Disease	2 (6.9%)		
Missing Values			

Table 1: Demographic characteristics of pediatric participants.

What has it been like to be sick?
What has bothered you the <i>most</i> while you have been sick?
Whom did you talk with about how you were feeling?
Do you think that (<i>caregiver/provider/other</i>) understood what it was like for you?
Did (<i>caregiver/provider/other</i>) do something or give you something that helped?
What do you think would have made it easier or harder to talk about how you feel with (<i>caregiver/provider/other</i>)?

Table 2: Child Interview Prompts.

belittled, and felt persistent sadness about losing their valued activities. Physical limitations had an impact on social functioning—children often felt left out when they are unable to function in the activities they see their friends participate in. An interesting idea expressed by a few of the children was the importance of not letting the pain and physical limitations dictate one’s life. These children would prevent their physical limitations from affecting their ability to reach their goals at all costs, even if this meant ignoring their doctors’ or parents’ orders, or their own pain, in favor of having fun. One child expressed the thought that he would rather die having fun than not have fun at all.

One teen boy remarked: “It’s not really the way they treat me it’s more like how I feel when I’m in the hospital. Like I feel like you know. I kind of feel like imprisoned like in the hospital like I can’t do anything... Especially when you’re like in the hospital and you got like tubes, you got like an IV on you and you’re hooked up to machines and you can’t really do anything but lay there. And like the more time you’re in there the more you feel like a slug and you can’t do anything.”

Psychological Quality of Life was defined through emotional and cognitive states, positive and negative affect, and behavior in relation to the child’s perception of QoL. Children made several statements about their mental and emotional states in relation to their illnesses that affect their daily psychological functioning. Common negative psychological effects of being sick were experiencing depression, anxiety and being uncomfortable. These mental states had several important consequences for the child’s QoL. Children often stated that feeling sad or uncomfortable in the hospital made them miss being home and they wanted to go home even more, which made them more globally unhappy about their illness. One child stated that the physical limitations of being sick accompanied by being made fun of and feeling left out from his peer group made him depressed and caused him to think about suicide, though he said would never actually do it.

Anxiety limited children from immersing themselves completely in the activities that they wanted to do the most. Feeling self-conscious and losing confidence made children more wary of returning to normal activities such as going back to school. Some children expressed that they created a negative self-perception, making them feel that they were not good enough to accomplish normal things. Some children attributed a negative outlook on life to persistent negative thoughts because it was hard to keep themselves from focusing on the bad parts of life. This negative thinking caused the child to be depressed, creating a vicious cycle in which other kids did not want to befriend the child, which led to more depression.

On the other hand, children did state some positive effects of being ill on their psychological functioning. For instance, children stated that their illness made them appreciate and be more thankful for things in life, giving new importance to things that, before, they had not considered. Children, thus, recognized the importance of having a positive outlook on life to help prevent them from focusing on the bad parts of the day, which in turn, helped them to enjoy life and what they had. An example of this effect is stated here by one 12 year old girl:

“A couple days after my big brain surgery that had taken the tumor

out, I became aware all of the things that I had to be thankful for.... I had a fabulous brain surgery with some really amazing brain surgeons working...I was being treated at, you know, some of the best hospitals, probably in the world, one could argue, um, you know, and that was really good. I had a doctor who was amazing, and really bright, and really tuned-in, and really solid. And I had amazing nurse care, and you know all these things I realized I could be grateful for. And having kind of this gratitude kept me from focusing on, kind of the bad parts of the day. You know, and it helps me kind of see kind of the plus side. And helped me to see all the things that could have gone wrong.”

Social Quality of Life refers to the ability to maintain social relationships, often defined as the number or quality of social contacts in relation to their subjective perception of QoL. Many of the children expressed the importance of their relationships with others as a major part of their overall quality of life. The quality of these relationships was often defined by how understanding, good at listening, and easy to talk to another person was. Benefits they derived from their social relationships included: having someone to talk to, giving the child hope for the future, keeping a positive perspective on life, keeping humor in life, and making life easier and more comfortable. However, children often expressed the difficulties of being ill in relation to their social functioning. Children spoke of losing relationships when they were unable to participate in activities with peers and go to social events. For these children, it was hardest to lose their friends and grow apart from their siblings. Moreover, it was also difficult to get along with the other children at school. They stated that one of their biggest challenges in dealing with their illness was being treated differently by others, especially by their peers. Finally, the limited nature of their interaction with family and friends seemed hardest for these children. Many expressed, including the child quoted here, that they missed their family and desired more contact from them:

“The worst thing I would say is just being separated from everybody because everyone keeps continuing what they were doing, but you kind of like have to take a break and step aside for a while so it’s the worst thing.”

