

Identifying domains of quality of life in children with cancer undergoing palliative care: A qualitative study with professionals

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(RECEIVED May 6, 2016; ACCEPTED December 6, 2016)

ABSTRACT

Objective: The goal of pediatric palliative care (PPC) is to maintain the quality of life (QoL) of children whose lives are threatened. However, there are sparse scientific data on the domains of QoL in this particular context, and no measurement strategies are available. The present study aims to describe the domains of QoL in the context of PPC in oncology, according to the perceptions of professional caregivers.

Method: Semistructured interviews were conducted with a random sample of 20 professional caregivers from the Division of Hematology/Oncology at Le Centre Hospitalier Universitaire Sainte-Justine (Montréal, Canada). The caregivers were asked about their perceptions about the QoL of the children they have cared for in this context. The data were analyzed using inductive thematic content analysis.

Results: The analysis allowed us to identify seven domains of QoL: “physical comfort,” “alleviation of psychological suffering,” “fun and the present moment,” “sense of control,” “feeling valued and appreciated,” “feeling that life goes on,” and “meaningful social relationships.”

Significance of Results: Caregivers recount the regard that should be accorded to maintaining well-being and a sense of fun, as well as fostering the child’s abilities, taking account of the progression of the disease, and to fulfilling his or her needs, especially social ones. Our results also demonstrate that all domains were positively referred to by professional caregivers. The data from our study will lead to better assessment of QoL according to the trajectory of a child with advanced cancer while undergoing PPC.

KEYWORDS: Pediatric palliative care, Quality of life, Cancer, Professionals, Qualitative study

INTRODUCTION

Recent advances have contributed to improving the curative care of children with cancer and increasing their survival rate. However, no less than 20% of

young individuals with cancer die each year (Comité Consultatif de la Société Canadienne du Cancer, 2015). Pediatric palliative care (PPC) is about helping children and their families deal with this medical condition while optimizing their quality of life (QoL) (Association Canadienne de Soins Palliatifs, 2006; Gouvernement du Québec, 2006; World Health Organization, 2013).

In order to describe and evaluate QoL in the specific context of PPC in oncology, various authors

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have collected the points of view of children with advanced cancer or those of their parents (Barrera et al., 2005; Friedrichsdorf et al., 2015; Hechler et al., 2006; Tomlinson et al., 2011; von Lützu et al., 2012). These studies depict a portrait of QoL that highlights the traditional dimensions of physical, emotional, and social QoL (Pépin et al., 2015). Functional deficits in terms of mobility, sensation, and self-care, as well as pain and fatigue levels, were the main indicators used to evaluate the QoL of these young individuals (Tomlinson et al., 2011). Research has also highlighted the more positive components of QoL—such as maintaining the child's sense of normalcy, focusing on family activities, maintaining hope, and having fun or taking pleasure (Barrera et al., 2005; Friedrichsdorf et al., 2015; Hechler et al., 2006; Kamper et al., 2010; von Lützu et al., 2012).

In contrast with these reports, the instruments that are now available to evaluate QoL in the pediatric context—and are thus likely to be applied in PPC—remain focused on symptoms or functional deficits and are based on inappropriate time perspectives (e.g., months) (Hinds et al., 2006; Liben et al., 2008). Importantly, no specific QoL instruments have been developed for the PPC context, as was evidenced in a recent systematic review conducted by Coombes and colleagues (2016). As can be seen from the research reviewed, sensitivity is an essential quality of PPC, but it is typically not documented on available measures, probably because the dimensions and timeframes are not appropriate for evaluating changes occurring during PPC. Widely employed instruments in pediatrics (like the Pediatric Quality of Life Inventory [PedsQL]) have inadequate validity when used in PPC, suggesting that there are different QoL constructs in children with life-limiting illnesses and in other populations (Huang et al., 2010). A recent research program was aimed at developing a tool to measure QoL in the PPC context—the Pediatric Advanced Care Quality of Life Scale (PAC-QoL)—but it was not based on domains generated by the participants or their caregivers and thus evaluated the same traditional domains (Cataudella et al., 2014; Morley et al., 2014). As the definition of QoL may be specific for PPC and the child's status may change drastically over relatively short periods of time, there is a need to develop a new approach adapted for PPC.

In summary, while the mission of PPC is to promote QoL, the domains that QoL encompasses are still poorly defined. The traditional themes of QoL do not seem adequately specific for this population and are focused on deficits. Some studies have concentrated on a depiction of caregivers in this context, but more so on the definition of care quality criteria than on QoL itself (Andersen et al., 2004). Descrip-

tions are made retrospectively—for instance, by bereaved parents—and do not capture the very nature of QoL “in the here and now.” An increased awareness of caregiver representations of children's QoL would complement the dimensions identified by previous studies and could lead to more explicit definitions. Although not exempt from bias, professionals hold a unique view on children's status and well-being. Such a clarification of the concept of QoL in this area is a necessary preliminary step to developing a sound measurement strategy.

