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The Importance that the Pediatrician Talks to the Children with a Parent Affected by Cancer

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Simple Summary

Our main goal is to reach as many physicians as possible thanks to your very appreciated and read Journal. The purpose of the intervention described in the paper is to help children understand their parent's illness and related treatments using a language appropriate to their age, and to commit the physicians to take care of the communicating process, also with minors, to build up an open, positive, empathic relationship inside family. The issue managed in the paper has for us an important ethical responsibility.

Abstract

Although open communication about cancer between parents and children is crucial to reduce the family distress, it is often neglected or absent. Thus, effective psychosocial interventions aimed to help parents and children communicate more openly about cancer, related issues are more need than ever before. This study describes an innovative multidisciplinary family-based intervention in a child inclusive frame. This type of intervention is based on our belief that a strong collaboration among different clinicians - the multidisciplinary team (MDT) is formed by pediatric hemato-oncologists, psychologists and adult oncologists -, in full respect of their specific competences, can provide adequate support to families dealing with cancer. The first phase of this intervention consists of a series of meetings between the cancer patient's children and the MDT, during which a psychologist and a pediatric hemato-oncologist tell the children what is happening to one of their parents and identify what hopes, fears, and worries they may be experiencing. In the second phase, the children share with their parents what they have learned from the discussion. The specific methodology of this intervention is based on the dialogue between family members, and its outcome is measured by means of a self-reported questionnaire. From 2015 to 2023, fifty-six families and 73 children participated in the study. The results of the survey show that our interventions led to a dramatic reduction of psychopathological symptoms in the participating children, improved collaboration among family members, and provided more opportunities to talk openly about cancer. An overall high level of satisfaction was expressed by the parents. Thus, we conclude that psychosocial interventions helping family members communicate more freely about cancer-related issues should be considered an important ethical pediatrician's responsibility in oncological care.

Keywords: Communication; Cancer; Children; Psychosocial; Quality of Life; Ethics

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1. Introduction

Cancer diagnosis cannot be considered only an individual illness because it has a strong impact on the whole family [1,2]. Estimates indicate that about 18% of cancer patients have minor children

[3], which forces them to face the dual challenge of coping with their cancer diagnosis while trying to maintain a parenting role [4,5]. In this framework, parenting concerns may constitute a significant source of stress [6, 7].

Children with a parent suffering from cancer have a higher risk of developing psychological disorders, such as anxiety, depression, psychosomatic problems, worsening of scholastic performance, and difficulties in maintaining concentration [8]. They can also develop aggressive behaviors toward their parents or other children, as well as feelings of guilt and shame. Parental cancer jeopardizes the availability of the attachment figure for the child, which may be compounded by separation due to hospitalization, decreased parental availability, and disruption of usual roles and routines [5,9].

Family functioning is more predictive of children's psychological adjustment than of any other disease-related parameter [10]. In particular, open communication seems to be crucial to support children [11-15]. It has been, in fact, associated with improved coping strategies and reduced psychological distress among children [11]. Unfortunately, parents are hesitant to discuss cancer and death with their children [8,16,17]. However, children often suspect something is wrong prior to being told, and a lack of information can often lead to misconceptions [18].

Another barrier to open communication is a tendency of parents with cancer to misunderstand their children's reactions and underestimate the emotional impact that their illness can have on them [19]. Even when parents wish to explain their illness, they might not have the required confidence and skills to succeed in communicating cancer information to their children [20]. On the other hand, children may find it hard to explain their thoughts and feelings because they fear this would increase parents' distress and/or because they may not know how to describe their emotions [8,21].

The objective of this study is to describe a novel multidisciplinary intervention designed for children whose parents have cancer. The program aims to: i) help children understand their parent's illness and related treatments using a language appropriate to their age; ii) understand the children's feelings and thoughts about their parent's illness; and iii) stimulate an open and truthful communication about illness-related feelings and fears among family members.

2. Materials and Methods

The study included parents with cancer treated at the Oncology Structure of the San Gerardo Hospital, Monza, Italy, referred to the intervention by the attending adult oncologist. We created a multidisciplinary team (MDT) including a psychologist, a pediatric hemato-oncologist, and the adult oncologist of San Gerardo Hospital, Monza, Italy.

The adult oncologist identifies a cancer patient with one or more minor children, and the former agrees to attend a parent-psychologist session. The oncologist explains to the psychologist the patient's cancer and treatments. The inclusion criteria used by the oncologists were:

parent affected by any type of cancer, phase of cancer in progression or in advanced treatment, parents with one or more siblings, Italian language, sibling age from 4 to 18 years, no life expectancy of the patient. The exclusion criteria used were: not understanding Italian, social barriers, reluctance of parents, siblings age < 4 years.

