

Parental Narratives of Children with Leukemia in the Second Week after the Diagnosis: The Ecocultural Family Interview-Cancer

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Abstract: The family system is an important and proximal factor for children with cancer. Parents are facing wrenching changes in their lives. Nonetheless, most reports in the literature on short- and long-term psycho-social consequences of childhood cancer on children and their families are drawn from questionnaires completed by the parents and/or doctors and nurses. In this report, we use a narrative, guided conversational method, the Ecocultural Family Interview-Cancer, to provide evidence from parents in their own voices, concerning their experiences early after the diagnosis, during the first hospitalization.

We identified 98 topics and themes from 128 interviews with parents of children with leukaemia at first hospitalization, and then combined those into a smaller set of 11 psychometrically robust global dimensions. Spearman inter-rater reliability in identifying items for these dimensions was high. The EFI is a promising research tool for systematic mixed method inquiry into family experiences and accommodations during difficult health crises.

Keywords: Parental narratives, children, cancer, interview.

1. INTRODUCTION

The diagnosis of a malignant disease is probably one of the most severe stressors that children and parents can experience [1]. Painful procedures, hospitalizations, and uncertain prognosis are common threats to the adjustment of children and families [2]. Young children newly diagnosed with leukemia come to the hospital in poor health and not infrequently in distressed mental circumstances and they may have serious difficulties in communicating verbally about their inner and bodily states. Parents become even more important here as they can inform health professionals about their children's states and quality of life especially during painful pediatric cancer treatments, when doctors and nurses do not yet know parents well [3]. The family system is an important and proximal factor for children with a chronic illness [4].

Some research studies focus on children's own perceptions and parents' verbal reports: examining both child and parent narratives during early hospitalization for leukemia or in the off-therapy time [5, 6], or describing the parents' narrative topic of "life is never the same" [7] and their perceptions on child's adjustment and behavior in relation to school,

friendship, appearance and understanding the illness [8], or focusing on their parenting behaviour in crisis [9].

Other than a few studies like these, the great majority of findings reported in the literature on short- and long-term psycho-social consequences on children with cancer and their families are drawn from questionnaires completed by the parents and/or doctors and nurses. Hence we know very little about the families' everyday adaptations to child cancer as these would be described by the parents themselves, reporting their own practical concerns, their points of view, their ways to deal with the emotional upheaval caused by the diagnosis of child cancer, and their use of their social networks and other supports. How do parents and families give meaning to their experience after a diagnosis of pediatric cancer? Parental perceptions of their children's illness, the child's and the parent's resources and skills are very important. All these things come together to constitute a complex network of meanings which orients the family adjustment to the experience of having a child diagnosed and treated for cancer.

In this report, we use a narrative, guided conversational method, the Ecocultural Family Interview (EFI), to provide evidence from parents, in their own voices, concerning their experiences early after the diagnosis, during the first hospitalization. The EFI method revealed a wide range of themes and

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topics which were scored with good internal consistency and good fit to this specific health crisis and family responses to it.

2. METHODS

2.1. Pilot Study

To start our work with families of children with cancer, we systematically interviewed 50 parents of children first admitted Haematology-Oncologic Clinic of the Department of Woman and Child Health, University of Padova, using the Ecocultural Family Interview (EFI) [10]. In this first phase, we deliberately sought a wide range of type of cancers (and treatments), child ages, family SES, days from the diagnosis, etc. in order to have a broad picture of the various circumstances which are related to the experience of having a child diagnosed with cancer.

The interviews were transcribed verbatim and then used to develop items which represented meaningful aspects of these families' lives. We also used a series of previous EFI studies of families with children with developmental disabilities, which helped us to focus our attention on ecocultural dimensions [11]. After reaching overall agreement on these topics and themes, we developed specific items, using examples drawn directly from the interviews for each of the items, capturing the variability in parent views across the sample; these items were then coded. The variability in each EFI item is expressed by a range from 0 to 8, so we found at least one example for each score level of each item: Low (0,1,2); Medium (3,4,5); High (6,7,8). Two independent judges then scored the first 50 interviews using the codebook. During this process the disagreements between the judges were resolved through team discussions.

