Much is left unspoken: Self-reports from families in pediatric oncology

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Abstract
Background: Communication about illness-related subjects is complex and difficult. To support entire families in pediatric oncology, health care professionals need to know what family members think, but leave unspoken. The aim of this study was to explore how families in pediatric oncology experienced illness-related information and communication with professionals and within the family.

Procedure: A cross-sectional web survey was used. Families were recruited from one pediatric oncology center in Sweden, 2-3 months after diagnosis. One hundred eighteen family members (ill children, siblings, and parents) representing 27 families filled out age-adapted surveys.

Results: Eighty-six percent of the parents and 71% of the siblings reported that they had not received enough or any information about how the cancer and its treatment could affect the child’s psychological health. The families reported that they did not dare ask professionals questions about psychosocial issues and future-related subjects. Nor did they talk with one another, even though 55% of the parents and 24% of the children wanted to reveal more about how they felt to someone in the family. The parents reported the lowest family communication, and few families had all members reporting the same perception of family communication.

Conclusions: Much is still left unspoken in pediatric oncology and the needs of the families are prominent. Assessments of each family member’s needs might form a basis for professionals to give each person adequate information and family support. An increased awareness in families about family members’ different needs might lead to mutual understanding.

KEYWORDS
palliative care, pediatric oncology, psychosocial, support care

1 INTRODUCTION

Childhood cancer leads to life changes, not only for the ill child, but also for the rest of the family. Studies show that ill children experience distress associated with the illness; for example, side effects of treatment and feelings of loneliness, isolation, and powerlessness.1 They also report feeling disempowered due to a lack of information and being neglected by clinicians who do not have time to talk or answer questions.2 Early physical and emotional distress has been found to predict long-term suffering among these children, which suggests...
that implementation of family interventions could reduce the risk of suffering in children with cancer.2,4 Siblings report difficulties dealing with the ill child’s suffering, loneliness in relation to their own feelings, poor school performance, and insufficient illness-related information from professionals.5 Both children with cancer and their siblings ask for honest information about the illness, and want to talk about their life situation with family, friends, and professionals.6,7 Although there is a shortage of studies following siblings over time, research indicates that child functioning is closely associated with—and often dependent on—parent and family functioning.8,9 For example, poor cohesiveness or having difficulty expressing feelings and emotions in the family unit can predict posttraumatic stress reactions in children.10 Parents play a significant role in providing support throughout a child’s development—whether the child is ill or healthy—but parents of children with cancer are at risk of own marked or prolonged distress or psychopathology.11 Parents experience multiple stressors throughout the illness trajectory, including managing treatment and side effects, financial strain, a sense of being dependent on the care provided, and balancing care of healthy siblings. The stress that follows a child’s cancer diagnosis may lead to family conflicts. Conflicts between parents tend to appear rather early in this process, while parent-child and sibling conflicts seem to occur with a few months’ delay.12 As parent distress peaks around the time of diagnosis and usually declines over time, it is not surprising that parental conflicts also arise near the time of diagnosis.13–15 A small number of parents of ill children seem to be at risk of long-lasting stress symptoms. Muscara et al15 reason that psychosocial factors may predict stress, which gives hope that interventions can prevent it. Parental distress has a negative impact on parental psychological and physical health, family functioning, and marital concord, for example, communication between couples.11,16

Health care professionals have a challenging role in supporting families by providing information and promoting communication about illness-related matters. Guidelines and recommendations regarding psychosocial care and communication in pediatric oncology have been available for many years.17–19 Communication occurs within the complex relationship between health care professionals, patients, and families. Functional communication provides emotional support, guidance, and understanding, and makes it possible to exchange information and respond to emotions.20,21

Communication in pediatric oncology is complex and difficult for all those involved,22 and poor communication impacts on long-term psychological morbidity in all family members.23–26 To support families, health care professionals need a greater understanding of what illness-related matters families find difficult to talk about. The aims of this study were to explore how families in pediatric oncology (ill children, siblings, and parents) experienced illness-related information and communication with health care professionals (Aim 1) and within the family (Aim 2).