The objective of our present study is to identify the domains of QoL for children with cancer in palliative care according to the perceptions of professionals working in pediatric hematology/oncology. Our strategy is to help generate positive as well as negative images of QoL in order to operationalize what is meant by “quality of life” in this context. We wish to identify practical domains that can be defined precisely and utilized for further development of outcome measures.

METHODS

Our study is based on a qualitative research design that calls for a descriptive inductive analysis (Braun & Clarke, 2006; Lapierre, 1997). Based on a constructivist epistemological framework, it aims to describe the concept of QoL from the perspective of individual caregivers who are currently caring for or who have cared for a child with advanced cancer.

It is of critical importance for us to mention our background and make explicit our preconceptions to satisfy the criterion of transparency. The authors who have been particularly involved in the data analysis include a doctoral candidate in psychology at the Centre for Psycho-Oncology at Le Centre Hospitalier Universitaire (CHU) Sainte-Justine (JAB) and her doctoral supervisors at the Université de Montréal (SS) and the Université de Sherbrooke (VP). JAB developed her clinical experience in a program targeting interventions for children and teenagers using a psychodynamic approach. Her experience in working with children with cancer has grown through volunteer activities with the Division of Hematology/Oncology at the CHU Sainte-Justine and other organizations in the field. SS has developed an expertise in pediatric psycho-oncology as a research unit director in the same hospital, originally developing research within a cognitive behavioral orientation, and he has been recently supervising qualitative research projects using interpretative phenomenological analysis and inductive thematic analysis on grief. VP is a professor of psychology and a specialist in behavioral and cognitive disorders in children. She brings a structured lay vision to interpretations.

Other of our authors have been major figures in the development of pediatric palliative care in French-language countries. NH is a clinician and director of the palliative care unit at the same hospital, and MD is a hematologist/oncologist with a long experience in clinical ethics (research and practice). ML has been a postdoc working on the initial development of the research protocol submitted to the ethics committee, after achieving her doctorate in pediatric psychology. She is currently supervising a replication of the present study at the Université Catholique de Louvain (Belgium). Overall, our team was guided by an evidence-based approach. As a consequence, the literature and the components of existing instruments guided our preconceptions that participants would mainly focus on the absence of pain and symptoms to describe QoL (e.g., Lyons et al., 2009; Tomlinson, et al., 2011; Varni et al., 1999). We also anticipated that QoL would be described within a shorter temporal perspective (i.e., weeks or days instead of months), in line with the usual clinical observation that a child's condition can change frequently and rapidly in palliative care (Coombes et al., 2016; Hinds et al., 2004).

Participants

Eligible participants were required to: be a member of the Department of Hematology/Oncology of our hospital, have cared for at least one child (≤ 18 years) with advanced cancer and treated in palliative care, and be able to speak French. A total of 20 health professionals were interviewed: 3 hematologist/oncologists, 1 psychiatrist, 5 members of the nursing staff, 2 clinical fellows, 1 nutritionist, 1 art therapist, 1 psychologist, 3 occupational therapists, and 3 physiotherapists. Participants included 17 women and 3 men, with a mean age of 41 ± 9 years. They had been active in the hematology/oncology department for 9 ± 7 years. No exclusion criteria were imposed.

Recruitment

We employed a maximum variation sampling recruitment strategy (Patton, 2002). Data were collected from caregivers from various professions to ensure the representativeness of different professions in hematology/oncology and data completeness. Potential participants were selected from a comprehensive list of the members of the department ($N = 103$). Each week, three professionals were randomly selected among three different professions. This random selection was chosen to favor the inclusion of different professions and avoid bias of a-priori selection. Eligibility was confirmed during the first contact by email or through subsequent reminders. The caregivers who provided their consent were in-

terviewed individually. Because the representations of QoL could differ from one profession to another, and because we wanted to make comparisons between them in a future analysis, we decided to include a number of participants higher than what would be normally expected in qualitative research (Patton, 2002). A total of 28 caregivers were contacted: 5 did not meet the inclusion criteria and 3 refused to participate (participation rate = $20/23$, 87%). We stopped recruitment when saturation was achieved in a sample including a sufficient variety of professions in three categories: physicians, nurses, and professionals. Notably, one factor in favor of saturation was that all participants were from one and the same site. The study received ethical approval from the CHU Sainte-Justine and the University of Sherbrooke. The first author (JAB) conducted the recruitment and the interviews with participants.

Data Collection

Data were collected through individual semistructured interviews (duration = 1 hour) in which participants were asked open-ended questions according to an interview guide developed by the research team (see Online Appendix A). The questions were adapted from Hinds et al. (2004).

The interview process and agreed-upon understanding of the questions from the interview outline were approved after pilot interviews were conducted with two caregivers not included in the final sample. During the interviews, the researcher adopted an open and empathetic attitude, trying to distance herself from prior knowledge regarding QoL and taking a step back from possible interpretive categories (Paillé & Mucchielli, 2012). At the end of the interview, participants completed a brief sociodemographic questionnaire. The interviews were recorded and transcribed verbatim for data processing.