2.2. Patients and Procedure

After this exploratory phase and a first draft of EFI codebook for this clinic population, we recruited a new sample of 128 leukemic children and their families at the Haematology-Oncologic Clinic of the Department of Woman and Child Health, 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 (16 years of school); 6.2% had second level degree (18 years of school) and 1.8% had 5 years of school. Parents' incomes were self perceived as average (52.7%), high (24.1%) and low (23.2%).

Children's mean age was 5.89 years (SD = 4.21, range = 10 months-17 years). Mostly children had Acute Lymphoblastic Leukemia (ALL) (N = 104), while 24 had Acute Myeloid Leukemia (AML). Children were quite equally distributed by gender with 61 girls and 66 males. All eligible families agreed to participate to the study except two families that declared that they didn't feel able to speak about their feelings to anyone at that point.

The families were contacted by the corresponding author, a clinical psychologist during the first hospitalization of their children. Project aims were explained and informed consent was asked for. The final version EFI-C interviews were carried out in a quiet room of the Clinic in the second week after the diagnosis and lasted about one hour. They were audio-recorded and later fully transcribed.

Different versions of EFI have been developed for the study of various issues in pediatric psychology, including studies with Italian families, such as reactivity to pain [12], or children with headache [13] and the final version for children with cancer (EFI-C) [14, 15]. 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. It is not a question-answer formal interview, but it has more 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 own words and emphases. The interviews start with a question such as: "Would you guide me through your daily life? What is your and your child's routine at this point/now?" "How are things going for you and your child now?" The EFI-C interview form flows from a 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 can reveal the emotions and motivations held in them. When people talk about their everyday life and routines, they almost always also talk about all these life circumstances, since these are attached to daily activities and recalled relatively easily and concretely in this way.

When the adaptation tasks are overloaded by negative emotion, as is often the case in our families,

the participants sometimes can find relief during the interview process [16, 17]. The EFI-C 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 to both parents and researchers. The EFI-C 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 [18]. Although there is a very naturalistic flow and ease during the interview, the interviewer gently but clearly guides the narratives to focus on events, facts, and actions that are linked to the health situation of their child and family accommodations (e.g., "What happened during the doctor's diagnosis communication?", "How did your child react?", "What did you do?").

3. RESULTS

3.1. Content Analysis and Scoring of Parental Narratives

A total of 98 specific items were extracted from the parental narratives by the entire research team in group discussions. An exploratory factor analysis was run to identify a smaller set of summary, global dimensions of all these items: 11 major dimensions, three dealing with the child in the hospital and eight concerning the family. One-fourth of the total 128 interviews (N = 32) were coded for presence and degree of salience for each parental interview, with a score ranging from 0 (low presence of variable) to 8 (high presence of variable) by two independent judges, showing a good Spearman inter-rater reliability ($\rho = .833$; $p = 0.001$).

First we will illustrate each EFI-C dimension identified, accompanied by examples drawn from representative samples from the qualitative parental narratives. Above each EFI-C theme we will report its internal coherence and the number of items of which it is composed.

3.1.1. Parental Emotional Coping ($\text{Alpha}=0.75$; 13 Items)

From the EFI-C parent narratives, we found that coping with the stress related to child cancer seems to be more a family and parental project or enterprise, not an individual one: *"It all depends on how strong a parent is, and how weak...it depends on the family circumstances. We, I...think myself lucky indeed because we are husband and wife – we also have the*

grandparents – we have a situation which could not be better".