2  | MATERIAL AND METHODS

2.1  | Study design and setting

This study used baseline survey data from a psychosocial intervention for families with childhood cancer.27 The goals of the intervention, called the Family Talk Intervention, were to support the families in talking about illness-related matters and to support parenting and coping. Families were recruited from one pediatric oncology center in Sweden between September 2018 and September 2019. Eligible families were those that included an ill child treated for cancer at the oncology center during this time period and at least one child (ill child or healthy sibling) between 6 and 19 years old. Another inclusion criterion was that 2–3 months should have passed since diagnosis or relapse. The entire family or part thereof could participate, but at least one parent/guardian and one child aged 6–19 years had to participate.

The families had to understand and speak Swedish. Nurses at the clinic identified families that met the inclusion criteria (n = 61). Of those, 27 families participated, encompassing 118 family members. The families were given verbal and written information about the study, and then the families gave their informed consent.

The study received ethical approval from the Regional Ethical Review Board in Stockholm (Dnr 2018/250-31/2 and 2018/1852-32), and is registered at ClinicalTrials.gov (Identifier NCT03650530).

2.2  | Data collection

For this study, data were collected through a web-based survey before the intervention began. All family members from 6 years and older answered the questionnaires and were thus included in this paper (n = 111). The survey was sent to the email addresses of all family members. In cases where a child did not have a personal email address, the survey was sent to a sibling or parent, depending on the child’s preferences. No reminder was sent to the families, as all but a few (where family members were too ill) responded, which might imply that the families were eager to begin the intervention.

2.3  | Measurements

For parents and children aged 13 years and older, family communication was measured using the Family Adaptability and Cohesion Scale IV (FACES IV) Family Communication (10 items), which focuses on exchange of information.28,29 It covers the constraints and degree of understanding and satisfaction experienced in family communication interactions. The items include if family members: are happy with how they communicate with each other, are good listeners, enjoy talking to each other, are able to ask each other for what they want, can calmly discuss problems, discuss their ideas and beliefs, can ask questions of each other in the family, try to understand each other’s feelings, say negative things about each other when angry, and express their true
FIGURE 1  Parents’ (n = 53) self-reports of illness-related information, presented as percentages.

Feelings. The response alternatives range between 1 and 5, where 1 is "strongly disagree" and 5 is "strongly agree." The sum of the item scores makes up the total score, which ranges between 10 and 50. Family communication is grouped as follows in the manual: 10-28 is very low family communication, 29-32 is low, 33-37 is moderate, 38-43 is high, and 44-50 is very high family communication. In this study, Cronbach's alpha was .87/.93/.89 (parent/ill child/sibling).

In addition, study-specific questions regarding illness-related information and communication with health care professionals and within the family from earlier studies were also used for all family members.

Seven survey versions were developed: one parent/guardian version, three ill child versions (6-7 years, 8-12 years, and 13-19 years), and three sibling versions (6-7, 8-12, and 13 years and older). The questions were pretested on five families (six parents and seven children) affected by childhood cancer. Based on the feedback, minor changes were made: the order of the questions was changed for the parent version, the versions for the youngest children (6-7 years) were shortened, and some minor stylistic changes were made. The study-specific questions and the response options are shown in Figures 1–3, Table 2, and the lower section of Table 3.

In conjunction with three study-specific items about communication ("I have chosen not to talk about everything related to the my child's illness with my family," "I have thoughts and/or feelings that I don't want to share with my family," and "I have thoughts about my child's illness that I do not dare talk about with health care professionals"), follow-up questions were asked: "Please describe what you do not talk about or share with your family" or "Please describe what you do not dare talk about with health care professionals." The responses given, which were a few words to a couple of sentences long, have also been included in this paper.

Data from the study are available on request.

2.4 Data analysis

The closed-ended questions were analyzed with descriptive statistics. FACES IV was scored in accordance with the manual. Due to the small sample size, FACES IV was used with three levels instead of five: very low was grouped with low and high was grouped with very high. Content analysis was applied to the answers to the three open-ended questions.