Data Analysis

QDA Miner 4.0 software was used for coding, and the analysis was then structured in Microsoft Word to allow for greater flexibility of the analytical process. The data were analyzed inductively according to the thematic analysis approach (Braun & Clarke, 2006; Paillé & Mucchielli, 2012). First, the principal investigator became acquainted with the data by transcribing and rereading the interviews. Then, according to a continual thematization process, the meaning of the text to be analyzed was extracted from each transcription by identifying codes in the margins (coding). The inventory of these codes was systematically created in a separate document (list of codes). From this list, we created the thematization journal, in which a systematic process of code

identification, consolidation, integration, subdivision, and hierarchization was performed as the data were collected. During the analysis, the themes were refined, clarified, and specified by rereading the interviews, through discussions and exchanges among the researchers, and by resorting to an external expert specialized in this approach. The themes were then hierarchized in the form of central themes in order to gradually build a synthetic and structured representation of the analyzed context (thematic tree). Finally, we proceeded to nomination and definition of these themes to describe a representation of QoL (Paillé & Mucchielli, 2012).

To ensure the rigor of our analysis, we employed recommended methodological strategies (Mays & Pope, 2000; Whittemore et al., 2001). To ensure the reliability of our study, we used a reflexive journal to record all steps and decisions made during the analysis. The coding of transcripts was performed by the first author (JAB) and checked by her supervisors (SS, VP). Consensus was sought in case of divergence. To ensure a sound application of the method, we called for an external qualitative analysis expert (MC, see acknowledgments). On two occasions, she checked our compliance with the rules of the analysis and provided corrective advice. To ensure the credibility criteria, triangulation was utilized by collecting the perspective of participants from various professions. We also validated the methodological approach by way of a feedback discussion on preliminary findings to the hematology/oncology department and at PPC/psycho-oncology congresses. Throughout the analysis, we discussed and exchanged information on coding of transcripts and thematization within the research. In this process, as recommended by the authors of descriptive inductive analysis (Braun & Clarke, 2006; Lapierre, 1997), specific attention was paid at all steps to the convergence and divergence of themes during their progressive definition.

RESULTS

Following the analysis, seven domains were identified to describe caregivers' perceptions of QoL in PPC in oncology: (1) physical comfort, (2) alleviation of psychological suffering, (3) fun and the present moment, (4) sense of control, (5) feeling valued and appreciated, (6) feeling that life goes on, and (7) meaningful social relationships. The final thematic tree is depicted in Figure 1.

Physical Comfort

All participants mentioned this domain as an important aspect of QoL. Mainly described by the absence

of pain or symptoms or by the relief of both, physical comfort is also characterized by the satisfaction of such physical needs as getting enough sleep, breathing properly, or eating without choking. Comfort is a necessary aspect of QoL, but it is not considered sufficient by caregivers.

Alleviation of Psychological Suffering

QoL is also characterized by a state of alleviation in which the cognitive symptoms (e.g., hallucinations, loss of consciousness) and psychological symptoms (e.g., anxiety, psychological distress) associated with the medical condition or perceived limitations are adequately controlled.

Fun and the Present Moment

This theme highlights the increasing importance of fun and being in the present moment for the QoL of children with advanced cancer. Professionals speak of "being in life" to describe how important it is for the child to experience fun at times when he or she is not anticipating the end of life but is rather able to enjoy the present moment:

P4: For now, I think his quality of life is high. It's good precisely because they are very much in life, having fun and enjoying it.

Fun would be reflected in daily life through activities the child likes to do or through the presence of small instantaneous pleasures:

P7: I have a little guy in mind. Well, maybe it's playing with his trucks [...] to be read a story by mom on her lap. Maybe it's simply to make soap bubbles. Maybe it's to be able to dress up as a princess. What does a child like to do? To play, to laugh [...] it can be very small joys, as small as going outside in a stroller, it can be as small as to just be sitting in bed and having friends over. It can be as small as just having a hand stroked.

Food also plays a crucial role from the perspective of the caregiver. Despite the fact that the disease and treatment often affect nutrition (dietary restrictions, chewing difficulties, stomach problems), some professionals have witnessed moments where the pleasure of eating appeared to be prominent in the child they were caring for:

P8: I saw several children at the end of their lives for whom their pleasure was to eat. [...] There are children, I swear to you, who love to eat and whose dream is really to have a big meal prepared