Through the process of coding the interview texts by the various domains (physical, psychological, social) of QoL, we found that there was an additional theme important enough to categorize and label as “lifestyle values.” There were few interview excerpts that fell under this category, but regardless, we felt they were significant enough to mention here and perhaps develop further in future studies. A *lifestyle value* was defined as other areas of life or lifestyles that the child valued. In this regard, children would state various “rules to live by” as well as values that contributed to improving their quality of life. An example of text coded under this category is the following:

“I try not to be overcautious, like, ‘Oh, can’t touch that, it has germs.’ I just handle things like before only more careful, but I try not to like, change my life over it...”

Without directly querying the pediatric patients, themselves, it is unlikely that we would have gathered the type of results we did. More informally, within each of the domains of QoL, we observed

1. Physical: ability to perform age-appropriate daily activities including self-care, physical activity, and role and leisure activities	Children n (%), N=29
Unable to play sports, one of favorite activities	7(24.1)
Wants to do what other children do	4(13.8)
Unable to go out anymore to be with friends or other people	3(10.3)
limited from daily activities due to decreased range of motion	1(3.4)
Being weak compared to others; can't fully immerse self in activities	2(6.8)
Due to limited energy feels imprisoned with limitations	1(3.4)
Can only handle physical limitations for so long before feeling mentally like needs to do something	1(3.4)
Would rather have fun dying than no fun at all	1(3.4)
Prevented from doing over half the activities that want to do.	1(3.4)
Unable to return to normal life as it was before	2(6.9)
Loss of ability to walk, being stuck in a wheel chair stressful	1(3.4)
Disappointed that must always be consciously aware of daily decisions, not as free as other children of the same age.	1(3.4)
Being unable to do anything alone makes frustrated and feels like an infant	1(3.4)
Limits place in isolation, feels lonely	2(6.9)
2. Psychological: emotional and cognitive states, positive and negative effects on behavior:	
Feels constantly scared	1(3.4)
Experience of being sick is depressing and not fun	2(6.9)
Feels sad and uncomfortable being sick	1(3.4)
Feeling sad, uncomfortable, or scared makes child wish to go home to feel better	2(6.9)
Caused child to think about suicide has bad attitude, focuses on the negative	1(3.4)
Special help makes child feel not good enough to do anything by self	1(3.4)
Being depressed and gloomy makes other children not want to be around child	2(6.9)
Experience of being sick causes anxiety	2(6.9)
Has gained gratitude and appreciation for life	1(3.4)
Has lost confidence to think positively	1 (3.4)
Paranoid and frustrated -	1 (3.4)
Fears losing people who will be there to take care of child	1 (3.4)
Difficult to stay positive	1(3.4)
Feels self-conscious due to effects of illness	1(3.4)
Scared and worried for family's emotional suffering and pain	1(3.4)
Negative outlook due to loss of plans for the future because of illness	1(3.4)
had to stop school because needed to keep life fun and stress-free, which going to school would not allow	1(3.4)
Being sick is like a nightmare	2 (6.9)
3. Social: ability to maintain social relations, often the number or quality of social contacts:	
Having a best friend who listens, comments, and understands child makes child more comfortable	3 (10.3)
One of hardest parts of being sick is not being with family; desires more contact from family and friends	4 (13.8)
Being close with mom makes child comfortable and makes life easier	1(3.4)
Important to have people to talk to that understand child	1(3.4)
Child and mom have a dual relationship of strength	1(3.4)
Physical limitations make child feel left out from other kids	1(3.4)
Hard to get along with kids, so doesn't have friends own age	1(3.4)
Family helps keep humor in life	1(3.4)
Being separated and in isolation from everyone one of worst parts of being sick, it's depressing	1(3.4)
Being sick has made family closer	2(6.9)
Feels weird to be treated differently by people child used to know	1(3.4)
Hard to grow apart from family while sick	1(3.4)
4. Lifestyle values: other areas of life or lifestyles that child values:	
Just wants to be normal and be treated normally	3(10.3)
Living is important- key to not be overcautious, to not change life because of the sickness, to not be afraid of doing anything. Don't stop living life.	1(3.4)
Important to achieve plans for future even though illness put them on hold	2(6.9)
privacy is an important component to keep in life	1(3.4)

Table 3: Domains of Quality of Life identified by children.

children's responses contained words demonstrating distress levels of a time-sensitive or time-pressured nature, such as "constantly," and "can only handle physical limitations *for so long*," to describe their physical, psychological, and social quality of life. Some examples of these statements include:

"I am disappointed that *I must always be consciously* aware of daily decisions."

