

Parental perceptions of health-related quality of life in children with leukemia in the second week after the diagnosis: a quantitative model

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Abstract

Purpose The focus is on describing the child's health-related quality of life (HRQL) at the time of diagnosis as perceived by parents, by using an empirical model of their psychosocial context.

Patients and methods Patients were 128 leukemic children and their families recruited at the Haematology–Oncology Clinic of the Department of Pediatrics, University of Padova. The families were interviewed by a clinical

psychologist during the first hospitalization of their children using the Ecocultural Family Interview—Cancer (EFI-C). This interview aimed at understanding the family daily routines as it relates to the child with cancer and the meaning and experience of the situation. Demographic data about children and their families also were collected.

Results The EFI-C interviews were read for content and then coded; these items were grouped into 11 major dimensions, three dealing with the child in the hospital and eight concerning the family. An empirical model of path analysis was estimated to evaluate perceived child's HRQL at the second week from the diagnosis inside the psychosocial context. This model shows that perceived child's HRQL is predicted by parental trust in the medical staff, perceived child coping, and perceived child adaptability. These last two predictors are in turn moderated by the fixed factor child age and mediated by parenting.

Conclusion A better knowledge of parents' views and expectations regarding their children's HRQL during the first treatments for pediatric leukemia may facilitate the communication processes in the hospital and may help to provide improved psychosocial care for the child during the first treatments for leukemia.

Keywords Children · HRQL · Leukemia

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Introduction

This paper focuses on how parents of children with leukemia view the health-related quality of life (HRQL) of their children during the first treatments and on possible HRQL associations with psychosocial factors. The post-diagnosis is a sensitive period for the patients and for their

families [1]; parents report that most children show behavioral and mood difficulties [2]. The stressors related to cancer and the therapies are numerous: medical procedures (needles, lumbar punctures, bone marrow tests), chemotherapy sequelae (pain, weakness, nausea, vomiting, and toxic reactions), loss of control, hospitalization, hair loss, infections, isolation from friends, and disruption of normal activities (e.g., not going to school) [3, 4]. The management of stressors can be often difficult, with children perceiving this invasiveness with high intensity and with a related high level of anxiety and lower self-esteem [5].

Quality of life (QOL) assessment is a complex challenge for pediatric researchers and clinicians. Several instruments have been used to assess survivors of childhood cancer [6, 7], but their application in studies of children receiving active therapy for cancer has been limited. An interesting study [8] comparing respectively in and off treatment children's QOL with healthy controls shows that children undergoing cancer treatment report low overall QOL, physical functioning, and outlook-on-life scores than healthy controls, while off-treatment children report a superior overall QOL than healthy controls.

It is important to note that the evidence on HRQL in children with cancer is mostly based on preformatted, rigid measures such as questionnaires [9]. In order to be sensitive to developmental differences in HRQL markers, instruments must evaluate HRQL domains that are appropriate for the developmental stage considered [10]. Sometimes, questionnaire-based information may not facilitate the communication between doctor and patient, especially when the patient is a young child and the communication must pass through the parents. Thus, the existing questionnaire-based evidence on the HRQL of children with cancer should be complemented by evidence drawn from open-ended verbal reports by the parents [11, 12] and also by the patients, when they are mature enough to report their HRQL by complex verbal means [13–15]. We also have to take into consideration that HRQL is only one part of QOL; nonetheless, it can be a useful clinical tool to devise a psychosocial intervention program.

We do not know much on how parents mentally represent the HRQL of their children with cancer, whether they attribute importance to the same issues which have been identified by the experts, or whether they have something new to tell. We strongly believe that both parents and child do have a great deal to contribute to our understanding of QOL, which many clinicians experience and do recognize, but which has not been systematically captured in a form useful for practice and intervention.