Parents do a lot of emotion-focused coping for themselves, and for the children. Parents have post-traumatic emotion and symptoms to deal with (*"Inside me...cancer equals death", "I went to bed and I actually saw my son already dead, in a tomb"*). While talking about their lives, parents also talk about their ways of coping with such traumatic emotional states. They described five basic ways in their own words (which were used to define this item in the EFI codebook) to deal with emotional crises. The first is to focus their attention and energies on the child: *"with my child I try to carry out a life as normal as possible, and I strive to be the same as I was before...with some more attention, of course. For example, before he had to wash his teeth and no question, now I help him to wash his teeth"*. One mother summed this up with the phrase that she is *"leaving the tears outside"*. Related to this theme, parents described the ability to adopt flexible strategies of emotional control, such as communication with significant others, working to re-frame bouts of negative emotion as normal, as OK, etc. Emotional coping as described by parents includes the capacity to frame the present time in a larger life-continuing context (*"These things are part of the life course...life is made up of good and of bad. One must learn to accept the one and also the other, even if it hurts"*). Parents also report active cognitive strategies, such as splitting the big cancer problem into smaller problems which can be faced one at the time (*"As long as the problems arise one after the other, we can face it one at the time. Now he has a fever, we will solve that; later we will solve the liver problem, and so on"*). Parents also described thinking positive (*"We put aside the negative part of all this. We summon our strength. We give strength to our son, we think positive. If we started thinking negative, we would not be here...I would have to leave and go somewhere else to cry"*). A realistic search for information is a notable component of emotional coping, not only as an informational/cognitive strategy for many parents. However, this strategy was more commonly mentioned in highly educated parents who have access to the Internet or to parents organizations, etc. Sometimes parents may seemingly overdo that, and start reading specialized medical books, which then often confound them, but most parents do not actually go to medical literature (which more often than not can lead to real anguish), and eventually ask doctors for more specialized information, or for summaries.

3.1.2. Levels of Communication Regarding the Child's Illness (Alpha=0.57; 8 Items)

The kinds and amount of communication and information parents have about the child's illness with their social network (relatives, friends, co-workers...) is another important theme. Sometimes parents feel somewhat vulnerable about this: *"Everybody asks me 'How is he?'. I say 'He's fine', I do not explain that we must wait, that we will know for sure in two years time, etc.. I just have to say-- even rather curtly -- that he's fine"*. Even though most parents do appreciate the community participation, a few families feel intruded on by the larger community: *"In villages people thrive on gossip, and our child is 'the case of the season'. My village has 1000 inhabitants... so everybody knows...there is a sort of curiosity, yes even sometimes a somewhat perverse kind of gossip and interest... not that they enjoy that things go badly -- but nonetheless, this is how it goes sometimes and how I am feeling it..."*. So even many well-intended requests for information and updating can be a strain or burden on parents quite often we found. There was variability in how such social concerns were expressed and received. An important new part of the communication network are the other parents in the Clinic: *"..and then you have the chance to talk with other parents here who went through this before you and that also prepares you for what you have on your hands, on what you are going through, on what you are facing"*. Here also there is variability, as some parents actively avoid communication with other parents in the Clinic, while other seek it out and find great help there. *"I avoid talking about cancer with the other parents here in the Clinic...to avoid the chance to hear stories, well there may be positive stories also, naturally, but some are relapses...I don't want to get negative external inputs, as far as I can and to the extent I am able to. But of course my ears are not closed to both kinds of information, either..."*. Parents also reported that the extent and quality of communication with the nurses/doctors seem to be very important to them in many ways: *"Sometimes the nurses come here just to talk a bit...with the kids. This also helps us parents because they show that they are active, present"*. Parents are reassured by these kinds of informal contacts with their children and with them to provide them with human contacts, knowing that their children are around such staff, and they can have somewhere to go when children need to be with someone other than parents and family.

3.1.3 Parenting the Child in the Hospital (Alpha=0.81; 9 Items)

Parenting refers here to caretaking – that is, to the parent's capacity to sustain their child's needs in these difficult times in several ways. Parents described the active creation of links between home and hospital (for example one parent gave an elaborate description of the child being immersed into all kinds of messages, letters, posters and so forth, that reminded him/her of the world outside the hospital). Other parents used special strategies to help the child cope with daily medical procedures (*"during the difficult medical procedures she always stays with me, I make the soap balls for her, before she is sedated"*). Parents developed new capacities, such as leaving the child with others during the day or of being next to the child during his/her sleep (for example the mother holds the child in her arms to maintain his/her sleeping during the night when she is not there), increasing the level of parent-child empathy (*"she doesn't want to see me crying... if we arrive at the clinic with a high morale it's better for her and for us, but we have to work to make that happen"*), by increasing the parents' sense of self-efficacy in soothing their child's cry/desperation even when they are not able to understand the reasons for it (*"I don't understand anymore why he is crying, what he wants..."*), or through perceiving difficulties they had not ever recognized before while taking care of the child during hospitalizations (*"In the hospital my baby and I don't have our familiar things, our routines together and our privacy...all is different, more complicated"*).

