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The needs of siblings of children with a life-threatening illness, part 1: Conceptualization and development of a measure

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ABSTRACT

Objective: The presence of a child afflicted with a life-threatening illness is a difficult situation for the child's siblings, especially when their own needs are left unmet. The present article describes the first three phases of research involved in the conceptualization, development, and content validation of an initial version of the Inventaire des Besoins de la Fratrie d'Enfants Malades Sévèrement (IBesFEMS) [Needs Inventory for Siblings of Critically ill Children].

Method: The first phase of the development of this instrument was conducted using qualitative methodology (focus groups: 6 siblings, 8 parents). The second phase consisted of validating the content of a pool of items developed according to the needs identified in the first phase. Some 21 participants (3 psychometricians, 3 researchers, 9 clinicians, and 6 siblings) evaluated each item for relevance and clarity. Finally, during the third phase, the acceptability and administration procedures of the preliminary version of the instrument were assessed qualitatively by five siblings.

Results: The first phase led to production of a typology made up of 43 needs in 10 different environments. The second phase allowed for selection of the items that were clearest and most relevant, based on expert opinion. This procedure gave rise to a first version of the IBesFEMS, which consisted of 48 items.

Significance of results: The IBesFEMS appears to be a promising tool for specifically assessing the needs of the adolescent siblings of seriously ill children.

KEYWORDS: Needs, Sibling, Pediatric, Palliative care, Questionnaire development

INTRODUCTION

The presence of a child with a life-threatening illness has numerous repercussions for the family. This situation is known to upset the balance of the entire family unit, not just that of the parents and the sick child (Institute of Medicine [IOM], 2003; Knapp & Contro, 2009; Lane & Mason, 2014). Siblings are identified as silent witnesses to the ordeal, and their vulnerability appears to be exacerbated by an inadequate response to their specific needs (O'Brien et al., 2009; Brennan et al., 2012).

Clinicians and researchers in the field lack reliable and valid tools with which to assess the needs of siblings (IOM, 2003; Wolfe & Siden, 2012). Such measures would enable practitioners to offer family interventions tailored to the specific needs of the sick child's siblings. Furthermore, with the appropriate measurement tools, the scientific community would be better equipped to document the specific situation of these vulnerable young people. Researchers

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and clinicians working with this population would benefit from such a needs assessment tool that illuminates the reality of the siblings of children afflicted with any life-threatening illness.

The present article reports the initial development and validation of a new instrument to measure the unmet needs of the adolescent siblings of children with a life-threatening illness, that is, the Inventaire des Besoins de la Fratrie d'Enfants Malades Sévèrement (IBesFEMS) [Needs Inventory for Siblings of Critically Ill Children]. We describe the first steps involved in the conceptualization, development, and content validation of the initial version of the instrument. A second article examines the psychometric properties of the IBesFEMS (Olivier-d'Avignon et al., 2016). Adolescence was the period chosen because of the similarities in cognitive capacities for youths between 12 and 18 years of age, compared to school-aged children of 5 to 12 years, where many more differences can be observed (Piaget & Inhelder, 1966). Moreover, most children of this age have achieved a mature conception of death (Speece & Brent, 1984).

The Siblings of Children with a Life-Threatening Illness

In Canada, 3,472 infants, children, and adolescents died from various causes in 2014–2015 (Statistics Canada, 2015). These deaths, while representing a small proportion of all deaths in Canada, are nevertheless vitally important when considering all psychosocial issues related to pediatric death. Serious pediatric illness and death during childhood present emotional and even spiritual challenges to those who love and care for these patients (Feudtner et al., 2015). There is no international consensus on the definition of a life-threatening illness (IOM, 2003; Lenton et al., 2006). However, certain organizations have identified important criteria for recognizing this population:

> Life-threatening conditions are those that (1) carry a substantial probability of death in childhood, although treatment may succeed in curing the condition or substantially prolonging life, and (2) are perceived as potentially having a fatal outcome. Life-shortening conditions describe those children and young people that have a health condition for which there is no reasonable hope of cure and from which children or young people will die, especially during childhood. (IOM, 2003, p. 37)

For the purposes of this article, the term "life-threatening illness" will be used to refer to any illness or condition that threatens or shortens the life of a child. The prognosis for these illnesses is difficult to establish, and they can evolve over the course of several years, affecting the family in many different ways (Lenton et al., 2006; Feudtner et al., 2011). Support for the family of a child whose life is threatened is an essential part of pediatric palliative care (IOM, 2003; World Health Organization [WHO], 2010; Jones et al., 2011). In the clinical or research context of pediatric palliative care, it is therefore important that special attention be paid to the experience and situation of the sick child's siblings.

Brothers and sisters of children with a life-threatening illness are often forgotten in the midst of such trying family ordeals (Sidhu et al., 2005; Dighe et al., 2008; Long et al., 2013). The consequences they face can be significant, for they are recognized as being at greater risk of developing psychological problems than the general population (Ballard, 2004). The scientific literature shows that their needs are important and that when they go unmet, serious affective, developmental, and behavioral consequences can ensue in the short, medium, and long terms (Williams, 1997; Stillion & Papadatou, 2002; IOM, 2003; Ballard, 2004; Hynson, 2006; Lewis & Prescott, 2006; Hutson & Alter, 2007; O'Brien et al., 2009; Hashemi & Shokrpour, 2010). Every aspect of the siblings' lives can be affected, disrupting both their academic and family life (Jones et al., 2011; Olivier-d'Avignon, 2006; 2013).

The hypothesis that the brothers and sisters of children with a life-threatening illness have special needs is reinforced by the many changes the ordeal imposes on their daily lives, the emotions it generates, and the behaviors and coping strategies observed (Stallard et al., 1997; Williams, 1997; Sloper, 2000; Ballard, 2004; Nolbris & Hellström, 2005; Sidhu et al., 2005; Jones, 2006; Olivier-d'Avignon, 2006; Brennan et al., 2012). Furthermore, it appears that, among members of families who have a child with a life-threatening illness, it is the siblings who suffer the most in terms of quality of life, and whose emotional needs are most often overlooked (Zeltzer et al., 1996; Murray, 1999; Sloper, 2000; Lähteenmäki et al., 2004; von Essen & Enskär, 2004; Kenney, 2010).

The failure to respond to the needs of siblings can stem from their parents' anxiety about the demands placed on them by the life-threatening illness, a certain confusion in the roles played by healthcare professionals, a lack of awareness among some actors as to the importance of meeting sibling needs, or the reluctance of the siblings themselves to express their needs openly in an attempt to protect their parents or mask their guilt with regard to the ill child (Stillion & Papadatou, 2002; Olivier-d'Avignon, 2006; Woodgate, 2006; O'Brien et al., 2009; Hashemi & Shokrpour, 2010; Brennan et al., 2012; Lapwood &

Goldman, 2012; O'Shea et al., 2012; Long et al., 2013).

Recognizing that the needs of siblings are specific and different from those of the parents and the sick child is crucial to the development and introduction of effective interventions to support them and promote their well-being (O'Brien et al., 2009; Lane & Mason, 2014). To our knowledge, only a few questionnaires measuring the needs of the siblings of severely ill children have been developed, and some of them have methodological limits. The Sibling Cancer Needs Instrument (SCNI) (Patterson et al., 2011; 2014) is an assessment tool developed recently by an Australian team. Its purpose is to identify the unmet needs of young people between the ages of 12 and 23 who have a sibling with cancer. Though similar to the SCNI in some respects, the IBesFEMS is designed for a broader population. Moreover, it was developed using a typology of specific needs based on evidence collected from these siblings and their parents, and uses a validation process that is consistent with the technical guidelines in the Standards for Educational and Psychology Testing (American Educational Research Association, American Psychological Association, and National Council on Measurement in Education, 2014). The differences between the two measures are examined in the discussion section of this article.

TOWARD A SIBLING LIFE-THREATENING ILLNESS (UNMET) NEEDS ASSESSMENT TOOL

General Methods

This new tool to assess the unmet needs of the adolescent siblings of children with a life-threatening illness was developed using classical test theory, which offers the stringent conceptual and methodological foundations required to develop and validate concepts with nonhierarchical indicators (DeVellis, 2012; Crocker & Algina, 2006; Streiner & Norman, 2008). This condition is central to the concept of need, which in our study is viewed from a clinical perspective whereby it is defined as the difference between an actual and desired state (Baldwin, 1998). With that perspective, needs can be defined as the gap between a situation experienced and the required minimal level of satisfaction. This gap becomes the standard by which to recognize the existence of a need. Moreover, this situation of need should be qualified as important for the individual (Hassanein, 1988).