This paper addresses two main questions: First, what is the parents' definition of the HRQL of children with leukemia? We did this through a qualitative interview, listening closely to what the parents had to say in their own

narrative voices. After this initial qualitative phase (which we cannot fully show in this report), we transformed these narratives into quantitative dimensions of family routines and parent perceptions by coding the interviews using techniques from the Ecocultural Family Interview—Cancer (EFI-C). Second, after coding our qualitative data, we explored which child characteristics, such as age or type of leukemia, and which family factors may have affected parents' definitions of children's HRQL in the second week after the communication of the diagnosis.

Materials and methods

Patients and recruitment

Patients were 128 leukemic children and their families recruited at the Haematology–Oncology Clinic of the Department of Pediatrics, University of Padova. All parents (111 mothers and 17 fathers) were Caucasian with a mean age of 37.39 years (SD=6.03). Most parents had 13 years of school (51.3%), 33.6% had 8 years, 7.1% had first level degree, 6.2% had second level degree, and 1.8% had 5 years of school. Parents' incomes were average (52.7%), high (24.1%), and low (23.2%) compared to Italian norms, but all were above poverty. In a preliminary analysis, we examined differences between fathers and mothers. There were no significant differences in our variables so we decided to consider all interviews together.

Children's mean age was 5.89 years (SD=4.21, range=10 months–17 years), 28.9% of them were infants ($N=37$), 39.1% preschoolers ($N=50$), 17.2% children in primary school age ($N=22$), and 14.8% pre-adolescents and adolescents ($N=19$).

Most children were affected by acute lymphoblastic leukemia ($N=104$), while 24 had acute myeloid leukemia. Children were equally distributed by gender with 61 girls and 66 males. All eligible families agreed to participate to the study and gave their informed consent except for two families that declared that they did not feel able to speak about their feelings to anyone at that point. The study was approved by the Institutional Ethics Committee, and it has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki.

Data collection

The families were contacted by a clinical psychologist during the first hospitalization of their children. Project aims were explained and informed consent was asked for. The interviews were carried out in a quiet room of the clinic in the second week after the diagnosis and lasted about 1 h. They were audio-recorded and later fully transcribed. We

used the EFI [16] to understand the family daily routines as their routines related to the child with cancer. The EFI was originally devised to study the adaptation process in families of disabled children [17]. Different versions of this interview have been developed for the study of various issues in pediatric psychology, including studies with Italian families about reactivity to pain [18], or with children with headache [19], and finally, for families of children with cancer (EFI-C) [11].

The EFI-C is a parent interview which explores the daily routines of family life and the salient concerns regarding how that routine is organized. The EFI is not a question–answer formal interview, but it has more on the sociolinguistic form of an everyday conversation about daily life. The interview is a mix of conversation, probing questions by the interviewer and preplanned questions. Participants use their words and emphases. The interviews start with a question such as: “Would you guide me through your daily life? Walk me through your day at this point. How have things been going? What is your and your child’s routine at this point/now?” The EFI interview form flows from our theoretical and epistemological approach, which starts with the observation that the family daily routines and actions are aimed at adaptation tasks, in which various people participate. Such tasks are carried out in practice according to the family resources and through specific scripts or sets of actions, which are meaningfully linked to the beliefs and values of the broader ecology and culture and which show the emotions and motivations held in them. When people talk about their everyday life and routines, they spontaneously talk about all these things as this is how the topic is stored in memory.

When the adaptation tasks are overloaded by negative emotion, as often in our families, the participants sometimes can find relief during the interview process itself [20]. The EFI can also be experienced as a kind of life review—a chance to step back from the ongoing flow of events and reflect on them—which is itself of potential value. The EFI is also based on the theory that by using the parents’ own categories and stories, with the themes and topics embedded in them, the researcher gets closer to the parents’ points of view and experiences [21, 22]. Despite the naturalistic flow and ease of the talk, the interviewer gently but firmly guides the narratives upon events, facts, and actions (e.g., “What happened during the doctor’s last visit?”, “How did your child react?”, “What did you do?”). The themes and topics emerge from this guided conversation for subsequent coding.