3.1.4. Trust in the Child's Medical Care and in the Hospital Community (Alpha=.79; 6 Items)

An important part of the social support perceived by the families comes through their relations with the doctors and the nurses in the Clinic. *"We can talk freely with the doctors, with great ease...thousands of questions and still they are always available, really...yes, this is a good thing because...for something which hits you so out of the blue, all together, this helps, yes, this helps greatly...even a simple word which may be banal, for us is a big help, yes, a big help"*., *"They seem all very nice to me, very...human, very...I feel as if we were in a large family here"*. An important aspect of this is the extent to which these parents feel that they can actively carry out everyday routines while their child is in the clinic. For example, parents felt included and wanted and helpful by being able to change their child's bed sheets (as many times as they want in the same day, and the parents can do it themselves if that pleases them, as it

usually does), or by being able to ask staff to do so, or by bringing in cooked food from home and keeping it in the kitchen fridge, etc. so that they can feed their own special meals to their child (and themselves) Mothers especially appreciate that they can take care of their kids themselves in small, but meaningful, routines, such as being able to take the child's temperature, without the nurses taking over everything. A mother reported about a terrible bout of desperate crying she had during the night before her daughter had surgery and how she appreciated that the nurse came, and simply stood silently by her, waiting for her to pour it all out; *"I felt completely accepted. With all my burden of pain...and.. I would have felt rejected if she had said "No, dear lady, no...come on"*.

We cannot emphasize sufficiently enough how important these kinds of routines and activities were in our parents' accounts, and how meaningful they were to them. Although they may seem mundane, or seem to add problems to the clinic routine - - they were very important to mothers. These kinds of communication patterns and sense of inclusion in the clinic, and the trust and care thereby offered by the hospital to parents, is rarely if ever mentioned in the current literature on this topic. Yet when parents were able to simply tell their story and what was meaningful to them – this came up frequently as a central, supportive, and meaningful event this was for them. These ways of providing ease of communication with doctors and nurses and the trust in the care offered by the hospital, is very important for these parents.

3.1.5. Routine and Time Reorganization (Alpha=0.79; 16 Items)

Most parents are actively involved in reshaping their everyday lives. Rebuilding a meaningful routine is an important task, which is shared by the two parents: A father says, *"Here in the hospital, I come for awhile, than my wife comes for another period of time. So that the burden is not only upon one person. I see families here in which everything is on the mother's shoulders...and sooner or later she is going to explode, or it has already happened. We divide the task between the two of us, the labour is half – no doubt about it"*. Very often the whole family, including the siblings, change their roles in the family. A common pattern is that characterized by the mother spending most of the time in the hospital, the father carrying out his job as the family breadwinner and an adolescent sibling taking care of the life in the house. In other cases, the father takes a long leave from work and

shares the burden of caring for the child in the hospital with the mother. Grandparents are very often involved. They usually take care of the younger siblings. Also, they take turns with parents at the hospital, to give them some respite. However, this happens more often after the first week of hospitalization. At the beginning, the child does not want to be separated from his mother and father, and that is reciprocal. These complex re-organizations emerge slowly in family routines, and sometimes examples come from throughout an entire interview, and so cannot be exemplified by short excerpts, but the overall pattern comes through clearly in parental narratives about family reorganization of daily routines. Sometimes, however, parents express a sense of loss for their previous life. They sometimes combine that sense of loss of their past routine with making a kind of causal connection to what is happening to them now. As a young mother said: *"Yes, I was too happy, perhaps, I do not know, too happy...eh I cannot say...whether this happened because we were too happy. How could a thing like this happen? I cannot understand why..."*.