The inspiration for the development and validation of the IBesFEMS came from the process for developing and validating new assessment instruments recommended by Streiner & Norman (2008) and DeVellis (2012). Our study involved three phases: (1) production of a typology of needs, (2) validation of the content of the initial pool of items, and (3) preliminary validation of the first version of the IBesFEMS with the target clientele. Both the methods and results for each phase are presented together, before description of the next phase.

It is worth noting that the choice of the title of the questionnaire was motivated by ethical considerations. Even though the questionnaire is intended for siblings of children with a life-threatening illness, we felt it was important to leave this term out of the title. It is up to the parents to decide whether or not to share this information with their children. However, siblings who are old enough to complete the questionnaire are able to understand the seriousness of their sick brother or sister's illness or condition. This assessment instrument was developed and validated in French with a population of French-speaking siblings residing in Québec, Canada.

Sibling Population and Sampling

The term "sibling" was defined for the purposes of this study as all brothers, sisters, half-brothers, and half-sisters who share a blood relationship with the sick child, as well as stepbrothers and stepsisters who are not related but whose respective parents are together in a new conjugal relationship. These brothers and sisters may or may not have cohabited with the sick child. Siblings were aged 12 to 18 with a brother or sister older than 1 year who was diagnosed with a life-threatening illness. In addition, siblings had to reside in Canada and be able to speak, read, and write in French. Adolescents themselves suffering from a life-threatening illness, cognitive impairment, or psychiatric disorders were excluded from the study.

PHASE 1: CONCEPTUALIZATION OF THE NOTION OF NEEDS FOR THIS POPULATION: DEVELOPMENT OF A TYPOLOGY OF NEEDS

Perspectives and Method

The goal of the first phase was the development of a typology of the needs of adolescent siblings of children with a life-threatening illness. This typology played an important theoretical role in the development of the new instrument by paving the way for a detailed description of the study concept.

The conceptual framework for the development of this typology of needs draws on three theoretical contributions. The first is Piaget's (1977) theory of cognitive development, which provides a means to recognize a child or teen's main developmental challenges and to associate them with certain needs. These fundamental needs were then studied in the context of life with a child suffering from a life-threatening illness. The second theoretical contribution is the theoretical model of children's concepts of death, depending on their age (Lonetto, 1980; Speece & Brent, 1984). Given the distinct possibility that the ill child will die, this model offers a number of precise concepts to help identify the specific needs required to prepare siblings for that eventuality. Lastly, Bronfenbrenner (1979), in his human bioecological theory, proposed a socioenvironmental analysis of the issue under study. With this theoretical contribution, the consequences and needs of the siblings in relation to the condition of the sick child are studied in a systemic manner that goes beyond the family environment.

The typology was developed using a retrospective qualitative study that allowed the researcher to obtain the point of view of the siblings and parents with regard to the difficulties and needs experienced by siblings when the child was at the end of his or her life. Siblings and parents were recruited with the collaboration of Leucan, a support organization for the families of children with cancer. These collaborators briefly presented the study to families of children deceased 12 to 24 months prior the study and obtained permission to pass along their contact information. The interested families were then contacted by the first author, who obtained written informed consent if they were willing. Ethical approval was obtained in advance from the research ethics committee at Laval University. Separate focus groups were held with the siblings and parents of deceased children, each on average two hours in length. Two group sessions were held with brothers and sisters aged 14 to 18, with 3 participants in each group ($n = 6$) and 2 with parents with 4 participants in each group ($n = 8$). The average age of the sibling group was 16 years. This group consisted of four boys and two girls. The most common diagnosis of the sick child was acute lymphocytic leukemia (ALL). The average duration of illness of the deceased children was 25 months. For four participants in this group, the end of life of the sick child was carried to the hospital, compared to two participants who testified about the end of life of the sick child at home. The selected parents had an average age of 43 years. This group consisted of seven women and one man. The most common diagnosis of the sick child was ALL. The average duration of illness of deceased children was 38 months. For six participants in this group, the end of their child's life took place in a hospital, compared with two parents who experienced the end of their child's life at home. A thematic content analysis conducted according to the steps recommended by Mayer and colleagues (2000) identified the various needs experienced by the siblings, on one hand, and the parents' perceptions of these needs on the other.

Content analysis was employed to categorize the various themes and ideas according to a mixed procedure whereby certain predetermined categories were borrowed from the theoretical referents of Piaget's theory, the model of children's concepts of death at different ages, and Bronfenbrenner's theory, while others emerged during an inductive analysis.

Results

A typology of 43 nonhierarchical needs in 10 different living environments was created, ranging from basic needs associated with the sibling's developmental stage to specific needs related to the context of a serious childhood illness (see Appendix A). These specific needs included those associated with death and the anxieties it engenders. The environments in which the various needs are felt are those associated with the young person's ontosystem (their intrinsic experience), their relationship with the sick child, and with school, parents, family, significant adults, peers, recreational activities, hospitals, associations, and the community. The typology breaks down each need into three different forms, so that it is easier to make the connection between the way the need is expressed verbally, the identified need, and the described need (see Table 1).

PHASE 2: VALIDATION OF THE CONTENT OF THE INITIAL POOL OF ITEMS

Perspectives and Method

An initial list of items or questions measuring needs was drawn up. More specifically, for each of the 43 needs identified in the typology, 3 to 4 items aimed at measuring the same need, but worded differently, were written. Thus, a total of 135 items were created, each specifically associated with one of the siblings' living environments. The goal of this second phase was to select the items that were clearest and most relevant, based on expert opinion. In addition, this second phase allowed for comprehension of the selected items and prevented redundancy between each one.

The content of this initial pool of items was validated by four groups of experts selected according to the recommendations of Grant and Davis (1997). They included groups of psychometricians, researchers in pediatric palliative care, clinicians working with children with a life-threatening illness, and siblings of children with a life-threatening illness (see

Table 1. *Example of a need taken from the typology of needs of the siblings of children with a life-threatening illness*

Environment shared with the sick child		
Expression of the need	Identification of the need	Description of the need
Need for the sick child to be happy and thankful for what I do for him/her "*Me, I felt useful for that (moral support), and it was a pleasure to be with her. I knew that my sister was really happy when I was with her, she said so many times. Me, it gave me a greater desire to stay with her.*" Brother 4	Need for acknowledgment from the sick child	In response to various actions, the sick child shows their siblings and reassures them about their usefulness

Table 2). These experts were recruited on a volunteer basis, and the names of the experts in the first three groups were obtained by the first author using the snowball technique. The siblings were recruited with the collaboration of nurses and social workers at a university pediatric hospital and through a support group for families of children with cancer. These collaborators briefly presented the study to families with both a child with a life-threatening illness and a healthy teen and obtained permission to pass along their contact information. The interested families were then contacted by the first author, who obtained written informed consent if they were willing. Ethical approval was obtained in advance from the institution's research ethics committee.

All experts except the siblings evaluated the items using a self-administered questionnaire. The siblings completed the questionnaire during a face-to-face meeting with the first author. The psychometricians assessed the clarity of the items and were asked to comment on their structure. The researchers, clinicians, and siblings gave their opinions on the relevance and clarity of each item—for example, "I need to have some time to have fun with the members of my family." The scales used had four response levels. The response options for relevance were: (1) irrelevant, (2) somewhat relevant, (3) relevant, and (4) highly relevant. The response options for clarity were: (1) unclear, (2) somewhat clear, (3) clear, and (4) very clear. Subsequently, they identified any items they felt were lacking, with a view to improving the comprehensiveness of the questionnaire. Finally, they were asked to identify any terms the study population might have difficulty understanding (Lynn, 1986).

The questionnaires used to gather data from the experts were inspired by the Content Validity Index (CVI) developed by Waltz and Bausell (1981), recognized as an appropriate procedure for quantifying the judgment of experts (Lynn, 1986). The CVI uses a score to quantify the level of agreement between experts with regard to characteristics assessed (i.e., relevance and clarity in the present study) for each item (Item−CVI or I−CVI) and for the entire instrument (Scale−CVI or S−CVI) by calculating the average of the I−CVIs (Polit et al., 2007). The threshold of 0.80 is considered the lower acceptable limit when constructing a new instrument (Davis, 1992). This means that 80% of the experts consulted recognized the item as relevant or highly relevant, and as being clear or very clear. The I−CVI calculation allowed us to identify the items that experts believed should be removed so as to keep only those with the greatest clarity and relevance.