The EFI-C complements other measures of families of children with cancer, or with children with other health problems. EFI-C serves the aim to have reliable descriptions of how parents sustain their life routines when a health problem arises in their children. EFI-C can highlight the

parents’ new goals and concerns and how they enact them. Some information drawn from EFI-C narratives may overlap with what researchers in the field already know, but other information may surprise us. The parental narratives elicited by EFI-C have the potential of opening a window into the complex mental and practical job of parenting a child with cancer, or with other challenging diseases. They may help us to get to know better the inner and interpersonal reality of these families. That narrative may be somewhat unique to every family and child, but we have identified clear items, and overall dimensions that can be reliably scored.

There are several relevant observations about this type of instrument.

The first is that the EFI-C can usefully complement other instruments, especially when we want to understand the coconstruction of the new daily routines affected by the cancer diagnosis and treatments, across parents, children, and other kin and friends.

The second observation is that we can find new variables (probably “modifiable moderators” of child and parent coping and adaptation in their routines) which, to our knowledge, were never reported in the literature (i.e., the level of trust they have concerning their medical care and trust in the hospital community; the salience, meaning, and consequences of changes in family routine and time reorganization of their home and clinic life). These seem to be two important and meaningful goals for these parents, and they certainly are part of the active search for new everyday life meanings which occur during the first child hospitalization.

The third observation is that several of these dimensions or concepts in parents’ minds which emerged in the EFI coding are close to variables already reported in the literature, thus confirming construct validity for our technique.

We also gave a Socio-Economic Status Questionnaire to parents, including the number of years of school achievement, type and average hours of job, economical status, and the number of familiars and sons in the family.

Statistical procedures

Exploratory factor analysis was run to identify the EFI-C dimensions once the interviews were coded and reliability established. Data were first examined for skewness, kurtosis, outliers, and normalcy (Kolmogorov–Smirnov test): No transformations were necessary as the distribution was normal for all dependent variables. Descriptive analyses and Pearson’s bivariate correlations were used to examine the associations between our variables. Finally, a path model was constructed to evaluate the correlations and covariances between variables of interest and to guide the modeling of the effects of family and child factors on perceived child’s HRQL during the first hospitalization.

Results

Scoring of parental narratives: parents' definition of the HRQL of children with leukemia

A total of 98 items, or coding topics and themes, were extracted from the parental narratives, basing upon the original codebook for this instrument, the literature about leukemic children HRQL and several research group discussions. One fourth of the total 128 interviews ($N=32$) was coded with a score ranged 0 (low presence of variable described in the item) to 8 (high presence of variable) by two-independent judges showing a good Spearman interrater reliability ($\rho=0.833$; $p=0.001$). An exploratory factor analysis was run to identify the dimensions saturated by these items. The items grouped into 11 major dimensions, three dealing with the parental perceptions on the child in the hospital and eight concerning the family. A good internal consistency in the 11 dimensions was demonstrated. Table 1 presents for each dimension the internal consistency, means, and standard deviations.

We can note how child's coping and child's HRQL as perceived by parents are low in this early postdiagnosis time and with a considerable standard deviation, showing variability between the patients. The other dimensions are average in variability.

The specific EFI-C dimension which is the focus of this paper, namely perceived child health-related quality of life in the hospital, will be presented here accompanied by examples drawn from representative samples from the qualitative parental narratives.

The parents of children newly diagnosed with cancer define their children's HRQL mostly as the capacity to be able to keep meaningful links with the world *outside*