Informed consent from children's parents was obtained.

Interventions

The intervention included individual parent's sessions (only the psychologist), individual children's sessions (the MDT), family sessions (the MDT) and individual parental counseling (only the psychologist).

1. Parents' sessions. The psychologist explains to the parents the program and answer their questions, and, in addition, analyzes the family dynamics and the usual communication and coping styles.
2. Children's sessions without the presence of their parents. The interventions were focused on the direct involvement of children in the discussion process. These sessions aimed to listen

children's questions and identified their emotions. It also promotes an open dialogue between MDT and the child. The psychologist gets acquainted with the children by meeting them in the hospital garden or in a dedicated hospital room with specific toys, which help minimize the emotional impact with the hospital structure. Then they meet with a pediatric hemato-oncologist to start the session. The clinician talks to the kids about their parent's cancer and its treatment in simple and easy-to-understand language using scientifically correct nouns alongside images and metaphors appropriate to their age. For instance, the pediatric hemato-oncologist uses the "flowered garden" metaphor, in which he compares the body to a garden and the weeds to the illness that the therapy has to eradicate. To better understand the children's feelings and ease their disclosure, the clinicians use a series of drawings and images from which the children have to choose those that best represent their emotional state. Lastly, the clinicians tell them how to best cope with their parents' cancer.

3. Family sessions. During these meetings, children and parents can openly discuss and share their concerns and emotional reactions with the support of the MDT.

4. Parent counseling sessions. These sessions are aimed to improve parental competence and foster the parents' emotional sharing with their children. The psychologist helps parents stimulate an open communication within the family to better recognize, understand, and manage their children's emotional reactions and needs.

Outcome measurements

We created specific ad hoc self-reported questionnaires (how many) including multiple-choice close-ended questions.

We previously conducted a similar psychosocial intervention on a limited number of parents and children [22]. A specific ad hoc questionnaire for the evaluation of the intervention was prepared with the collaboration of a university researcher and her team who have specific competences in realizing psychological researches and measurement designs. The self-reported questionnaire given to the parents one month after the sessions with children is characterized by items with multiple-choice close-ended questions. It investigates different topics: psychological symptoms in children, families atmosphere (cohesiveness and communication intensity about the illness in the family), and satisfaction with the intervention.

This questionnaire was given to the parents one month after the children's session. The time requested to fill out this form was on average 30 min. The psychologist was available if parents had some doubts or did not understand some questions.

This tool addressed various topics, such as:

i) help children understand their parent's illness and related treatments using a language appropriate to their age;

ii) understand the children's feelings and thoughts about their parent's illness

iii) stimulate an open and truthful communication about illness-related feelings and fears among family members.

Only those items we thought would be more meaningful for our project were analyzed.

3. Results

Up to the time we started collecting the data for this manuscript: we have received 81 questionnaires from 56 families with 73 children. Unfortunately, some parents from the study population passed on (n=11) or could not fill out their questionnaires (n=10) because they lived far away from the hospital.

The characteristics of the sample are described in Table 1.

Table 1. Demographic and clinical characteristics of the study population.

Children's age	
4 – 7 yrs.	25
8 – 11 yrs.	23

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12 – 15 yrs.	15
16 – 18 yrs.	10
Children's sex	
Males	38
Females	35
Family structure	
Only child	39
Two or more children	11
Single parent	6
Ill parent	
Mother	43
Father	13
Patient's age	
30-35 yrs.	15
36-40 yrs.	17
41-46 yrs.	13
> 47 yrs.	11
Patient's education	
Post graduate school /university	20
Secondary school	30
School left before 24 yrs.	6
Patient's employment	
Employed	32
Not employed	24
Parent's diagnosis	
Breast cancer	40
Lung cancer	10
Pancreas cancer	3
Gynecological cancer	1
Colon cancer	2
Parent's Oncological treatment	
Chemotherapy	52
Radiotherapy	4

It is interesting to notice that the majority of parents did not notice worsened scholastic performance (70%) or feelings of shame (78%) or guilt (93%).

The parents' answers through the questionnaires showed a low incidence of distressful psychological impact after the intervention.

Furthermore, most parents did not report any worsening of aggressive behaviors toward them (83%) or other children (76%).