Results

From the initial pool of 135 measurement items, 6 were removed because their wording generated discomfort among respondents in the sibling group. A total of 52 items were removed because the I−CVI was below the desired threshold, either in terms of relevance or clarity. In the case of items that were highly similar and had an identical I−CVI above 0.80, the choice of which item to keep depended on the responses obtained from the sibling group so as to ensure that the selected items offered the greatest degree of clarity and relevance in the eyes of the brothers and sisters from the population the IBesFEMS is intended for. Some 39 items were eliminated in this way. Following this step, the pool of items was reduced to 38, or 28% of the initial pool. Two other items were removed because their content was deemed too similar by the principal researcher (M.O.-d'A.) and the psychometrician (P.V.), who took part in the final item review. For the remaining 36 items, the S−CVI for relevance was 0.93, while the S−CVI for clarity was 0.89. Finally, to ensure adequate representativeness of the content for each environment, 12 items to measure factors deemed lacking

Table 2. *Overview of the sample for the content validity study*

Group of experts 1	Group of experts 2	Group of experts 3	Group of experts 4	Total
Psychometricians	Researchers in the field of pediatric palliative care	Clinicians	Brothers and sisters	
$n = 3$	$n = 3$	$n = 9$ 3 social workers 3 nurses 2 pediatricians 1 psychologist	$n = 6$ 5 sisters 1 brother	$N = 21$

by the experts consulted were added to the list, for a total of 48 measurement items. The relevance and clarity of these newly added items were not assessed at this stage in the development and validation of the IBesFEMS. In sum, this second phase of research yielded the first version of the IBesFEMS. It assessed needs in the 10 living environments in which they are likely to be experienced. These environments represent the dimensions of the questionnaire.

The first version of the IBesFEMS consists of two subscales. The first measures the importance (I) of each need, while the second measures the degree to which each is satisfied (S). Each was rated on a 4-point scale. A few items may not apply to a respondent's specific situation, in which case they have the option to respond "does not apply to me." The total score per item, or for the entire instrument, is calculated based on items for which a response applies to the respondent.

The IBesFEMS score is calculated according to a procedure proposed by Hassanein (1988), who emphasized the importance of obtaining a single score for each item by combining the two subscales. The algorithm that allows us to obtain a single score per item, referred to here as the "unmet need score" (*UNS*), consists of attributing a weight to the scale of satisfaction based on perceived importance of the need. The algorithm used is $UNS = I * (4 - S)$. The higher the *UNS* single score, the more the item with which it is associated indicates an important unmet need, that is, important, but not satisfied. Item *UNS* values can range from 0 (all needs completely satisfied) to 12 (all needs important and unsatisfied). For example, a *UNS* of 8 is obtained on a specific item by combining a score of 4 on the subscale assessing the importance of a need and 2 on the subscale assessing the degree to which the need is satisfies: $8 = 4 * (4-2)$. The individual's total score is the sum of all the 48 *UNS* scores; therefore, the instrument's total score can range from 0 to 576. A high score indicates a large number of unmet needs. Table 3 shows how an item's single score can be broken down according to sibling responses with regard to the importance and satisfaction subscales. Score values are distributed between 1 and 4 in each subscale, where 1 means not important or not satisfied and 4 means very important or very satisfied.

PHASE 3: ASSESSMENT OF THE ADMINISTRATION PROCEDURES OF THE FIRST VERSION OF THE IBESFEMS

Perspectives and Method

The goal of this phase was to assess the administration procedures and acceptability of the questionnaire in its proposed form. This phase provided information on optimal conditions of use for this new questionnaire and offered a means to identify problems and make the desired changes (Waltz et al., 2005). To achieve this goal, 5 brothers and sisters who had siblings with a life-threatening illness and were between the ages of 12 to 18 were recruited. To do so, collaboration from nurses and social workers was requested after approval from the pediatric hospital research ethics committee had been received. The siblings expressed their agreement by signing an assent form, while their parents signed a consent form. The teenagers had access to a password-protected website where they could complete

Table 3. *Score breakdown based on need importance and satisfaction*[a]

$UNS = I * (4 - S)$

	Satisfaction			
Importance	1	2	3	4
1	3	2	1	0
2	6	4	2	0
3	9	6	3	0
4	12	8	4	0

[a] Score values are distributed between 1 and 4 in each subscale. 1 = not important or not satisfied; 4 = very important or very satisfied.

the questionnaire online. Soon afterwards, the researcher contacted each participant to ask about how easy they found it to complete the online questionnaire, any problems they experienced in completing it without assistance, the clarity of the instructions, the layout, and any other questionnaire-related issues they found problematic. Table 4 provides an overview of the sample recruited to assess the administrative procedures of the questionnaire.

Results

The results obtained during the assessment of the administration procedures confirm that the questionnaire lends itself well to self-administration. The siblings reported that the clear instructions and wording allowed them to complete the questionnaire on their own. Furthermore, some of the siblings mentioned that they appreciated the fact that the questionnaire was self-administered and confidential, as they felt it gave them more freedom in their responses. A few siblings reported that their responses would have been different if their parents had been at their side. They also mentioned that the online procedure for completing the questionnaire was appropriate. Consequently, no changes were made to the questionnaire at this stage.

DISCUSSION

The principal conclusions drawn in phase 1 of this study relate to the typology of needs produced, composed of 43 needs of the sibling population of children with life-threatening illnesses. The Bronfenbrenner bioecological theory allows for a needs classification based on 10 sibling living environments (Olivier-d'Avignon, 2006). Usually, the primary environments considered in needs assessment initiatives for adolescents are family and clinical settings (hospitals). The original contribution from this study now allows for a systemic analysis, considering siblings' needs over a broader perspective (Wood, 2006; Contro & Scofield, 2006; 2012). These results are consistent with certain needs that have already been identified by researchers or clinicians in serious pediatric illness environments (Ballard, 2004; Contro & Scofield, 2006; Gaab et al., 2013; Nolbris & Ahlstrom, 2014). However, the typology is person-centered in that it also includes broader needs associated with the developmental stage of adolescence, not just those related to the specific experience of illness (Adams & Deveau, 1987; Lapwood & Goldman, 2012). This approach provides the opportunity for a comprehensive analysis of the needs of brothers and sisters, both in the nature of these needs and in the living environments and specific actors related to these needs.

The second phase of this study led to a significant reduction in the initial items generated from the typology. This phase generated an appropriate indicator for content validation: the CVI that quantifies expert judgment (Polit et al., 2007). The 36 items retained at the end of the process obtained a CVI of 0.93 on the relevance scale and 0.89 on the clarity scale. This is above the recommended threshold of 0.80 (Davis, 1992; Waltz et al., 2005). The different steps in the development of the IBesFEMS were consistent with the standards set out by the joint committee of the American Educational Research Association, the American Psychological Association, and the National Council on Measurement in Education (2014). In fact, at certain stages the procedures employed went beyond the recommended guidelines. For instance, during the content validation stage in phase 2, 21 experts, rather than the 5 recommended by Lynn (1986), were consulted to assess the relevance, clarity, and representativeness of the items.

The results observed in the third phase indicate that the procedure for administration of the IBesFEMS is optimal. Several past studies addressing the needs of the siblings of children with life-threatening illnesses have used proxies (Ballard, 2004; von Essen & Enskär, 2004; Jones, 2006; O'Shea et al., 2012). The evidence obtained suggests that self-administered procedures are relevant and important to the respondent and allow for more freedom in their response. Therefore, it seems preferable to obtain the testimony directly from the brothers and sisters concerned (Guide et al., 2004; Houtzager et al., 2005; Lapwood & Goldman, 2012).