3.1.6. Social Support (Alpha=0.71; 5 Items)

The amount of social support available to the families of children with cancer is considered an important factor for their adjustment and coping with the situation. Yet, social support is perhaps an over-broad concept. It would be interesting and useful to understand the aspects of social support which are more meaningful to parents and how they relate to each other. In our EFI-C interviews, parents talk about support almost exclusively as *emotional* support: *"To know that there are so many people who are emotionally close to me...it makes me feel good...every letter that I open, every note which I read...I burst into a desperate cry...this is a release and I feel sad (smiles)..but, after that...it makes me feel much better"*. It is important to note that during the few first days after the diagnosis and the hospitalization, the dramatic changes which have occurred simply yank the family out of their normal, everyday social ambience. As a mother put it *"I have friends, good friends...perhaps more than I expected and who are emotionally close to me...and that is something...but at the beginning I felt completely abandoned, alone with my tragedy"*. In most cases, the feelings of solitude, etc., are probably more related to the traumatic effects of the diagnosis than anything else, yet it is true that a few days or weeks must pass before the whole social network may take over again and function normally. A huge amount of coping is required from the traumatized

caretakers, so it is not surprising that emotional comfort is almost more appreciated than practical help: *"My sister asked for news, brought me fresh things to wear – something that everybody forgot – and brought me books for Laura (all names used are fictitious), bought a new nightdress for her...she tried to cheer us up...thus Laura's first laughs were with my sister and her husband...this was last Sunday. The first external people who came since I was in the hospital...she has started to laugh again because of them"*. Note that many other kinds of more instrumental support are mentioned – for example the reorganization of family roles and routines, grandparents taking over their home, or older siblings doing so. Even the sister brings clothes and a dress for Laura. Parents talk about having their own food at the clinic and so forth. But within the daily routine narrative, these are typically framed as providing emotional help by parents.

3.1.7. Connectedness of the Parental Couple (Alpha=0.93; 9 Items)

There are numerous ways in which the parents define their marital accord in these circumstances. The first is the extent to which they can talk to each other (*"we have very long phone calls in the evenings, one hour, one hour and a half, to just tell everything to each other"*), especially about the child's medical and psychological condition (*"We sometimes have things to tell to each other and we don't, because while talking on the phone we simply forget, since the main thing is to talk about how she (the child) is, so that we forget other important things, sometimes that we really did need to talk about too."*). There is of course variability here, with some mothers complaining that they are not able to talk with their partners in the hospital because the child has, and is entitled to, all his father's attention during his visits. Another aspect of marital accord rests in the partner's understanding and acceptance of their differences in reactions or in coping: *"There are two points of view...each of us must find his or her way to solve it. She tells me "I cannot do it. I must be as I am" and I tell her "Of course you must". I accept her ways, which are different from mine"*. Linked to this is the capacity to accept bouts of emotion, such as crying, etc., in the other person. Often mothers are not able to accept this in their husbands and they seem to protect ferociously the child and themselves from their partner's vulnerability (*"He loves the child, but in this period he cries all the time...so I have eliminated him a bit from seeing her, because it just makes things worse when I am trying to be positive"; "I see that he would like to cry when he visits here, but I tell him that I do not*

have time for the dead ones, understood? If you want to cry, of course – but do it at home"). Trust in the partner is very important: *"My husband...ah, he is the motor of the situation! When I am stressed or depressed, I call him (laughs) and he pulls me up, I always perceive his strength and his courage"*. Unfortunately, this does not always happen. As the wife of an alcoholic told us: *"He is irritated by the children, he thinks that the children draw his woman away from him. He does not say "My poor boy is ill", he says "Oh God, my woman is not here for me"*". These cases were (fortunately) rare in our narratives, but they did occur.