3 RESULTS

3.1 Background characteristics for the families

About half of the ill children had a central nervous system-related tumor (brain and/or spinal cord tumor). Most families were nuclear families and the gender distribution among the participants was about 50:50. The 27 families included 53 parents, 27 children with cancer, and 38 siblings. Sixty-eight percent of the parents had a university-level education (Table 1). To date (September 2020), six of 27 children have died.
Illness-related information and communication with professionals (Aim 1)

A clear majority of the parents, 85% (45/53), reported that they had not received any information or enough information about how the cancer and its treatment could affect the child’s psychological health (Figure 1). The corresponding number for information about the child’s physical health was 55% (29/53). Over half of the parents (55%, 29/53) reported that they had not received enough information or any information about where or whom they could turn to for own support.
TABLE 1  Demographic characteristics of the families (n = 27)

| Family constellation                                      | Number of families = 27 |
|----------------------------------------------------------|-------------------------|
| Nuclear family (mother, father, and child/children)      | 22 (81)                 |
| One parent with children                                 | 3 (11)                  |
| Divorced/separated parents in new family constellations  | 2 (7)                   |
| Number of siblings                                       | 0/1/2                   |
| Parents, n = 53                                          |                          |
| Ill children, n = 27                                     |                          |
| Siblings, n = 38b                                        |                          |

| Sex                                                      |                         |
|----------------------------------------------------------|-------------------------|
| Female                                                   | 29 (55)                 |
| Male                                                     | 24 (45)                 |

| Age (years)                                              |                         |
|----------------------------------------------------------|-------------------------|
| Mean (SD)                                                | 45 (6.4) 10 (4.1) 12 (5.2) |
| Min-max                                                  | 34-65 1-17 3-24          |

| Educational level (parents)                              |                         |
|----------------------------------------------------------|-------------------------|
| University                                               | 36 (68)                 |
| Secondary school                                         | 15 (28)                 |
| Elementary school                                        | 0                       |
| Folk high school, vocational training                    | 2 (4)                   |

| Type of cancer (parental report)                         |                         |
|----------------------------------------------------------|-------------------------|
| Central nervous system tumor                             | 13 (48)                 |
| Leukemia                                                 | 5 (19)                  |
| Lymphoma                                                 | 5 (19)                  |
| Sarcoma                                                  | 2 (7)                   |
| Other (Wilms' tumor, lung cancer)                        | 2 (8)                   |

family had told them about the cancer illness, but 24% (6/25) of the ill children and 45% (15/33) of the siblings wanted to know more about the illness (Table 2). A few teenagers who were ill (one to three teenagers out of seven) reported insufficient or poor illness-related information, especially regarding prognosis and psychological health (Figure 2). A vast majority of the siblings aged 13 years and older reported that they had not received information or that they wanted more information regarding several areas: prognosis (64%, 9/14), how the cancer and its treatment could affect the child’s physical (64%, 9/14) and psychological health (71%, 10/14), where or whom they could turn to if they have questions about the ill child’s care (57%, 8/14), and where or whom they could turn to for own support (50%, 7/14) (Figure 3).

Forty-two percent of the parents (22/53) reported that they had thoughts about the illness that they did not dare talk about with health care professionals, while only 7% (4/58) children (one ill child and three siblings) reported the same. One ill child described, in a free-text comment, that he/she did not dare talk about the use of alcohol during treatment or about thoughts regarding his/her appearance. The siblings described that they did not dare talk to health care professionals because “they talk around things,” which resulted in even more uncertainty. Moreover, the siblings reported that health care professionals interpreted everything as negative criticism, which led the siblings to keep silent. The parents described that they did not dare talk to health care professionals about the prognosis, side effects and risks of treatments, the family’s psychosocial well-being, the child’s future fertility, and staff routines. The parents reported that reasons for not daring to talk to health care professionals could be the presence of their child, being afraid of the answers they might get, or being afraid to be perceived as bothersome due to focusing on the psychosocial aspects of the cancer experience. Some parents also described having difficulties talking to health care professionals due to lack of time or that the physicians did not want to or could not respond. There was also...
DISCUSSION

Of the parental couples who lived together their ideas and beliefs with each other, and that they tried to under-
other items at the same level: that the family members could discuss
ily members liked talking to each other (the ill children also scored two
children and siblings, the highest scoring item was related to that the fam-
related to honesty when a family member asked questions. For ill chil-
ill children, and siblings all scored lowest on the item related to saying bad things
uncertainty among “extra” parents regarding their rights to informa-
tion, which affected their communication with professionals.