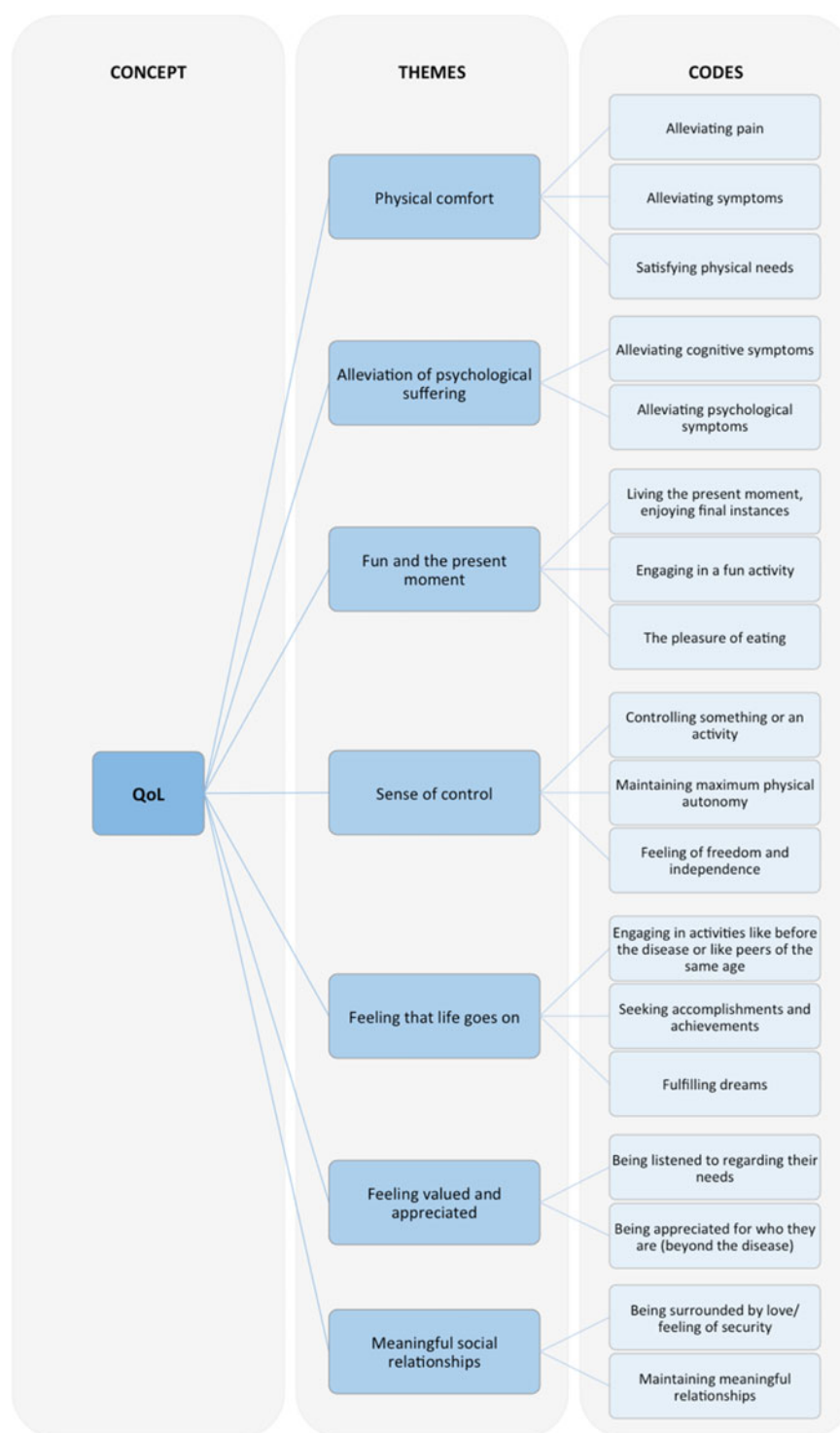


Fig. 1. Quality of life definition and domains as reflected by professional caregivers' views in pediatric oncology.

by their mother and to eat that during the last weeks of . . .

Sense of Control

According to the professionals, a part of QoL is linked to the feeling children have of controlling aspects of their daily life and their environment. Many caregiv-

ers reported that being in control of a situation, like being able to partake in their own care, is a crucial aspect of their QoL:

P3: We took the opportunity, when he was better, to have him partake as much as possible in his diaper change [. . .] keeping him active as much as possible in his activities of daily life, too.

Similarly, the loss of physical autonomy is pervasive, especially in older children and teenagers. Young individuals often find themselves confronted with functional losses resulting in amputations, paralysis or a lack of energy that prevent them from performing tasks without assistance. The professionals reported that the QoL of these young individuals is characterized by their ability to do things on their own so that they can maintain as much physical autonomy as possible:

P7: It's the fact of going on his own. So, for him, he would go with someone, but it wasn't, he wasn't required to go with daddy, mommy, or things like [...] So, he would go with all his independence, and he was the one to make the decisions, and so on. He had brought his money, and he paid for his meal. That had been really, really interesting.

These young individuals are also dependent on the care provided by their relatives, which undoubtedly affects their intimacy and freedom. It is therefore essential for their QoL for them to be able to experience moments of independence by having the freedom to make decisions and to do what they want to do.

Feeling Valued and Appreciated

Quality of life was here associated with the feeling of appreciation the child can experience and the feeling that he or she is being valued and considered as a person, beyond his or her deficits and the difficulties linked to the disease. The fact of being listened to and respected along with his or her needs and desires is also a central aspect of this theme:

P7: [...] the quality of life, it would be to be appreciated for who he was. To say his name and to not see him for all that he was missing, but for who he was. I would say that was his quality of life.