3.1.8. Sibling Involvement (Alpha=0.68; 5 Items)

Siblings have their own special role in this overall picture of parental and family adaptations. As amply reported by the literature, the siblings of children with cancer suffer from the situation. Parents report that they often become very quiet and sad, cry or have sleep problems. It is important to stress that in our study parental clarity about telling the siblings about the diagnosis and what is happening and could happen, is positively correlated with their active involvement and their wish to be of help: *"My other daughter called me, crying "M.is in hospital, I am not able to stay at home without her any longer, I do not want her to die". So now E. (the other daughter) hurries up with her homework and comes here. She is happy to come even on Saturday nights, that for a girl of her age...well that's the time for having fun"*. When they talk about their other kids at home, parents sometimes say something like *"I would like to be able to split myself in two"*. However, at the first stage of the illness, when the family is changing very fast, an excess of concern for the children at home on the part of parents, was actually associated with preventing siblings' positive involvement and participation in the family roles and daily routine reorganization we have described above.

3.1.9. Child Coping with Procedures and Hospitalization (Alpha=0.89; 12 Items)

Most of children's behavioural coping goes to face the medical exams, physical control of the clinic and of the therapies. Parents talk about children's ability to understand the doctors' explanations before or during the procedures (*"I thought "how could my child be able to keep still? He who never is quiet at home."* Yet, when the doctors or the nurses explain to him *"we are going to do this and that"...then, he understands. He cherishes what they tell him and he keeps still, quiet"*). Parents often describe their children's willingness to

learn more by addressing questions to doctors and nurses, and their strategies to cope with the procedures, especially monitoring what is happening to them (*"He is very curious. Also with nurses...when they do something to him, he always asks: "What are you doing to me? what are you going to do now? Why?"*). Special attention is given to children's coping with pain (*"He sometimes fusses, but he usually does not -- blood samplings, analyses are no problem with him now."*). Parents also 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 then I must not talk. He is elaborating the experience, I think. And then he wants to write things down about the clinic, or other things while I am there with him."*). Children especially don't like the sudden change of their everyday lives, particularly the restriction of choices and physical movements (*"She is not able to adapt. She knows that here she must undergo therapies, be so 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 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"*. Some children find solace in a predictable routine: *"He watches TV, but then he is tired, or thinks about the food. Maybe his bigger appetite is the effect of the medicines which he is taking (indeed, the cortisones some of these children were taking do increase appetite)...but he has these daily rhythms organized by dishes of pasta that I make for him ...he sees that in his days; so it is good, all things considered"*. Note that here again, these seemingly mundane features of the daily routine for children and parents are often mentioned as very meaningful for them, marking positive rhythms in the child's life. And here again, these kinds of activities are not well described nor highlighted in most studies of stress, accommodation and adaptation in the literature, but are often incorporated in the more open parent narratives about these topics.

3.1.10. Child Quality of Life in the Hospital (Alpha=0.72; 7 Items)

The parents of children newly diagnosed with cancer define their children's quality of life 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.). Very important are the ways in which parents themselves help children sustain 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"*). Rather important is 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 belong to this dimension of the quality of life in the clinic (*"She had radiotherapy, but she is fine. She has some stomach ache, but no vomit nor headache"*). Also the degree of children's knowledge of their cancer diagnosis, treatments, and prognosis belongs to this dimension on 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 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 and moving ways to explain the illness to their young kids (*"Come on, send the lions out from your blood stream to eat all the blasts up!"*).

3.1.11. Child Adaptability (Alpha=0.91; 8 Items)

This theme deals with the child's temperament and his/her reactivity to the illness and to the hospitalization by several modes: sleep, cry, curiosity, anger outbreaks, etc.

For example this mother said to us that "when her child sees the white coats she starts a desperate cry even if I try to soothe her". Another mother explained that her child "doesn't sleep anymore and she only wants to just be staying in my embrace throughout the night" or that "He did not used to be like that..."

Another father underlined the curiosity of his child about the illness and the whole clinic: "he is very curious, controlling the movements of other children in the corridors" or his capacity "to rise again and to keep calm soon after the pain phase and start up again riding his three-wheeler bike along the corridors". Many parents saw a much more rational, sensible side of the child: "he is always active, curious...if we told him "Let's go", he is always ready to go".