Table 4. *Characteristics of adolescent participants and sick children*

Sibling	Gender	Age	Number of children in the family	Principal diagnosis of the ill child	Ill child's age	Length of illness
1	M	13	6	Lennox–Gastaut syndrome	13	13 years
2	M	15	6	Lennox–Gastaut syndrome	13	13 years
3	M	17	6	Lennox–Gastaut syndrome	13	13 years
4	F	15	2	Epileptic encephalopathy	17	17 years
5	M	14	3	Cancer (soft tissue sarcoma)	12	10 months

One of the concerns throughout the instrument development process was to ensure consistency between the selected items and the actual situation of the siblings of children with a life-threatening illness. The contribution of members of the study population is considered essential to the development of self-administered questionnaires to ensure that they are detailed and comprehensive (Haynes et al., 1995; Klassenet al., 2010). The recognized expertise of the families was therefore sought right from phase 1, while in the second phase experts from the scientific community were approached. In this way, measurement item development and selection were enhanced by triangulating data culled from the experience of siblings and their parents, the scientific literature on the population in question, and the opinions of research and clinical experts.

The originality of the IBesFEMS lies in the theoretical construct of "need" according to which a need is the gap between an actual and a desired state (Baldwin, 1998; Bonuck, 1996). This definition of the concept of need is then operationalized using an algorithm to provide a single score that reflects not only the extent to which each need is satisfied, but also the importance attributed to it by the respondent. This differentiates the IBesFEMS from other measures of needs in adolescent siblings of children with life-threatening illness (i.e., Patterson et al., 2014) and is, we believe, an improvement in measurement. Furthermore, due to its generic nature, the IBesFEMS appears consistent with clinical reality in pediatric palliative care as it is not exclusive to the field of pediatric oncology. Pediatric palliative care teams worldwide are faced with considerable heterogeneity in the diagnoses of the children they treat (Duncan et al., 2007; Together for Short Lives, 2009; Feudtner et al., 2011; McNamara-Goodger & Feudtner, 2012). For instance, in Canada, pediatric cancers account for only 20 to 22% of the ill children in the care of palliative care specialized teams (Widger et al., 2007; Vadeboncoeur et al., 2010). Access to a non-disease-specific measure is therefore highly desirable.

The IBesFEMS addresses a number of other concerns of the pediatric palliative care community, where the care philosophy revolves primarily around the family. For example, parents' ability to meet the needs of all their children is valued and recognized (CHPCA & CNPCC, 2006). The IBesFEMS provides the opportunity to help them put their expertise to the most effective use. Parents should not, however, be identified as the only ones responsible for satisfying the needs of their children, since this task also involves, to varying degrees, the members of the care team and school professionals. The IBesFEMS's multidimensional environmental perspective provides a global assessment. The goal is to support and promote the involvement of the various actors working with siblings, making it easier to identify and address their specific needs in all their environments.

Finally, the IBesFEMS may have a preventative function with the education of and outreach to parents regarding their children's needs. For professionals, using the IBesFEMS could facilitate discussion and information about siblings' needs with parents. The potential preventative use of the IBesFEMS deserves to be considered, and the effectiveness of this use should be evaluated. This could be especially useful in cases where the choice is made to integrate a palliative approach from the moment the child is diagnosed with a life-threatening illness (CHPCA & CNPCC, 2006). The IBesFEMS provides an opportunity to assess the unmet needs of siblings on a regular basis and when important changes occur in the sick child's care trajectory.

With regard to subsequent IBesFEMS validation steps, a fourth stage in the research project was carried out to validate the psychometric qualities of this new questionnaire. This step is described in the companion paper to this article (part 2). The fourth phase of the research involved collecting evidence from a larger sample so as to assess the construct validity and the reliability of the IBesFEMS, both for the instrument as a whole and for its various dimensions.

The preliminary steps in the development and validation described herein have certain limits. First, it is worth keeping in mind that they were carried out in a population of young, French-speaking Québécois with the collaboration of healthcare professionals working in Québec pediatric hospitals. The presence of a potential cultural bias must therefore be taken into consideration. In addition, recruitment efforts were hampered by the limited access allowed to young brothers and sisters in certain care units, including pediatric intensive care, which led to underrepresentation of this population. Moreover, female siblings were underrepresented in the sample recruited to assess the administration procedures of the questionnaire, with four males and one female.

The introduction of this new measurement instrument could provide clinicians with a better tool for working with families who have a child with a life-threatening illness because of the wide range of needs it allows them to assess. As a result, they will be able to better target their interventions with the child's siblings and create a collaborative partnership with other actors surrounding the child.

CONCLUSIONS

It is well known among clinicians and researchers alike that children with a life-threatening illness and their families have important needs that are likely to exacerbate their psychological distress if they are left unmet (Contro et al., 2004; Knapp & Contro, 2009). Furthermore, pediatric palliative care is a field based on still-emerging practical, methodological, and theoretical knowledge. Given this, the IBesFEMS has a role to play in better identifying the specific needs of siblings and supporting the development of practices and research in this field.

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REFERENCES

Adams, D.W. & Deveau, E.J. (1987). When a brother or sister is dying of cancer: The vulnerability of adolescent sibling. *Death Studies*, *11*(4), 279–295.

American Educational Research Association, American Psychological Association, and the National Council on Measurement in Education (2014). *Standards for educational and psychological testing*. Washington, DC: American Educational Research Association.

Baldwin, S. (1998). *Needs assessment and community care: Clinical practice and policy making*. Oxford: Butterworth–Heinemann.

Ballard, K.L. (2004). Meeting the needs of siblings of children with cancer. *Pediatric Nursing*, *30*(5), 394–401.

Bonuck, K.A. (1996). Theory and method: A social work approach to unmet needs. *Administration in Social Work*, *20*(2), 29–40.

Brennan, C., Hugh-Jones, S. & Aldridge, J. (2012). Paediatric life-limiting conditions: Coping and adjustment in siblings. *Journal of Health Psychology*, *18*(6), 813–824. Epub ahead of print Sep 4. Available from http://journals.sagepub.com/doi/pdf/10.1177/1359105312456324.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge: Harvard University Press.

Canadian Hospice Palliative Care Association [CHPCA] & Canadian Network of Palliative Care for Children [CNPCC] (2006). *Pediatric hospice palliative care: Guiding principles and norms of practice*. Ottawa: CHPCA and CNPCC. Available from http://www.chpca.net/media/7841/Pediatric_Norms_of_Practice_March_31_2006_English.pdf.

Contro, N. & Scofield, S. (2006). The power of their voices: Child and family assessment in pediatric palliative care. In *Oxford textbook of palliative care for children*. A. Goldman et al. (eds.), pp. 143–153. New York: Oxford University Press.

Contro, N. & Scofield, S. (2012). The power of their voices: Assessing the child and family. In *Oxford textbook of palliative care for children*, 2nd ed. A. Goldman et al. (eds.), pp. 58–67. New York: Oxford University Press.

Contro, N.A., Larson, J., Scofield, S., et al. (2004). Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics*, *114*(5), 1248–1252.

Crocker, L. & Algina, J. (2006). *Introduction to classical and modern test theory*. Mason, OH: Cengage Learning.

Davis, L.L. (1992). Instrument review: Getting the most from a panel of experts. *Applied Nursing Research*, *5*(4), 194–197.

DeVellis, R.F. (2012). *Scale development: Theory and applications*, 3rd ed. Thousand Oaks, CA: Sage Publications.

Dighe, M., Jadhav, S., Muckaden, M.A., et al. (2008). Parental concerns in children requiring palliative care. *Indian Journal of Palliative Care*, *14*(1), 16–22.

Duncan, J., Spengler, E. & Wolfe, J. (2007). Providing pediatric palliative care: PACT in action. *The American Journal of Maternal and Child Nursing*, *32*(5), 279–287.

Feudtner, C., Hexem, K. & Rourke, M. (2011). Epidemiology and the care of children with complex conditions. In *Textbook of interdisciplinary pediatric palliative care*. J. Wolfe et al. (eds.), pp. 7–17. Philadelphia: Elsevier Saunders.

Feudtner, C., Zhong, W., Faerber, J., et al. (2015). Pediatric end-of-life and palliative care: Epidemiology and health service use. In *Dying in America: Improving quality and honoring individual preferences near the end of life*. Committee on Approaching Death: Addressing Key End-of-Life Issues (eds.), Appendix F. Washington, DC: National Academies Press.

Gaab, E.M., Owens, G. & MacLeod, R.D. (2013). The voices of young New Zealanders involved in pediatric palliative care. *Journal of Palliative Care*, *29*(3), 186–192.

Grant, J.S. & Davis, L.L. (1997). Selection and use of content experts for instrument development. *Research in Nursing & Health*, *20*(3), 269–274.

Guide, J., Lobato, D., Kao, B., et al. (2004). Discordance between sibling and parent reports of the impact of chronic illness and disability on siblings. *Children's Health Care*, *33*(1), 77–92.