Feeling that Life Goes on

This theme refers to the maintenance of daily activities "like before the disease," and to the aspiration to accomplish or achieve dreams despite the limitations caused by the disease, such as fatigue and pain. The professionals described a sense of normalcy by stressing the importance children attribute to maintaining activities they used to participate in before the disease or that children of the same age do:

P16: I think that at some point, too, not being at home anymore, she had been to the movies, well with the wheelchair and everything, with a friend or a couple of her friends and mom was probably

there. [...] To have an activity like kids her age [...] I think all of that was like, "Wow, I was able to go see this movie, even though I was in a wheelchair!" And, you know, like eating popcorn. [...] Anyway, I remember that she was very very happy. But I think it's the fact of doing things of her age and to see the movie of the year, of that summer.

Self-actualization and the fulfillment of personal projects also constitute an important aspect of the QoL of young persons in PPC: pursuing secondary education, doing handiwork, being able to sit up in bed:

P6: The best days were the days when he was able to say that he had achieved something. It was much less than what he was able to achieve before. It could be an outing. I'm thinking of the time he went to go see the Canadians [Montreal's hockey team]. It can be simpler things than what he would do before, but to have achieved something.

Thus, vitality is an essential aspect of QoL. Although the nature of the achievement can vary from child to child, it is the inner feeling gained that is important for QoL. Finally, these children still need to dream about projects that stimulate them. Thus, the possibility to daydream, to live out a childhood dream, and to have desires also characterizes their QoL.

Meaningful Social Relationships

P12: In quality of life, there is also the family environment. There are children who are lucky to have amazing support from their family and very attentive parents [...] siblings who are very involved and who play an important role.

Maintaining meaningful relationships with those around him or her is also considered essential to QoL. When caregivers were asked to say what they thought was the most important for the child they were caring for in PPC, most stated that it seemed to be the fact of being surrounded by his or her loved ones: parents, families, and friends, but also the caregiving staff.

DISCUSSION

Our study found a descriptive model of QoL in the context of PPC based on the views and experience of professional caregivers from a hematology/oncology department. This model distinguishes itself as previous studies have primarily focused on the perspectives of children and parents (Barrera et al., 2005; von Lützu et al., 2012; Friedrichsdorf et al., 2015; Hechler et al., 2006).

The first three themes—“physical comfort,” “alleviation of psychological suffering,” and “meaningful social relationships”—are consistent with the physical, emotional, and social dimensions usually utilized to conceptualize QoL and are present in all QoL assessment tools utilized in pediatric oncology (Coombes et al., 2016; Pépin et al., 2015). That the caregivers recalled these dimensions highlights the fact that in the palliative phase of cancer, as at other points along the disease trajectory, the central aspects of QoL are the alleviation of disabling symptoms and pain, treatment of emotional distress, anxiety, and sadness, and maintaining meaningful social relationships that contribute to a sense of affiliation and the need for love and security.

In addition to social ties with family and friends, our results also bolster the importance of fostering meaningful relationships with professionals. Particular attention was paid by participants to the impact of interpersonal communication on children's QoL. The role of communication between children and their parents has been described previously (Barrera et al., 2005). In our study, the role of communication with professionals and within the professional team was particularly underlined. Inconsistency among team members was cited as a factor that negatively affected children's QoL.

In addition, our professional caregivers reported four other themes that are rarely mentioned or not listed at all in the literature of QoL in PPC as perceived by children and their parents: “fun and the present moment,” “sense of control,” “feeling valued and appreciated,” and “feeling that life goes on.” These themes are positively formulated and based on positively worded transcripts. This differs from the usual portrayal of QoL from previous studies in which indicators are generally related to deterioration of health, limitations, or deficits (Knapp et al., 2012; Tomlinson et al., 2011).

First, the “fun and the present moment” theme focuses on the presence of short pleasurable moments and the ability to live in the present moment. In addition to confirming the relevance of focusing on the child's degree of pleasure or on enjoyable family activities as previous studies have done (Barrera et al., 2005; Friedrichsdorf et al., 2015), our caregivers' discourse explains that the child's QoL depends on his or her ability to remain rooted in the present moment. This input also emphasizes the need to be sensitive to a child's sense of satisfaction with regard to his or her expectations and desires. It is interesting to note that caregivers' examples were always specific and focused within a short temporal perspective. The professionals spoke of “moments” and “days”—the envisioned perspective was never that of a month, as it is in the tools adapted to other contexts (e.g., PedsQL).

The theme “sense of control” attests to the caregivers' concerns regarding the pervasive influence that loss of autonomy and a sense of freedom has over a child's QoL in PPC. Although autonomy is a central aspect in many QoL models, the very concrete examples and suggestions given by professionals to foster and maintain autonomy in children constitute something new. This suggests that professional teams can do a lot on this topic. This is all the more important since caregivers believe that the perception of control also serves to offset deterioration of health. It is beneficial for a child's QoL to favor this sense of control by allowing them to partake in care decisions. This theme is relevant to the child's life potential in relation to his or her current abilities and again contrasts with the tendency to evaluate a child's QoL solely based on deficits (Knapp et al., 2012).