3.2. Factor Analysis

We also wanted to create a further reduced psychometrically robust set of dimensions which could then be used to answer research questions in a quantitative fashion. We ran a Varimax rotated factor analysis on the 11 dimensions, that yielded three clear factors, which explained 69.2% of the variance. The first factor explained 25.9% of variance and grouped the Parenting dimension (loading: .66) and the three child dimensions: Child coping with everyday life and stressors in the hospital (loading: .93); Child quality of life in the hospital (loading: .73) and Child adaptability (loading: .87). This is the *child* factor. The second factor explained 23.86% of variance and grouped Reorganization and flexibility of everyday routine (loading: .85), Support (loading: .72) and Couple connectedness (loading: .81). This is the *parent's available resources* factor. The third factor explained 19.41% of variance and grouped Emotional coping (loading: .78), Trust in the medical care and in the hospital community (loading: .88) and communication towards the illness (loading: .50). This is the *parent's coping* factor.

This exploratory, summary three-factor solution covers child coping and quality of life; parent coping; and parent's social and other resources – a straightforward and we think useful way to group three important dimensions of the parental narratives. The 11 dimensions are also of considerable importance and are valuable regardless of doing this further reduction to three dimensions. We also have pointed out that even the 98 specific topics, themes, and items that parents mention when they are able to just talk about their experience can offer new insight and depth to our understanding of parents' concerns and adaptations. The three levels of data summary and data reduction move from the transcripts themselves and the contexts of each child and family, to 98 topics important in parents ethnopsychology and concerns, to the 11 central themes, to three very summary dimensions. Each of these levels has research and practice value.

4. DISCUSSION

Questionnaires given to parents can measure their mental health status [19], resources (SES) or psychosocial risk level [20]. They certainly inform us about the mental functioning of parents of children with cancer and they also inform us about their chances for positive adaptation. However, they tell us little about how parents of children with cancer strive to extract a meaning from their ongoing experience and how they use it to create a routine which can be meaningful to them and their child in the clinic. Everyday life must somehow be lived out, hour after hour. Especially in the face of such an enormous challenge to their child's health and survival, families must find a meaning for how they are living and for what they are doing [21]. The questionnaires can, and indeed do, measure the starting and the end points of various family adaptations to child cancer. At one end, at the start of the adaptation process they measure risk factors and resources and at the other end they measure the outcomes of such processes, such as mental health or marital and career satisfaction, etc.. Such psychosocial outcomes may be measured at different time points or phases of the child illness and treatments. We draw interesting and useful information from such an approach.

However, questionnaires cannot capture the complex, delicate interweaving of everyday actions by which families create a meaning for what is occurring to them and to their ill children. Questionnaires do not give detailed information on the pathways which lead families from one point to the other, from their resources (or lack of resources) for making adaptations. They are not specific to the circumstances of the parent and child situation and are not using the experiences of parents directly to assess coping and meaning.

The Ecocultural Family Interview-Cancer (EFI-C) can help us understand how parents of children with cancer are able to sustain their two worlds of home and hospital when a shocking and fearful pathway previously unknown to them, made of new daily routines, happens to them. The EFI-C, can usefully complement other instruments, especially when we want to understand the co-construction of the new daily routines across parents, children and other kin and friends.

There are several relevant observations about these quantitative data. The first is that the internal reliability

of the items and dimensions coded from these data is strikingly good, especially considering that they are derived from quite open-ended qualitative narratives. This shows that an EFI-C approach to the study of family life can give psychometrically robust measures, as has been found in other studies using the EFI.

The second observation is that we found two variables (probably “modifiable moderators” of child and parent coping and adaptation in their routines), which, to our knowledge, were never reported in the literature. Parents seem to give notable importance to the level of trust they have in the medical care and in the hospital community and also to the routine and time re-organization of their home and clinic life. These seems 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.

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 is additional evidence that many parents report some psychological benefit from being able to tell their story to a sympathetic and guiding listener. Such knowledge 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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