Hashemi, F. & Shokrpour, N. (2010). The impact of education regarding the needs of pediatric leukemia patients' siblings on the parents' knowledge and practice. *The Health Care Manager*, *29*(1), 75–79.

Hassanein, R.S. (1988). Barriers to research in allied health. *Journal of Allied Health*, *17*(3), 175–187.

Haynes, S.N., Richard, D.C.S. & Kubany, E.S. (1995). Content validity in psychological assessment: A functional approach to concepts and methods. *Psychological Assessment*, *7*(3), 238–247.

Houtzager, B.A., Grootenhuis, M.A., Caron, H.N., et al. (2005). Sibling self-report, parental proxies, and quality of life: The importance of multiple informants for siblings of a critically ill child. *Pediatric Hematology and Oncology*, *22*(1), 25–40.

Hutson, S.P. & Alter, B.P. (2007). Experiences of siblings of patients with Fanconi anemia. *Pediatric Blood and Cancer*, *48*(1), 72–79.

Hynson, J.L. (2006). The child's journey: Transition from health to ill-health. In *Oxford textbook of palliative care for children*. A. Goldman et al. (eds.), pp. 14–27. New York: Oxford University Press.

Institute of Medicine [IOM] (2003). *When children die; Improving palliative and end-of-life care for children and families*. M.J. Fields & R.E. Behrman (eds.). Washington, DC: The National Academies Press.

Jones, B.L. (2006). Companionship, control and compassion: A social work perspective on the needs of children with cancer and their families at the end of life. *Journal of Palliative Medicine*, *9*(3), 774–788.

Jones, B.L., Gilmer, M.J., Parker-Raley, J., et al. (2011). Parents' and siblings' relationships and the family experience. In *Textbook of interdisciplinary pediatric palliative care*. J. Wolfe et al. (eds.), pp. 135–147. Philadelphia: Elsevier Saunders.

Kenney, K. (2010). *Social support and health-related quality of life among healthy middle-childhood aged siblings of chronically ill children*. Doctoral dissertation. New York: Columbia University.

Klassen, A.F., Strohm, S.J., Maurice-Stam, H., et al. (2010). Quality-of-life questionnaires for children and childhood cancer survivors: A comparison of available measures. *Supportive Care in Cancer*, *18*(9), 1207–1217. Epub ahead of print Oct 16, 2009.

Knapp, C.A. & Contro, N. (2009). Family support services in pediatric palliative care. *The American Journal of Hospice and Palliative Care*, *26*(6), 476–482. Epub ahead of print Oct 16.

Lähteenmäki, P.M., Sjöblom, J., Korhonen, T., et al. (2004). The siblings of childhood cancer patients need early support: A follow-up study over the first year. *Archives of Disease in Childhood*, *89*(11), 1008–1013.

Lane, C. & Mason, J. (2014). Meeting the needs of siblings of children with life-limiting illnesses. *Nursing Children and Young People*, *26*(3), 16–20.

Lapwood, S. & Goldman, A. (2012). Impact on the family. In *Oxford textbook of palliative care for children*, 2nd ed. A. Goldman et al. (eds.), pp. 117–129. New York: Oxford University Press.

Lenton, S., Goldman, A., Eaton, N., et al. (2006). Development and epidemiology. In *Oxford textbook of palliative care for children*. A. Goldman et al. (eds.), pp. 3–13. New York: Oxford University Press.

Lewis, M. & Prescott, H. (2006). Impact of life-limiting illness on the family. In *Oxford textbook of palliative care for children*. A. Goldman et al. (eds.), pp. 154–178. New York: Oxford University Press.

Lonetto, R. (1980). *Children's conception of death*. New York: Springer Science.

Long, K.A., Alderfer, M.A., Ewing, L.J., et al. (2013). The role of contextual threat in predicting self-reported distress among siblings of children with cancer. *Journal of Clinical Psychology in Medical Settings*, *20*(2), 199–208.

Lynn, M.R. (1986). Determination and quantification of content validity. *Nursing Research*, *35*(6), 382–385.

Mayer, R., Ouellet, F., Saint-Jacques, M.-C., et al., (eds.), (2000). *Méthodes de recherche en intervention sociale* [*Research methods for psychosocial intervention*] [in French]. Montréal: Gaëtan Morin Éditeur.

McNamara-Goodger, K. & Feudtner, C. (2012). History and epidemiology. In *Oxford textbook of palliative care for children*, 2nd ed. A. Golman et al. (eds.), pp. 3–12. New York: Oxford University Press.

Murray, J.S. (1999). Siblings of children with cancer: A review of the literature. *Journal of Pediatric Oncology Nursing*, *16*(1), 25–34.

Nolbris, M.J. & Ahlstrom, B.H. (2014). Siblings of children with cancer: Their experiences of participating in a person-centered support intervention combining education, learning and reflection. Pre- and post-intervention interviews. *European Journal of Oncology Nursing*, *18*(3), 254–260. Epub ahead of print Feb 6.

Nolbris, M. & Hellström, A.L. (2005). Siblings' needs and issues when a brother or sister dies of cancer. *Journal of Pediatric Oncology Nursing*, *22*(4), 227–233.

O'Brien, I., Duffy, A. & Nicholl, H. (2009). Impact of childhood chronic illnesses on siblings: A literature review. *British Journal of Nursing*, *18*(22), 1358–1365.

Olivier-d'Avignon, M. (2006). *Identification des besoins de la fratrie d'enfants en fin de vie* [*Identifying the needs of siblings of dying children*] [in French]. Master's thesis. Québec: Université Laval.

Olivier-d'Avignon, M. (2013). *Élaboration et validation d'un outil d'évaluation des besoins de la fratrie d'enfants atteints d'une maladie à issue potentiellement fatale* [*Development and validation of a need measurement for siblings of children with a life-threatening illness*] [in French]. Doctoral dissertation. Québec: Université Laval.

Olivier-d'Avignon, M., Dumont, S., Valois, P., et al. (2016). The needs of siblings of children with a life-threatening illness, part 2: Psychometric validation of a measurement instrument. *Palliative & Supportive Care*, 1–12. Epub ahead of print May 27.

O'Shea, E.R., Shea, J., Robert, T., et al. (2012). The needs of siblings with cancer: A nursing perspective. *Journal of Pediatric Oncology Nursing*, *29*(4), 221–231.

Patterson, P., Millar, B. & Visser, A. (2011). The development of an instrument to assess the unmet needs of young people who have a sibling with cancer: Piloting the Sibling Cancer Needs Instrument (SCNI). *Journal of Pediatric Oncology Nursing*, *28*(1), 16–26. Epub ahead of print Aug 25, 2010.

Patterson, P., McDonald, F.E.J., Butow, P., et al. (2014). Psychometric evaluation of the Sibling Cancer Needs Instrument (SCNI): An instrument to assess the psychosocial unmet needs of young people who are siblings of cancer patients. *Supportive Care in Cancer*, *22*(3), 653–665.

Piaget, J. (1977). *The development of thought: Equilibration of cognitive structures*. New York: Viking Press.

Piaget, J. & Inhelder, B. (1966). *La psychologie de l'enfant*, 19$^{\text{ième}}$ édition [*The psychology of the child*, 19th ed.]. Paris: Presses Universitaires de France.

Polit, D.F., Beck, C.T. & Owen, S.V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in Nursing & Health*, *30*(4), 459–467.

Sidhu, R., Passmore, A. & Baker, D. (2005). An investigation into parent perceptions of the needs of siblings of children with cancer. *Journal of Pediatric Oncology Nursing*, *22*(5), 276–287.

Sloper, P. (2000). Experiences and support needs of siblings of children with cancer. *Health & Social Care in the Community*, *8*(5), 298–306.

Speece, M.W. & Brent, S.B. (1984). Children's understandings of death: A review of three components of a death concept. *Child Development*, *55*(5), 1671–1686.

Stallard, P., Mastroyannopoulou, K., Lewis, M., et al. (1997). The siblings of children with life-threatening conditions. *Child and Adolescent Mental Health*, *2*(1), 26–33.

Statistics Canada (2015). *Table 051-0002: Estimates of deaths, by sex and age group. Canada, provinces and territories, annual (persons)*. Available from http://www5.statcan.gc.ca/cansim/a26?lang=eng&id=510002.