The third theme, “feeling valued and appreciated,” is rarely mentioned as a component of QoL in the literature. It mainly echoes an appreciation of the individuality and subjectivity of a child's experience with respect to his or her QoL. Our professionals mostly referred to concrete actions that should be taken to favor a child's QoL. Beyond the few examples given, it is possible that this theme is particularly influenced by the norms of patient-centered care that are often discussed in oncology. It is recommended to provide respectful care that has an affinity for a patient's personal preferences, needs, and values, and to ensure that the patient's values guide clinical decisions (Institute of Medicine, 2001).

Finally, with regard to the theme “feeling that life goes on,” our results suggest that it is particularly important for the child to continue to engage in the activities he/she performed before, despite the symptoms and losses associated with the course of the disease. This is consistent with the results of multiple studies which showed that fatigue is one of the most common symptoms and one of the most poorly supported for children throughout the cancer trajectory, particularly when it is longlasting (Barsevick et al., 2013). Having the opportunity to engage in activities allows them to feel alive. The maintenance of activities is also related to a quest for normalcy vis-à-vis the child's peers, but also with respect to him or herself. This theme is in line with transcripts obtained from children and parents on maintaining normalcy (Barrera et al., 2005; Kamper et al., 2010). The members of the medical team emphasized the importance of a sense of accomplishment and achievement of dreams for a child's QoL. Having the opportunity to experience small accomplishments or to live out a dream can certainly provide hope and strength during this time of hardship, a component that has been associated with QoL in previous research (Barrera et al., 2005; Cataudella et al., 2014; Morley et al., 2014).

One of the explanations for the differences between the themes identified in our study and those from previous research (e.g., Barrera et al., 2005; Cataudella et al., 2014) is that we collected caregivers' perspectives. It is possible that the positions of the professional caregiver affords some degree of objective separation that could make it possible for certain themes to emerge more clearly. While children are often in a difficult position when it comes to articulating their QoL, caregivers are in the powerful position of being able to put the experiences of the child into words. Of course, this implies a high degree of responsibility, as such perceptions can be biased by one's own impressions and/or misunderstandings. Another reason is that, in contrast to the establishment of the PAC-QoL dimensions, which relied on a literature review and expert panel discussions (Cataudella et al., 2014; Morley et al., 2014), our dimensions were determined inductively by the participants themselves. We attempted to disregard prior assumptions in our research process. Thus, the description of QoL offered herein is based on caregivers' experiences rather than on domains defined *a priori*.

An important notion that emerges from our study is the specific and individual nature of a child's QoL. Most professionals were conscious of the limitations of their position. They strongly held that the professional caregiver is only one of several informants on the child's status, but that the best informant is most probably the child him/herself. These results are in line with the utmost precision required in the clinical context, as various authors have showed that the trajectory, the stage of disease development, and the type of cancer should be taken into account in the assessment of QoL (Tomlinson, 2011; Varni et al., 2007).

A final important idea that emerges from our results concerns the limited timeframe to be considered when conceptualizing QoL in the context of pediatric palliative care. This presents several advantages, such as focusing on daily activities or achievements and thus providing a greater opportunity for expression of positive life events instead of limitations and/or losses. Moreover, children who receive PPC often have frequently changing symptoms, which can itself affect their QoL. At the same time, a reduced timeframe makes it more possible to evaluate individual changes (Coombes et al., 2016). In other words, focusing on short periods of time increases the evaluator's sensibility regarding the variability of QoL over time. Particularly in pediatrics, children and adolescents are known to use different markers to elaborate the concept of time, and such markers change over the course of their development (Michel et al., 2012; Rebok et al., 2001). This would probably make a longer timeframe more valid in older children. Shorter re-

call periods (i.e., 2 days) have already been used with success in some pediatric disease-specific measures (e.g., the Memorial Symptom Assessment Scale [MSAS], Collins et al., 2002).

LIMITATIONS AND IMPLICATIONS OF THE STUDY

One limitation of our study is its sample. Even if the themes concern children's QoL, they were not identified by interviewing children and their families, and therefore cannot be put forward as representing the child's point of view. However, the perspective of professional caregivers is particularly important in cases where a multi-informant strategy is employed. Updating professionals' representations of the QoL of children they care for in PPC can foster better communication and enhanced consistency within the care team. In addition, although we tried to meet caregivers from different professions, the sample allocation was not representative of oncology staff. It is possible that this introduced biases in the frequency of certain codes, but it is unlikely to be reflected in the thematic categories, since categories were not determined on the basis of frequency. Finally, the interview guide (Hinds et al., 2006) encouraged a shorter timeframe through questions about good/bad days. However, it should be noted that a large proportion of professionals spontaneously described QoL according to a greatly reduced timeframe, associated with the present moment, which is far shorter than that proposed by interview questions focusing on "a good day."

Despite these limitations, our research could have important implications. In practice, professionals could share and exchange ideas related primarily to the identified themes and delineate avenues for improving QoL using this framework. In the research framework, one could present the findings to children and parents in PPC and get their impressions by using, for example, a participatory action research model. This would test the robustness of our present findings and foster development of a practical evaluation strategy for the validated themes. The identified components of QoL could lead to a better assessment of QoL according to the trajectory of a child with advanced cancer by allowing for the creation of a rating scale. Recent research has asserted the lack of outcome measurement in PPC (Coombes et al., 2016). Exchanging details on these components would help identify targets for individual progress, involving many aspects of care—for example, providing comfort by changing a child's position in bed or by giving the child an opportunity to draw or write.