"I feel *constantly* scared."

"I can only handle physical limitations *for so long* before feeling mentally like I need to do something."

Discussion

Our findings support the work of other qualitative studies which call for a multidimensional (physical, psychological, and social) framework for defining QoL [2,3], and also suggests the importance of directly asking the pediatric patient what is meaningful in his/her life in order to determine individual QoL [11,12].

The study that most closely resembles the objectives of our current study is Hinds et al.'s [11] qualitative examination of children's responses to interview questions relating to pediatric QoL. Her results primarily revealed that by directly asking pediatric patients the meaning of being ill to them, researchers and healthcare providers could more accurately assess what QoL is for children diagnosed with cancer and undergoing initial stages of treatment. However, the concept of what is quality of life and what is valued by the child during stages of advanced pediatric disease was not deciphered. A unique element of our study was our exploration of the pediatric patient's perception of their QoL during advanced disease.

Although our study did not ask specifically about what patients felt brought meaning to their life, pediatric patients, nevertheless, initiated discussion regarding this topic on their own. Thus, in addition to categorizing QoL into physical, psychological, and social domains, we also created a separate category termed *lifestyle values*. This proposed new domain of quality of life consisted of statements made by children which were "rules to live by" or values that facilitated their quality of life. Future study is needed to validate this emerging concept since the current study consisted of a small sample size. The qualitative results we uncovered here would be important to incorporate into already existing quantitative instrumentation that have not been standardized on pediatric patients with advanced illness. For example, after administering a quantitative instrument assessing pediatric quality of life on domains of physical, psychological and social well-being, it may be important to then query the child using an open-ended question such as, "What does good *physical* well-being/QoL mean to you?" This question can then be repeated for each other domain of quality of life (e.g. *psychological, social*). The interviewer can then ask a more general question regarding the child's rules that she or he lives by and what values in life they hold as a priority. Information derived from this type of quantitative-qualitative assessment can allow healthcare providers and family members to achieve a better, more individualized understanding of a particular patient's quality of life needs, which can, in turn, inform decision-making and goals of care.

With regards to some informal observations we made regarding children's responses containing words/phrases demonstrating distress levels of a time-sensitive or time-pressured nature (e.g. "constantly," and "can only handle physical limitations *for so long*"): this sense of urgency relating to factors affecting their QoL appeared to be different from the type of answers that would be gleaned from a typical pediatric QoL

assessment instrument (e.g. "How much of a problem is it for you to run more than one block?" with Likert scale response choices of "never, almost never, sometimes, almost always, always") [8]. It is possible that at an advanced stage of disease, certain physical, psychological, and social limitations create a more driving sense of urgency and distress than perhaps at an earlier stage of treatment. Therefore, level of distress experienced by patients regarding any physical, psychological and social limitations' impact on their QoL would be important to assess at an advanced stage of disease. For example, it is likely that a child just beginning cancer treatment after being diagnosed may feel that an extended hospital stay is less distressing and plays less of an impact on his/her QoL than a child with advanced disease who has endured years of hospitalization and/or more severe episodes of illness. The level of distress or urgency on the part of the patient to ameliorate any particular domain (physical, psychological, social) of his/her quality of life may be moderated by their stage of disease. Thus, based on our observations, it may be important for healthcare providers to inquire, using open-ended questions, about distress level and meaning associated with physical, psychological, social domains of QoL as an approach for assessing overall quality of life.

An extension from this study may be a survey derived from these findings that could be used by healthcare providers during advanced stages of pediatric illness to measure quality of life. From this information, healthcare providers may learn from their pediatric patients how to balance goals of care involving life extension with those involving comfort measures.

Additional future studies can aim to compare QoL responses between children with newly diagnosed conditions and those with recurrent hospitalizations, as well as examine whether children experiencing chemotherapy have different ideas and language for how they describe their QoL, as opposed to those children receiving a heart transplant.

As this study is a work-in-progress, as well as a first step to understanding quality of life from the perspective and language of children with advanced disease, some limitations to the current study include: small sample size, bias towards two specific disease categories, a broad age range, and a limited socio demographic representation. Next step studies could then prospectively take into account the limitations as well as the findings we have presented here and improve on future study methodologies. With better techniques to more accurately assess pediatric QoL, healthcare providers may better understand pediatric patients' overall experience when confronting advanced stages of their illness and be able to improve pediatric palliative care for their patients.

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