3.3 Family communication (Aim 2)

Parents reported the lowest family communication in FACES IV, fol-
lowed by siblings (Table 3). The mean scores for family communication
for parents, ill children, and siblings were roughly in line with the norm
values (mean norm values: 36.2 vs 35.4 for the parents, 39.1 for the
ill children, and 36.6 for the siblings in this study). Parents, ill children,
and siblings all scored lowest on the item related to saying bad things
to one another when angry. The highest scoring item for parents was
related to honesty when a family member asked questions. For ill chil-
ren and siblings, the highest scoring item was related to that the fam-
ily members liked talking to each other (the ill children also scored two
other items at the same level: that the family members could discuss
their ideas and beliefs with each other, and that they tried to under-
stand each other’s feelings). Of the parental couples who lived together
(n = 24), nine (38%) reported the same family communication levels
within the couples; the rest (15/24, 63%) had differing levels within
the couples. In nine of 15 cases (60%), the female partner scored family
communication higher than the male.

Forty-two percent of the parents reported that they had chosen
not to talk about everything regarding the illness with their family
(Table 3). The parents described, in response to the open-ended ques-
tions, that they did not talk about the following areas with their family:
(a) the future, which included a poor prognosis, side effects, and risks
of medical treatment; (b) their own feelings and coping strategies, if
they thought it could affect the family negatively or if the other family
members coped with the situation in other ways; and (c) full informa-
tion about the illness; they avoided full disclosure to members of the
family and extended family as a way of protecting them.

All children, except four of 25 ill children, could talk with someone
in the family about the illness. Only two of 25 ill children and four of 33
siblings had questions about the illness that they did not dare ask their
family (Table 2). Eight out of 25 ill children (32%) reported that they had
feelings or thoughts that they did not want to share with their family
(Table 3). The corresponding number for siblings was 17/33 (52%).
The feelings and thoughts they did not want to share were related to
disappointment in oneself (ill children), their school situation, sadness
at night, feeling neglected, and anger/disappointment at the parents
(siblings). In the six of 24 families where both an ill child and a sibling
answered the survey, the ill child’s and the sibling’s responses were
the same; four child-sibling dyads had no thoughts/feelings they did
not want to share, while two did. Sixty-eight percent (36/53) of the
parents reported that they did not share their thoughts or feelings
with their families (Table 2). Of the 24 parental couples that lived
together, 12 couples reported that they did not want to share their
thoughts or feelings with their families, four reported that they did,
and in eight couples, the parents did not respond in the same way as
one another. The thoughts and feelings they did not share were related
to uncertainty regarding the illness, the prognosis, and a variety of
feelings (worry, anxiety, fear, pain, loneliness, stress, anger, frustration,
etc) that they did not want to share because they did not want to put
pressure on other family members. Within five of 27 families, all family
members’ responses were the same; the members in one of these
families had thoughts or feelings they did not want to share and those
in the other four did not have such thoughts or feelings.

Fifty-four percent (29/53) of the parents and 24% of the ill children
(6/25) and siblings (8/33) reported that they wanted to reveal more
about how they felt to someone in the family. Within three of 27
families, all family members gave the same response (no one wanted
to reveal more). Of the 24 parental couples who lived together, 12
responded in the same way within the couples (nine reported that they
wanted to reveal more about how they felt to someone in their family
and three reported that they did not) and 12 did not. Within 10 fam-
ilies, all siblings gave the same response (they did not want to reveal
more about how they felt), while children from 12 families did not (the
rest of the families had only one child participating in the survey).

4 DISCUSSION

In this study, majority of the parents and siblings reported insufficient
or poor information related to the ill child’s prognosis and psychological
TABLE 3  Family communication reported by parents, ill children, and siblings

|                           | Parents/adults, n = 53 | Ill child, 13-19 years, n = 7 | Sibling, ≥13 years, n = 14 | Ill children, 6-12 years, n = 18 | Siblings, 6-12 years, n = 19 |
|---------------------------|------------------------|-------------------------------|-----------------------------|-------------------------------|-------------------------------|
| **Family communication (FACES IV)** |                        |                               |                             |                               |                               |
| Mean (SD), min-max        | 35.4 (6.1), 21-48       | 39.1 (5.4), 32-50             | 36.6 (7.2), 24-47           |                               |                               |
| Very high + high          | 18 (34)                | 5 (71)                       | 7 (50)                      |                               |                               |
| Moderate                  | 22 (42)                | 1 (14)                       | 3 (21)                      |                               |                               |
| Low + very low            | 13 (25)                | 1 (14)                       | 4 (29)                      |                               |                               |
| **Study-specific questions** |                        |                               |                             |                               |                               |
| Has chosen not to talk about everything related to the illness with their family | Agreed                  | 22 (42)                      | 3 (43)                      | 4 (29)                        |                               |
|                              | Has thoughts and feelings they do not want to share with their family | Agreed                  | 36 (68)                     | 3 (43)                       | 8 (57)                       |
|                              | Concerned about someone in the family | Agreed                  | 48 (91)                     | 7 (100)                      | 9 (64)                       |
|                              | Can show someone in the family how they feel | Agreed                  | 48 (91)                     | 7 (100)                      | 13 (93)                      |
|                              | Wants to show how they feel more to someone in the family | Agreed                  | 29 (54)                     | 1 (14)                       | 2 (14)                       |