Stillion, J.M. & Papadatou, D. (2002). Suffer the children: An examination of psychosocial issues in children and adolescents with terminal illness. *American Behavioral Scientist*, *14*(2), 299–315.

Streiner, D.L. & Norman, G.R. (2008). *Health measurement scale: A practical guide to their development*, 4th ed. New York: Oxford University Press.

Together for Short Lives (2009). *A guide to the development of children's palliative care services*, 3rd ed. Bristol: Together for Short Lives. Available from http://www.togetherforshortlives.org.uk/assets/0001/1649/ACT_Guide_to_Developing_Services.pdf.

Vadeboncoeur, C.M., Splinter, W.M., Rattray, M., et al. (2010). A paediatric palliative programme in development: Trends in referral and location of death. *Archives of Disease in Childhood*, *95*(9), 686–689. Epub ahead of print Jul 7, 2009.

von Essen, L. & Enskär, K.G.L. (2004). Important aspects of care and assistance for siblings of children treated for cancer: A parent and nurse perspective. *Cancer Nursing*, *26*(3), 203–210.

Waltz, C.L., Strickland, O.L. & Lenz, E.R. (2005). *Measurement in nursing and health research*, 3rd ed. New York: Springer Science.

Waltz, C.W. & Bausell, R.B. (1981). *Nursing research: Design, statistics and computer analysis*. Philadelphia: F.A. Davis.

Widger, K., Davies, D., Drouin, D., et al. (2007). Pediatric patients receiving palliative care in Canada: Results of a multicenter review. *Archives in Pediatric & Adolescent Medicine*, *161*(6), 597–602.

Williams, P.D. (1997). Siblings and paediatric chronic illness: A review of the literature. *International Journal of Nursing Studies*, *34*(4), 312–323.

Wolfe, J. & Siden, H. (2012). Research in paediatric palliative care. In *Oxford textbook of palliative care for children*, 2nd ed. A. Goldman et al. (eds.), pp. 441–457. New York: Oxford University Press.

Wood, I. (2006). School. In *Oxford textbook of palliative care for children*. A. Goldman et al. (eds.), pp. 128–142. New York: Oxford University Press.

Woodgate, R.L. (2006). Siblings' experiences with childhood cancer. *Cancer Nursing*, *29*(5), 406–414.

World Health Organization (WHO) (2010). *WHO definition of palliative care and palliative care for children*. Geneva: World Health Organization. Available from www.who.int/cancer/palliative/definition/.

Zeltzer, L.K., Dolgin, M.J., Sahler, O.J.Z., et al. (1996). Sibling adaptation to childhood cancer collaborative study: Health outcomes of siblings of children with cancer. *Medical and Pediatric Oncology*, *27*(2), 98–107.

APPENDIX A

Typology of the Needs of Siblings of Children in Pediatric Palliative Care[1,2]

Appendix A

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
		SCHOOL ENVIRONMENT	
1	Need for encouragement and help with my schoolwork *"I still had to study, but I did a lot less, so my marks went down a lot. I did my stuff by myself, nobody helped me and I couldn't really concentrate on it."* Brother 4	Need to be encouraged and supervised to meet academic requirements	Siblings ask to be supported and supervised in carrying out schoolwork, both by their teacher when at school and by their parents when at home
2	Need for my teacher to be aware of what I am going through *"I think that just the fact that others know what's happening. That the teachers know a little. I don't necessarily want them to pull us aside, but just if we spent a night at the hospital, because I've done it, me, I would have liked for the teacher to say: OK. You don't feel too great, stay in the class like everyone else, but don't do the exam and I'll give you some time so that you have time to put things in order, I don't know . . . You know, we're young, what we are, is at home and then at school, so when we don't get by in school, we don't have all our energy."* Sister 1	Need to have access to a teacher who is informed and aware of the youth's particular reality	Through information transmitted to their teachers, siblings expect the teachers to be aware and understanding of their difficulties concentrating and decreased motivation

Continued

Appendix A *Continued*

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
3	Need for my teachers and parents to adapt academic planning and the school calendar to my particular situation *"Me, I remember that, sometimes, I had exams during the week, either Monday or Tuesday, so I studied on the weekend, but I was always at the hospital. At the hospital, there are nurses, people in the hallways—you're always being bothered. I would have liked for them [the teachers] to say, 'I'm giving you another day, so you have one more night to study.' That would have been more practical."* Brother 4	Need to benefit from an adapted school calendar	Siblings would like for their teachers and parents to facilitate their school lives by enabling them to go through events related to the disease of the sick child by giving them days off and special permissions
	PEER RELATIONS ENVIRONMENT		
4	Need to be distracted from worries by having fun with my friends *"I went out a lot with my friends to take my mind off of things, I wanted to have fun and to think about other things than sickness and all that. I didn't talk a lot about my sister. Most knew she was sick and didn't dare talk about it too much, and me neither, but there were two or three people with whom I talked about it."* Brother 4	Need to have the opportunity to distract oneself from preoccupations	Siblings seek pleasure and a distraction through contact with peers; the topics addressed are different from those of the illness and are discussed in an environment outside the family home and the hospital
	RECREATIONAL ENVIRONMENT		
5	Need to receive help pursuing my usual activities by driving me to and from them *"Sure, I was skiing a lot less because I was going skiing with my brother, and then for other activities. Well, we can forget them, because I didn't have a ride. I asked for them from time to time, but I often didn't."* Brother 3	Need to have access to transportation to ensure continuity with regard to usual activities	Sibling wish for sports, artistic, and/or social activities in which siblings are involved before the pediatric palliative care situation in the family is maintained and facilitated by access to transportation
6	Need to experience new types of activities *"Me, I think he especially needed what is normal! At 12, 13 years of age, he needed to live a normal life, like others—to be active and try new things."* Father 1	Need to have access to new activities	Siblings want to have the opportunities to try and discover new and unknown sports, and artistic and/or social activities that are attractive to them

Continued

Appendix A *Continued*

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
7	Need to unwind through intense physical activities "*Me, I always did team sports, and it makes me think about a family because everyone is together. I gave everything I had . . . It helped me to think about other things*." Brother 1	Need to have the opportunity to find an outlet through sports	Sports demand a high level of energy that enables siblings to release impulses, emotions, and various tensions that are ordinarily repressed
	HOSPITAL ENVIRONMENT		
8	Need for my presence to be accepted and desired when I visit my brother or my sister at the hospital regardless of my age and visiting hours "*Me, in my heart, I was afraid that she would die . . . angry because I couldn't go and see her very often*." Brother 2 "*Me, it would be [my advice] that we can always, when we want to, be with our brother or sister. That I can be able to, as soon as I want to go to the hospital, that I can have a ride right away*." Brother 4.	Need for opportunities to have free access to where the sick child is hospitalized	The hospital department and parents permit and encourage the maintenance of the relationship between the sick child and their siblings through the presence of siblings during hospitalizations; these visits could take place at any time and by siblings of all ages, in order to enable moments of fraternal intimacy
9	Need to be informed that professionals are available to help me if I want "*Me, I would have liked if there had been some support from someone from the hospital, it could be a nurse . . . someone who always took care of the same sick child, and so when you arrive, she knows you and is used to you, and you can talk to her, and it could be like a psychologist for you. It seems like it would be less heavy, and it would be easier to understand*." Brother 1	Need to know that there are clinicians available to meet with them and provide assistance	Siblings are informed that they may be able to meet, at the hospital, a helping professional (psychologist, social worker, nurse, pastoral agent) if they wish for help adapting to the situation
	ASSOCIATION AND COMMUNITY ENVIRONMENT		
10	Need to meet and exchange with other youths experiencing or who have experienced the same thing as me "*Leucan also helped a lot with the summer camps. It was good for her to be with kids who were experiencing the same thing as she was*." Mother 2 "*Me, I find that there really should be something to support them [siblings], but right after the death and even during the illness, that they be truly well surrounded and they meet other kids experiencing the same things*." Mother 7	Need for access to social support from youths exposed to the same situation or who have experienced this situation in the past	Through community associations and organizations, siblings receive support through contact with brothers and sisters having experienced, or who are currently experiencing the serious illness or end of life of a child