the hospital, even while they are in it. This capacity is sustained by different people, including the children themselves and also including some luck (e.g., positive reactions to the therapies, few side effects, etc.). Another very important feature in parents' narratives are the ways in which parents themselves help children in sustaining links with their previous lives ("He has heaps of friends who write. Heaps of letters. We pin them to a large cardboard in his hospital room") and the degree by which children actively ask to be connected to the external world ("There is a school mate in particular...he wanted to call him while we were coming here. Now, we help him keep in touch also with the other school mates"). The parents underline as particularly important the maintenance of the links with the child's school and also the possibility to work with teachers in the clinic. For younger children, their capacity to take part in organized play activities in the clinic is also important ("Sometimes she tells me: 'let's go to the playroom [that is available in the clinic]!'"). As both previous research and earlier work with the EFI anticipated, the children's physical reaction to the therapies belongs to this dimension of the HRQL maintained in the clinic ("She had radiotherapy, but she is fine. She has some stomach ache, but no vomiting or headache"). Also the degree of children's knowledge of their cancer diagnosis, treatments, and prognosis belongs to this dimension of children's quality of life. Children may greatly vary in the level of explicitness of information that they have received concerning their diagnosis from parents. Doctors often expressed concern about that. A mother talked about not telling her son about his tumor: "Enrico does not know what he has, nor do I want him to know...but he suspects something because when his brother said 'My back hurts badly', Enrico said: 'You have a tumor like me'...but as long as nobody tells him

Table 1 Descriptive statistics of EFI-C dimensions

Dimension (range 0–8)	Alpha	Number of items	Mean	SD
Parental emotional coping	0.75	13	4.89	0.83
Levels of communication on the child illness	0.57	8	4.62	0.91
Parenting the child in the hospital	0.81	9	5.16	0.95
Trust in the medical care and in the hospital community	0.79	6	4.95	1.07
Routine and time reorganization	0.79	16	4.28	0.72
Social support	0.71	5	4.46	1.33
Connectedness of the parental couple	0.93	9	5.13	1.34
Sibling involvement	0.68	5	5.61	0.97
Parental perceptions of child coping with procedures and hospitalization	0.89	12	3.94	1.36
Parental perceptions of child HRQL in the hospital	0.72	7	3.93	1.22
Parental perceptions of child adaptability	0.91	8	5.39	1.22
Total	0.94	98		

what he has, he is fine”. Unfortunately, it is fairly common to find such situations, but most parents are clear about the diagnosis, and sometimes find ingenious ways to explain the illness to their young kids (“Come on, let’s send the lions out from your blood stream to eat all the blasts up!”).

Child and family characteristics affecting parental perceptions of the HRQL of their leukemic children in the second week after the diagnosis

We first used Pearson’s bivariate correlations to examine the associations between our child variables (EFI-C child dimensions, child type of leukemia, child age, child gender) and family variables (EFI-C parent dimensions, demographic information). We then established some path models to test our second main question about child and family factors responsible for HRQL of leukemic children. Using the current literature cited above, a significant path analysis model was found. Figure 1 shows its structural standardized coefficients, and Table 2 shows the explanation of the EFI-C dimensions involved into the path model.

This model showed that parental perceptions of child’s HRQL were predicted by parental trust in the medical staff, by parental perceptions of child coping, and by parental perceptions of child adaptability. These last predictors were in turn moderated by the fixed factor child’s age and by the modifiable factor parenting. Parenting was also directly predictive of parental perceptions of child’s HRQL, but less so than by parental perceptions of child coping, as a mediation effect. Child’s age influenced both parental perceptions of coping and of adaptability, which in turn was sustained also by parental trust in medical staff.

All the coefficients were significant at the $p < 0.005$ level. The model had good fit indices ($\chi^2(4) = 5.03$; $N = 128$; $p = 0.28$; $RMSEA = 0.045$; $NNFI = 0.99$; $CFI = 1$).

Discussion

Narrative methods are vital to understand parental perceptions of child’s HRQL. From narratives of parents of leukemic children, we identified 11 dimensions representing perceived child’s HRQL and family and child factors that can influence it. Being able to easily quantify narrative data in this clinical situation can be really useful both for research and clinical reasons.

Parents’ narratives in this sample expanded on the current literature on children’s HRQL and associations with it. For example, only communications with others [23] and child’s fatigue [14] have been identified as possible predictors of child’s HRQL. The predictor of child’s fatigue might be exacerbated by the emotional and mental energy needed to cope with facing the unknown, as well as the unfamiliar routine of coming to the clinic or hospital [24]. Together with the child’s age and her/his capacity of coping when she/he when diagnosed with cancer, the child’s and family’s entire environment shockingly changes, transforming itself from a regular developmental niche [25] to a caring niche [26]. This sudden and traumatic change requires an adaptation of the child, the parent, and the interaction of the two and puts child’s subsequent accommodation in a state of stress and risk.