1 The score ranges from 10 to 50.
2 Categorized based on the FACES IV manual.
3 Died within a few months.
4 One missing.
5 Two missing.
6 Three missing.

Parents reported that they did not dare ask health care professionals questions regarding these matters. All families had thoughts and feelings they did not want to share with their family, and half of the parents and a quarter of the children wanted to reveal more about how they felt to their family members. Parents reported the lowest family communication, followed by siblings. There were only a few families in which all members reported the same perception of family communication.

According to the family members’ reports, health care professionals were often reluctant to discuss psychosocial issues and prognosis with them. Reasons might include that prognostic information may take away hope—although Mack et al.35 reported the opposite—or that the professionals might have believed that families were not ready for information about the future early on in the care trajectory. The way in which information is conveyed to parents also matters, as it affects a family’s ability to grasp the information.36 Professionals’ communication skills mostly rely on apprenticeship models rather than more formal approaches, such as workshops and conversation guides.37,38 and staff are worried about “opening Pandora’s box” and having limited clinical time.39 Physicians in pediatric oncology have reported that they find it challenging to communicate about a poor prognosis, because it is emotionally and mentally draining, and also due to a lack of mutual understanding and uncertainty about communication skills.40,41

Since January 2020, the United Nations Convention on the Rights of the Child (UNCRC) is regulated in law in Sweden. The UNCRC Articles 12-15 state that all children have the right to express themselves, be asked about their opinion, and have their decision making taken into account in every decision that affects their situation. Moreover, in 1999, the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology published guidelines on how to assist siblings of ill children.42 However, in this study, the findings showed that siblings were in need of more information. While a remarkable change has occurred in the attention paid to siblings in the last decade, there might still be room for improvement regarding communication with health care professionals and family.26

In this study, family members left things unspoken within the family partly because they wanted to protect their partner and/or children. This somewhat misguided protection, resulting from a fear of hurting others and causing them worry, has previously been highlighted among both adults and children.26,43 Childhood cancer negatively impacts
the parent couple’s communication, which is important for parents in coping with the illness. When parents gave recommendations to other parents in similar situations, they suggested respectful and open communication and not shielding one another from difficult emotions. This study found that families said bad things to one another when angry and that they sometimes avoided talking about their emotions, ways of coping, and the future. Limited communication can result in family conflicts. Communication may help family members to come together and talk about what is on their minds, which often results in less stress. However, it is important to consider each family member’s standpoint, as this paper found that family members within the same family often have differing perceptions of family communication.

While this sample is rather small, the study is unique, as it includes self-reports from all the family members. However, it has limitations. Participating parents were well educated, which could be seen as a selection bias for high-functioning families. Furthermore, data were collected at only one cancer center in Sweden, meaning that the findings reflect the circumstances at that specific center. Moreover, the response options regarding received information did not take into account if respondents were satisfied with having received no information, or which type of information they would have wanted more of. With this in mind, the findings of this study are hard to transfer to all families in pediatric oncology, but can give insights into what family members experience as being unspoken with professionals and within the family.

In conclusion, this study suggests that the psychosocial support to families lag behind the available scientific evidence. It seems that further efforts are needed to improve communication about psychosocial aspects between families and professionals and within families. Assessments of each family member’s different needs might form a basis for professionals to give adequate information and tailored family support. Family interventions might serve as a tool for increased awareness about individuals’ different needs within families, which might lead to mutual understanding of the differing perceptions of family communication.

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CONFLICT OF INTEREST
The authors declare that there is no conflict of interest.

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