CONCLUSIONS

Our study offers a model of how professionals who have cared for children with advanced cancer in PPC conceive of QoL. Based on a descriptive inductive analysis of interview transcripts, we found three themes already present in the literature: “physical comfort,” “alleviation of psychological suffering,” and “meaningful social relationships.” Our professional caregivers suggested four new themes: “fun and the present moment,” “a sense of control,” “feeling valued and appreciated,” and “feeling that life goes on.” Future studies should explore these dimensions in children and their family members, which could help develop practical assessment tools to measure quality of life in the context of pediatric palliative care.

DISCLOSURES

The authors hereby state that they have no conflicts of interest to disclose.

ACKNOWLEDGMENTS

The authors are grateful to the Coast-to-Coast Foundation (Canada) for financially supporting our study. Additional funding came from the Sainte-Justine UHC Foundation through the Center of Psycho-Oncology (Dr. Serge Sultan, Montréal, Canada). We also thank Dr. Mélanie Couture (Centre de Recherche et d'Expertise en Gériatrie Sociale) for sharing her expertise on qualitative data management, Gabrielle Ciquier for translating the manuscript into English, and Léonor Fasse for providing comments on an earlier draft. We are indebted to the members of the Department of Hematology/Oncology, who graciously shared their experience and views.

SUPPLEMENTARY MATERIALS AND METHODS

To view supplementary material for this article please visit <https://doi.org/10.1017/S1478951516001048>.

REFERENCES

- Andersen, E.M., Seecharan, G.A. & Toce, S.S. (2004). Provider perceptions of child deaths. *Archives of Pediatrics & Adolescent Medicine*, 158(5), 430–435. Available from <http://jamanetwork.com/journals/jamapediatrics/full-article/485704>.
- Association Canadienne de Soins Palliatifs (2006). *Soins palliatifs pédiatriques: Principes directeurs et normes de pratique* [in French]. Ottawa: Association Canadienne de Soins Palliatifs. Available from http://acsp.net/media/34584/Normes_pediatriques-soins_palliatifs_31_mars_2006.pdf.
- Barrera, M., D'Agostino, N., Gammon, J., et al. (2005). Health-related quality of life and enrollment in Phase 1 trials in children with incurable cancer. *Palliative & Supportive Care*, 3(3), 191–196.
- Barsevick, A.M., Irwin, M.R., Hinds, P., et al., (2013). Recommendation for high-priority research on cancer-related fatigue in children and adults. *Journal of the National Cancer Institute*, 105(19), 1432–1440. Epub ahead of print Sep 18. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3888121/pdf/djt242.pdf>.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Bruera, E., Kuehn, N., Miller, M.J., et al. (1991). The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *Journal of Palliative Care*, 7(2), 6–9.
- Cataudella, D., Morley, T.E., Nesin, A., et al. (2014). Development of a quality of life instrument for children with advanced cancer: The Pediatric Advanced Care Quality of Life Scale (PAC-QoL). *Pediatric Blood & Cancer*, 61(10), 1840–1845. Epub ahead of print Jun 19.
- Collins, J., Devine, T., Dick, G., et al. (2002). The measurement of symptoms in young children with cancer: The validation of the Memorial Symptom Assessment Scale in children aged 7–12. *Journal Pain Symptom Management*, 23(1), 10–16. Available from [http://www.jpmsjournal.com/article/S0885-3924\(01\)00375-X/pdf](http://www.jpmsjournal.com/article/S0885-3924(01)00375-X/pdf).
- Comité Consultatif de la Société Canadienne du Cancer (2015). *Statistiques canadienne sur le cancer 2015* [in French]. Available from <http://www.cancer.ca/~media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/Canadian-Cancer-Statistics-2015-FR.pdf?la=fr-CA>.
- Coombes, L.H., Wiseman, T., Lucas, G., et al. (2016). Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use. *Palliative Medicine*, 30(10), 935–949. Epub ahead of print May 31. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5117129/pdf/10.1177_0269216316649155.pdf.
- Friedrichsdorf, A.J., Postier, A., Dreyfus, J., et al. (2015). Improved quality of life at the end of life related to home-based palliative care in children with cancer. *Journal of Palliative Medicine*, 18(2), 143–150. Epub ahead of print Nov 17, 2014.
- Gouvernement du Québec (2006). *Normes en matière de soins palliatifs pédiatriques: Groupe de travail sur les normes en matière de soins palliatifs pédiatriques* [in French]. Available from <http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2006/06-902-05.pdf>.
- Hechler, T., Blankenburg, M., Friedrichsdorf, S. J., et al. (2006). Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. *Klinische Padiatrie*, 220(3), 166–174.
- Hinds, P.S., Gattuso, J.S., Fletcher, A., et al. (2004). Quality of life as conveyed by pediatric patients with cancer. *Quality of Life Research*, 13(4), 761–772.
- Hinds, P.S., Burghen, E.A., Haase, J., et al. (2006). Advances in defining, conceptualizing, and measuring quality of life in pediatric patients with cancer. *Oncology Nursing Forum*, 33(Suppl. 1), 23–29.
- Huang, I., Shenkman, E.A., Madden, V.L., et al. (2010). Measuring quality of life in pediatric palliative care: Challenges and potential solutions. *Palliative Medicine*,