Our aim in the path analysis was to identify the weight of fixed factors and also modifiable moderators of parent-perceived child’s HRQL. In this model, we have followed some of the constructs and definitions of Hoekstra-Weebers et al. [27] in their very useful model of child and family adaptation to an important illness. There are several elements of our path analysis which show similarities to other studies, link directly to the *hospital experience and routine*, and point to the important of *trust* in the medical care and the people participating in that care.

Fig. 1 Structural standardized coefficients of hypothetical model of path analysis

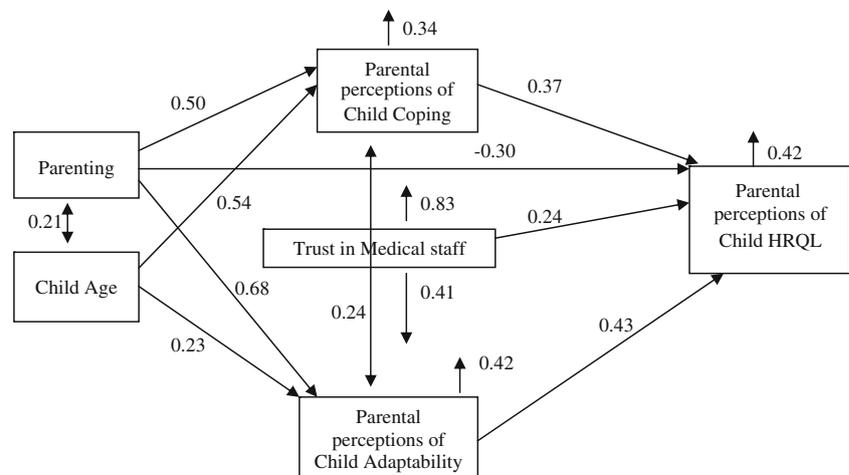


Table 2 EFI-C dimensions of the path model with their respective items

Dimensions	Items
Parenting the child in the hospital	Creation of links between home and hospital
	Use of strategies to help child cope with daily medical procedures
	Level of trust about leaving the child with others during the day
	Importance given by the parent about being next to the child during his/her sleep
	Level of parent–child empathy
	Perceived parental self-efficacy
	Perceived ability in soothing child cry/desperation
	Proximity to the child while soothing him/her
	Perceived difficulties while taking care of the child during hospitalizations
Trust in the medical care and in the hospital community	Level of trust in the hospital
	Search for specific members of pediatric staff
	Feelings of belonging to a community
	Level of the appreciation for what is offered
	Perceived emotional/psychological support from the clinic’s staff
	Importance of the other support figures in the clinic (psychologists, teachers, volunteers)
Parental perceptions of child coping with procedures and hospitalization	Acceptance/understanding of the explanations before medical procedures
	Use of different strategies during medical procedures
	Monitoring medical procedures
	Need for parents before, during, or after medical procedures
	Need for parents during daily life in the hospital
	Level of adaptation to the hospital routines
	Level of adaptation to daily restrictions related to illness
	Requests for information/reassurance from doctors
	Coping with painful procedures
	Tolerance to movement restrictions
	Level of acceptance of the possible physical changes
	Coping with emotional stress
	Parental perceptions of child HRQL in the hospital
Physical reaction to therapies	
Level of participation to the play activities in the hospital	
Level of child’s maintaining of some previous routines (sport and play activities)	
Tolerance of possible collateral effects of therapies (nausea, vomit, headache, fatigue) with associated fears and feelings	
Child’s activities of maintaining some previous routines (ask for phone, to do homework)	
Level of participation to the school activities in the hospital	
Parental perceptions of child adaptability	Level of child’s emotional intensity (crying, anger episodes) associated with specific causes (medical procedures)
	Sleeping problems
	Level of child’s general curiosity and attention about the hospital environment related with games and play
	Level of child’s consolable capacity
	Capacity of the child to become serene just after medical interventions
	Parent’s perception about the quality of change in child’s relations with doctors and white coats
	Parent’s perception of a stability in child’s characteristics
	Level of parent’s perception of sane aspects of the child in spite of the illness