Continued

Appendix A *Continued*

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
	ENVIRONMENT SHARED WITH CLOSE FRIENDS, EXTENDED FAMILY, AND LOVED ONES		
11	Need to feel safe when in the presence of close friends, family, and loved ones *"It's important to be well surrounded. You have to ask for help from the family, if it's possible. Making sure parents, uncles and aunts, grandparents disturb them [siblings] the least possible."* Mother 1	Need to feel safe when in contact with family and other significant people	Siblings experience calm, trust. and well-being when in contact with people who are significant for them, whether they are family members or not
12	Need to find, among people close to me and my friends, a place where I can express my feelings *"When I feel like talking about it, it's to my friends, I confide a lot to my friends, but not to my parents."* Sister 2 *"When I talked about it, it was with my grandparents, parents, or other people who are not directly related to my brother. But it had to be people who could still understand and with whom I felt understood."* Brother 2	Need for access to emotional support from close friends/family and peers	People who are close to the siblings, that is, grandparents, family members, other significant people (neighbor, teacher, friend of the family), and peer groups, represent a source of emotional support through sincere listening and counseling to them when they wish to confide
	FAMILY ENVIRONMENT		
13	Need for the same harmony and pleasure as before to be present at times when my family is together *"In my family, even if X was not well, we were still close. We teased each other and had fun together."* Brother 4	Need to maintain complicity and harmony during family encounters	Members of the family share harmony and enthusiasm during regular family encounters (meals, outings, etc.) and those relating to the state of health of the sick child (hospital visits, summer camps, etc.); subjects of discussion other than the illness unite and enliven family members
14	Need to go through the end-of-life ordeal of my brother or sister with my family *"He [the brother] and also liked talking to him [the sick child] on the phone or when the department at the CHUL [Centre Hospitalier de l'Université Laval] was almost empty, we brought our son so that he could spend time with his sister, and it was good for him to be among brothers and sister. So he could say, 'me too, I'm taking care of him,' be important and feel like part of the family."* Mother 4	Need to feel included in a family process	Parents foster feelings of inclusion among the siblings in the pediatric palliative care situation by circulating information and respecting their right to speak

Continued

Appendix A *Continued*

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
15	Need for a loving climate within my family and among people who are close to me *"Despite the fact that he was in the terminal phase, there was a lot of love between family members and everyone towards my brother. There was also love from the extended family, uncles and aunts, with support and help*." Sister 2	Need to perceive and feel love and emotional attachment between family members	Siblings need to perceive an ambiance of tenderness and caring, as well as emotional attachment among family members, as well as among those who are close to the family (grandparents, uncles and aunts, etc.)
16	Need to be reassured about changes that will take place in the different spheres of my life (personal, social and family) after my brother or sister has died *"I asked myself what would happen to our family after, how we will live afterwards, without her?*" Brother 4	Need to be reassured by their parents and other family members about different changes brought about by the death of the sick child	Siblings seek to be reassured about the new family organization that will structure the family's daily lives once the sick child is deceased; this reassurance also applies to changes that will occur in the siblings' personal lives and in their social relationships with friends and family
17	Need for support from my brothers and sisters *"Me, I think that always having been together as a gang of brothers and sisters, it was them that helped the most. The oldest one took his little brother and little sister under his wing. They reassured each other. They were the most important people for each other during that time*." Mother 1	Need for access to emotional support from healthy siblings	Empathy and consolation are felt by siblings within an equal relationship that siblings can only find within the fraternal link they share with other brothers and sisters of the family (those who are healthy)
18	Need for the daily family routine that I'm used to be maintained *"I wanted everything to be normal, that everything go on like normal. In the morning, I did my stuff by myself, I was independent. I don't think that my mother was there, but even before the illness, my mother always worked in the evening, so . . . My day-to-day life didn't really change*." Sister 2	Need for access to a reassuring daily family routine	A sense of normality is reassuring for siblings through the maintenance of a family life framework that is already known (mealtimes, types of meals, schedules, morning and evening routines, etc.) remain unchanged or as similar as possible
19	Need for special events in my life be celebrated by my family, as they would have been if my brother or sister was not seriously ill *"It sucked to not see my sister at my birthday. It was I who went to the hospital to see her on my birthday. I had a quick party and I went to the hospital*." Brother 2	Need to be acknowledged for successes and accomplishments	Siblings conserve their unique place and importance when family members celebrate their accomplishments (graduation, academic or sports merits, new job, etc.) or special days that concern them (birthdays, first day of school)

Continued

Appendix A *Continued*

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
20	Need for my level of responsibility and tasks assigned to me at the house remain the same as those I had before my brother or sister's illness *"Me, I had to make the meals, do the washing. My mother called from the hospital to tell me to do the washing, to do this and that. I had to play 'mother' and take care of everyone. It sucked . . . The youngest one was very jealous of the time my mother spent with X. I took care of her a bit, but still . . . I tried to play mother with her, but I'm not her mother. I did as best as I could, but she would throw a fit, but me, I'm only her sister."* Sister 1	Need to maintain the same level of responsibility	Siblings seek a feeling of normality through the maintenance of the same level of involvement in the tasks and responsibilities at home, without taking over responsibilities normally assumed by their parents
		PARENTAL ENVIRONMENT	
21	Need for my parents to respect my autonomy and my ability to make decisions relating to events that concern me *"A lot of the time, I was doing what I wanted when I wanted for activities. But I didn't go see him [the sick child] a lot. When I went, I took advantage of it, but I had a lot of things to do, and I also kept myself really busy. I mostly wanted to do my things and be with friends."* Sister 2	Need for their autonomy and decisional abilities to be respected	Siblings wish to continue fully existing at a personal level; a sensation of coherence is perceived between siblings'—their vision of their capacity for autonomy and the liberty given to them in their daily lives
22	Need to protect my parents *"I didn't want to talk about my brother with my parents by asking questions that would make them have to ask others questions as well."* Brother 1	Need to avoid additionally burdening one's parents	Siblings don't want their parents to worry more, because they see that they already have a lot on their shoulders; they try not to bother and/or not to criticize decisions made by their parents within the context of pediatric palliative care
23	Need for my parents to show understanding and empathy with regard to the ordeal that I'm going through *"One thing that frustrated me a lot was my mother, because my brother died on a Friday, and she just left us the weekend to get over it, because we had to go back to school the next Monday. I would have liked to have had more time to recover. It was my brother. I loved him a lot. I needed more time."* Brother 3	Need to be understood by one's parents	Parents show indulgence and sensitivity when siblings express their emotions regarding the state of health of their brother or sister, displays negative behaviors (aggressiveness, social withdrawal, etc.) or unpleasant moods (moody or depressed)

Continued

Appendix A *Continued*

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
24	Need for my parents (father/mother or both) to be more present at home, by my side *"Me, I would have liked to have spent more time with her [my mother]. And find people to work on the farm so that my father would come and play . . . spend more time with me."* Brother 2	Need to be reassured by the presence of one's parents	The presence of a parent (father/mother) among siblings and parents' involvement in spending quality time with them strengthens siblings' feelings of security
25	Need for my parents to come to me to give me information *" I would have liked to have asked questions, but with my parents, they often didn't have the time, so it ended there. "* Sister 1	Need to be informed by one's parents	Siblings are kept up to date regarding the progression of the state of health of the sick child by their parents, who proactively come to them to give them information
26	Need for my parents to alert me about the imminence of my brother's or sister's death once they have been informed *"I don't think we should hide anything from them [siblings]. I think it's worse to learn suddenly than little by little. Information has to be given as it comes, so they are not faced with a done deal, so they have time to gradually get used to death."* Mother 1	Need to be informed of the imminence of the death of the sick child	In cases where it is possible, siblings wish to be informed of how close death is in order to do or say things to the sick child that are important for them to say or do
27	Need for my parents to be affectionate with me *"At our house, for X [the middle brother] it was a really important need for him since the diagnosis. More important than for the other two. He needed so much to be loved, that child. He demanded a lot of affection."* Mother 1	Need to perceive and feel parents' love through touch	Manifestations of tenderness (hugs, cuddling, etc.) are given to siblings from the parents in equal or greater quantity of that which was given before the child became seriously ill
		ONTOSYSTEM	
28	Need to be reassured about the diagnosis of a serious illness or the possible death of a person from my family or of myself *"We didn't really talk about death as such, we didn't want to talk too much about it because we didn't really want it to happen, so we didn't talk about it a lot, but we certainly did talk about it after. Me, I was scared that other people would become sick or have an accident or something, that they would die too."* Brother 4 *"My boy also asked, 'did I have that too mom, did I lose my hair at that age too?' Or 'will I also get that?' He felt insecure."* Mother 3	Need to be reassured about the risk of diagnosis of a potentially fatal disease and/or death of a loved one or of oneself	Siblings seek to be reassured about the risk that a loved one (parents, grandparents, close friends, family members, etc.) will develop a significant illness or die from an illness or accident