- 24(2), 175–182. Epub ahead of print Dec 10, 2009. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3810279/pdf/nihms302465.pdf>.
- Institute of Medicine (2001). *Crossing the quality chasm: A new health system for the 21st century*. Available from <http://www.nationalacademies.org/hmd/~media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf>.
- Kamper, R., Van Cleve, L. & Savedra, M. (2010). Children with advanced cancer: Responses to a spiritual quality of life interview. *Journal for Specialists in Pediatric Nursing*, 15(4), 301–306. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3016439/pdf/nihms250397.pdf>.
- Knapp, C., Madden, V., Revicki, D., et al. (2012). Health status and health-related quality of life in a pediatric palliative care program. *Journal of Palliative Medicine*, 15(7), 790–797. Epub ahead of print Jun 11.
- Lapierre, A. (1997). La théorisation ancrée (grounded theory): Démarche analytique et comparaison avec d'autres approches apparentées [in French]. In *La recherche qualitative: Enjeux épistémologiques et méthodologiques*, J. Poupart (ed.), pp. 309–40. Montréal: Gaëtan Morin Éditeur.
- Liben, S., Papadatou, D. & Wolfe, J. (2008). Pediatric palliative care: Challenges and emerging ideas. *Lancet*, 371(9615), 852–864.
- Lyons, K.D., Bakitas, M., Hegel, M.T., et al. (2009). Reliability and validity of the Functional Assessment of Chronic Illness Therapy–Palliative Care (FACIT–Pal) Scale. *Journal of Pain and Symptom Management*, 37(1), 23–32. Epub ahead of print May 27, 2008. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2746408/pdf/nihms88516.pdf>.
- Mays, N. & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *BMJ*, 320(7226), 50–52. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1117321/pdf/50.pdf>.
- Michel, F., Harb, F. & Loayza Hidalgo, M.P. (2012). The concept of time in the perception of children and adolescents. *Trends in Psychiatry and Psychotherapy*, 34(1), 38–41. Available from <http://www.scielo.br/pdf/trends/v34n1/a08v34n1.pdf>.
- Morley, T.E., Cataudella, D., Fernandez, C.V., et al. (2014). Development of the Pediatric Advanced Care Quality of Life Scale (PAC–QoL): Evaluating comprehension of items and response options. *Pediatric Blood & Cancer*, 61(10), 1835–1839. Epub ahead of print Jun 19.
- Paillé, P. & Mucchielli, A. (2012). *L'analyse qualitative en sciences humaines et sociales* [in French]. Paris: Armand Collin.
- Patton, M.Q. (2002). *Qualitative research and evaluation methods*, 3rd ed. Thousand Oaks, CA: Sage Publications.
- Pires, A.P. (1997). Échantillonnage et recherche qualitative: Essai théorique et méthodologique [in French]. In *La recherche qualitative: Enjeux épistémologiques et méthodologiques*, J. Poupart (ed.), pp. 113–169. Montréal: Gaëtan Morin Éditeur.
- Pépin, A.J., Carret, A.S. & Sultan, S. (2015). Quality of life. In *Pediatric neuro-oncology*, K. Schneinmann & E. Bouffet (eds.), pp. 277–288. New York: Springer Science.
- Rebok, G., Riley, A., Forrest, C., et al. (2001). Elementary school-aged children's reports of their health: A cognitive interviewing study. *Quality of Life Research*, 10(1), 59–70.
- Tomlinson, D., Hinds, P.S., Bartels, U., et al. (2011). Parent reports of quality of life for pediatric patients with cancer with no realistic chance of cure. *Journal of Clinical Oncology*, 29(6), 639–345. Epub ahead of print Jan 18. Available from <http://ascopubs.org/doi/pdf/10.1200/JCO.2010.31.4047>.
- Varni, J., Seid, M. & Rode, C. (1999). The PedsQL: Measurement model for the pediatric quality of life. *Medicine Care*, 37(2), 126–139.
- Varni, J., Limbers, C. & Burwinkle, T. (2007). Impaired health-related quality of life in children and adolescent with chronic conditions: A comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL 4.0 Generic Core Scales. *Health and Quality of Life Outcomes*, 5(43), 1–15. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1964786/pdf/1477-7525-5-43.pdf>.
- von Lüttau, P., Otto, M., Hecher, T., et al. (2012). Children dying from cancer: Parents' perspectives on symptoms, quality of life, characteristics of death, and end-of-life decisions. *Journal of Palliative Care*, 28(4), 274–281.
- Whittemore, R., Chase, S.K. & Mandel, C.L. (2001). Validity in qualitative research. *Qualitative Health Research*, 11(4), 522–537.
- World Health Organization (2013). *WHO definition of palliative care for children*. Available from <http://www.who.int/cancer/palliative/definition/en/>.