Firstly, developmental differences have been found in several other studies: Particularly, older children use more cognitively oriented coping methods (emotion-focused coping, information seeking, problem solving), while younger children use more active coping to change the environment (approach, problem focused) [28]. Parents talk of the ways in which children cope with their difficult emotional situation (“She tends to shut down all the blinds. She does not talk”, “Sometimes he wants me there with him, but I must not talk. He is elaborating on, reflecting on the experience”) and with the sudden change of their everyday lives, including the restriction of choices and movements (“She is not able to adapt. She knows that here she must undergo therapies, be ill at ease, be linked to a machine. She cannot do what she wants, move freely”). Naturally, there is great variability along these issues often linked not only to the children’s age but also to their personalities and explicit efforts: “He stays in bed, but any time he can, he gets up, plays. He also tries to talk with other kids here”. Especially for the younger children, it is necessary to take into consideration parents’ description of their children’s and their own behaviors to understand their possible psychological reactions to the illness and to its treatments [29].

Secondly, parents become very important for their child’s health throughout the therapies because their capacity for parenting helps the child to cope better with the illness during the hospitalization [30, 31]. For example, the ways in which parents help children sustain links with their previous lives (“He has heaps of friends who write. We pin them to a large cardboard in his hospital room”) and the degree by which children actively ask to be connected to the external world (“There is a school mate in particular...he wanted to call him while we were coming here”) were very important themes in parents’ narratives about what made a positive change in the otherwise very difficult routine they and their child now faced.

Thirdly, parental trust in their medical care team seems to be a key element that sustains parental perceptions of positive child’s HRQL during the first hospitalization: Parents’ capacity to accept this new life environment (constituted by medical staff, volunteers, psychologists, nurses, and hospital spaces) made a significant difference. One mother said for example: “This is not a hospital, this is a family!” These relationship connections and trust seemed to allow parents to think that the child adapts better to the hospitalization with relatively more positive HRQL.

Conclusion

This study provides an empirical model that has linked several psychosocial and contextual variables useful to

maintain a positive quality of life in children with leukemia in their first hospitalization. This study stressed that the parental point of view on their children’s HRQL is not only relevant in itself but it is also useful for the clinical care of children with cancer which is provided by health professionals. Parents may be good reporters of child behaviors and can even give a reasonable proxy report of child HRQL, but not only that. In this study, they have been asked to give their point of view, providing their own personal perspective, not only a proxy for their child. This may be useful and valuable because parents are the ones who often request medical intervention for their child and make decisions. They clearly report their own perceptions of child coping, HRQL, and a range of adaptations, which are therefore likely to be influenced by their own conceptualization of the situation. A richer and more carefully assessed knowledge of the parents’ views and expectations on their children’s HRQL during the first treatments for pediatric leukemia may facilitate the communication processes in the hospital and may help provide better psychosocial care for the child during the first treatments and likely throughout care.

Specific psychosocial programs can be devised specifically during the first hospitalization directed respectively to children with leukemia and to their parents. Using the EFI-C narratives and items, care providers can suggest specific interventions directed to younger and less adaptable children, for example, or to children with a more restricted range of coping strategies. Other interventions can be directed to support parents in their important role of parenting children with cancer and in insuring and monitoring their trust of the medical care and the hospital community serving them.

In addition to providing these kinds of information to assist parents, children, and professional staff, there is a further benefit for doing the EFI-C type of conversational interview. Many parents report some psychological benefit from being able to tell their story to a sympathetic, interested listener guiding a conversation. Such structured conversations with parents may lead to better ways to organize psychosocial interventions in clinics and other settings which can be tailored to parents’ needs. Such knowledge may also lead to a more profound sense of respect and admiration for human parenting in the face of threat, for its ingeniousness, its creativeness, and its resilience and generosity.

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