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Appendix A *Continued*

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
29	Need to find meaning for the suffering of my brother or my sister during palliative care *"I don't know why it happened, but it seemed like it was just him that was able to go through that. When you looked at him, you'd say,' but how does he do it?' It seems as though we have our little lives, we go to school and we find it hard like that, and he [the sick child], he couldn't. He went to school just whenever he could. I had a lot of admiration for him."* Sister 1	Need to search for meaning during the sick child's end of life	Siblings seek to rationally and spiritually explain the reasons for the existence of the ordeal of sickness and suffering
30	Need for a place to feel comfortable asking questions and obtaining answers about illness and/or death *"I must say that he didn't get any help, huh! If we compare with us [the parents], the treatment we received, the medication treatment, and the psychological treatments, and support, there was quite a significant amount of things done for us, and for him there was nothing! It was all incumbent on us to support him and answer his questions, and we, we often weren't there."* Father 1	Need for access to informational support in which it is possible for the youth to ask questions about the illness and death, and to obtain answers to these questions	Resource people (parents, close friends, doctors, nurses, etc.) are identified by siblings to hear their preoccupying questions about the illness and/or death; these people attentively listen to the questions without judgment, but also provide complete and honest answers to the siblings; these responses would enable the siblings to better understand and further their search for meaning
31	Need to feel ready for the eventual death of my brother or sister *"Me, I learned 3 days before his death that he was going to die, but I already felt like it was going to happen because we were into experimental treatments and there was a lot of stress, and I felt something. It wasn't a surprise, and I took advantage of my time with him."* Sister 1 *"Yes, I would have liked that [ask questions about death] . . . but I didn't dare ask. I was uncomfortable, but I would have liked to."* Brother 4	Need to be ready for the eventual death of the sick child	Siblings wish to feel prepared to deal with the death of the seriously ill child when it occurs, as best as possible
32	Need to be reassured about how things will progress over the next weeks and months in regards to the progression of the sick child's disease, as well as any sudden disruptions to my daily life *"I am convinced that he [the brother] felt a lot of sadness, worry, and fear in relation to everything that was going to happen."* Mother 4	Need to be reassured about the progression of the sick child's disease and about possible disruptions to one's daily life	Siblings ask to be reassured about changes to their daily lives that will be brought about by palliative care, as well as about the possible trajectory that child's diseases' will take at the end of life

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Appendix A *Continued*

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
33	Need to stay at home rather than be supervised outside the home "*When I told them that I was taking them to their grandmother's, we could feel it that they would have preferred staying at home, with their friends, doing other things. For them, it was a total uprooting, and they know nobody at my parent's place. My parents worked hard and they had a lot of fun, but still, at a certain age, grandparents . . . And between our grandparents and friends, even if we love our grandparents, the choice isn't a difficult one*." Mother 1	Need to remain at home	When parents have to be absent in order to be with the sick child, siblings would prefer to stay in the family home rather than spend a few days elsewhere
34	Need to keep hope regarding the state of health of my brother or sister through positive information about the chances of healing or an improvement of his/her state "*Me, I figured that even if [the sick child] was in terminal phase, I always hoped that he would get well. I kept hope that a miracle would occur*." Brother 3	Need to keep hope	It is important for siblings to keep hoping that the health condition of the sick child will undergo favorable changes and that he/she will be brought out of danger
35	Need to feel like other kids my age "*X [the brother] could not have friends over to the house because of infections, no sports activities, because we didn't have time to drive him because of the farm and because of X's illness. That was missing, I find. I would have liked to give him a life that's normal for his age*." Mother 3	Need to feel similar to one's peers	Siblings don't want to be perceived or treated differently, but seek to have the same lifestyle, the same experiences, and to meet the same academic requirements as other youths their age
	ENVIRONMENT SHARED WITH THE SICK CHILD		
36	Need to be involved in the well-being and care for my sick brother or sister "*My advice is to try to do as much as you can for your brother or sister. Get him to have some good times and show him that you can be there for him [the sick child] in many ways. Me, I needed to feel useful helping him*." Brother 1	Need to be helpful for the sick child	Siblings wish to take part in various tasks and services being carried out for the sick child

Continued

Appendix A *Continued*

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
37	Need for the sick child to be happy and thankful for what I do for him *"Me, I felt useful for that [moral support], and it was a pleasure to be with her. I knew that my sister was really happy when I was with her, she said so many times. Me, it gave me a greater desire to stay with her."* Brother 4	Need for acknowledgment from the sick child	In response to various actions, the sick child shows their siblings gratitude and reassures them about their usefulness
38	Need to take advantage of life and to apply myself at school (or in other activities) in the name of the sick child *"I wanted to have fun. You know, he [the sick child] couldn't. I wanted to take advantage for him. And I didn't want to sit in my corner and find it sad."* Sister 2	Need to benefit from the opportunity of being healthy	In response to a decrease in the sick child's capabilities, siblings wish to seize the occasion of being healthy; their implication and appreciation of activities that the sick child is no longer able to do become more important and significant
39	Need to be assured that everything is being done to foster the well-being and alleviation of my critically ill brother's or sister's suffering *"There were nice gestures from the nurses. They are well treated, the children getting transplants on the transplant unit. There were not many patients, and you felt as though the nurses were there for you no matter what happens."* Sister 2	Need to be assured that everything possible is being done to relieve the sick child's suffering and foster his/her health and wellness	The alleviation of the sick child's suffering becomes a priority for siblings. This requires that everything be done so that the child at the end of life is comfortable, going as far forgetting oneself, reassuring their parents of their ability to stay alone, as well as contributing to the healing of the child as bone marrow donor
40	Need to be explained about what will happen in the body of my sister or brother when they will die *"Me, I had never seen a person die before, close to me. I wondered how she would die physically, and psychologically as well. I was afraid of what was going to happen."* Brother 4	Need to be informed about the physiological aspects of death	Siblings wish to receive information that will help them to understand the physiological process related to the death of a human being; providing knowledge will make it possible to relieve worries they have
41	Need for a person who I trust to give me information about my brother's or sister's illness on a regular basis *"Me, I would have liked for some support from someone from the hospital, it could be a nurse . . . someone who always took care of the same sick child, so when you get there, she knows you and is used to it and you can talk to her, and it could be like a psychologist for you. It seems it would be less gloomy and easier to understand."* Brother 1	Need to be regularly informed by a person one trusts	Siblings seek to understand the illness of the sick child. They wish to hear about all aspects of the illness (diagnosis, causes, treatments, side effects, etc.) from someone from the medical environment (nurse, social worker, psychologist, doctor) or someone from the family (parents, loved ones, friends of the family, uncles or aunts, etc.)

Continued

Appendix A *Continued*

No.	Level 1 Expression of need *Italic type* = verbatim quotations	Level 2 Identification of need	Level 3 Description of Need
42	Need to be assured that my brother's or sister's illness has nothing to do with me *"It affected me at the beginning to go and see him at the hospital because it was me who gave my bone marrow and it wasn't working . . . [silence] Sure, it bothered me at the start. It made me sad. It had the opposite effect of what I wanted. It was not the bone marrow that was doing it; it was his body that was doing it, but still. Even if they explained it to me and that I understood it, it still affected me. I felt guilty.*" Sister 2	Need to be reassured about one's responsibility in the pathogenesis of the child's illness	Siblings seek to overcome feelings of guilt related to self-attributing a portion of responsibility for the sick child's suffering; particularly if there is a rejection of the bone marrow transplant when a sibling was a donor or if there were disagreements between the sick child and sibling preceding moments of suffering for the sick child
43	Need to be reassured about the unique place I hold in the eyes of my brother or sister at the end of life *"Even during that period of terminal phase, you know his sister took good care of him still! Four days before dying, she explained math problems to him. They still shared a really beautiful relationship*." Father 1	Need to be reassured about the uniqueness of the relationship with the sick child	Siblings ask to be reassured about the strength of the uniqueness of the fraternal relationship shared with the sick child, despite hospitalizations, distance, suffering, and other negative aspects brought about by the illness

[1] Drawn from Olivier-d'Avignon (2006).
[2] The original French version is available from http://www.theses.ulaval.ca/2006/23726/23726.pdf.