As for the family atmosphere, the majority of the parents declared that they were feeling "very much" (37%) or "quite a lot" (43%) closer to one another. In addition, they felt there was "very much" (50%) and "quite a lot" (37%) more collaboration and there were "very much" (40%) and "quite a lot" (38%) more chances of communicating more openly about cancer.

Lastly, it emerged a high satisfaction level of the parents with the intervention: clinicians' explanation to the child (65% "excellent"); clinicians' way of relating to them (58% "excellent") and their children; (69% "excellent") (Table 2).

Table 2. Results of the questionnaires given to the parents after the intervention.

Children's psychological conditions after the intervention	Never	Rarely	Sometimes	Often	Always
More irritable	52(64%)	18(22%)	6(8%)	5(6%)	0 (0%)
More anguished	58(71%)	14 (17%)	7 (9%)	2 (3%))	0 (0%)
More depressed	76(94%)	5(6%)	0 (0%)	0 (%)	0 (0%)
More aggressive toward parents	67(83%)	7 (8%)	4 (5%)	3 (4%)	0 (0%)

More aggressive toward other children	61(76%)	7 (8%)	12 (15%)	1 (1%)	0 (0%)
Worsening of scholastic performance	57 (70%)	11 (14%)	12 (15%)	1 (1%)	0 (0%)
Blaming themselves for their parent's cancer	75(93%)	5 (6%)	1 (1%)	0 (0%)	0 (0%)
Feeling ashamed for their parent's cancer	63 (78%)	16 (20%)	1 (1%)	1(1%)	0 (0%)
Family atmosphere after the intervention	**Not at all**	**Very Little**	**Moderately**	**Quite a lot**	**Very much**
Feeling closer to one another	3(4%)	0 (0%)	13 (16%)	35 (43%)	30 (37%)
More open communication about the parent's cancer	1 (1%)	2(3%)	7 (9%)	30 (37%)	41 (50%)
More collaboration	5 (6%)	1 (1%)	12 (15%)	31(38%)	32 (40%)
Satisfaction with the intervention	**Poor**	**Fair**	**Good**	**Very Good**	**Excellent**
Clinicians' explanation to the child	0 (0%)	0 (0%)	0 (0%)	28(35%)	53 (65%)
Clinicians' way of relating to parents	0 (0%)	0 (0%)	12 (15%)	22 (27%)	47 (58%)
Clinicians' way of relating to children	0 (0%)	0 (0%)	4(5%)	21 (26%)	56 (69%)

4. Discussion

One of the most important characteristics of this intervention is the direct involvement of children in the discussion process. Indeed, we think that children play an important role in their families, and that, as such, they need all the attention and respect from their parents, especially in particular phases of family life, such as when one of them is diagnosed with cancer. In light of our findings, it is clear that also the attending clinicians should devote more of their time to inform children about the condition of their parents so that they can use this information to cope with their parent's illness. If parents and clinicians fail to communicate with children about cancer, these latter can develop trust issues that can have a negative impact on their self-esteem while growing up.

During the sessions, children asked clinicians many questions, which should be considered not only as a sign of interest in their parent's condition but also as a desire to deepen their knowledge of such condition. Thus, the mission of the clinicians should not just be that of answering satisfactorily to questions raised by their patients, but also to take into account—and possibly resolve—the concerns expressed by their children. This so called "dynamic" process for us turned out winning.

Another peculiar and innovative aspect of this intervention is its multidisciplinary nature. This means that the different clinicians forming the MDT integrate their specializations to offer a global care to cancer patients and their families. For example, in the children's sessions a pediatric hemato-oncologist can provide specific medical explanations about the parent's illness, while at the same time a psychologist can appraise the children's emotions and feelings. In this way, the MDT helps children develop the best coping strategies to face this critical condition. Indeed, it was not uncommon for children to tell clinicians how much they appreciated their availability to spend time with them and answer their questions. In particular, they expressed a sense of relief that they could finally disclose their fears and worries without being judged or pressured. They were grateful that they could share their feelings while being understood and reassured. During the sessions, the clinicians encouraged children to communicate more openly with their parents about their feelings and cancer-related thoughts so that they would not feel alone with their emotions.

Also the family sessions, with the simultaneous presence of children and parents along with the MDT, turned out to be particularly useful to establish a global approach to the patient that would take into account not just the illness but also the entire context of a patient's life.

Our survey also suggests that a better understanding of their children's state of mind can help parents to interact with them more freely, thereby increasing family collaboration. In most cases, parents feel quite uncomfortable talking about their illness, and they need guidance to build a healthy relationship with their children in this particular phase of their life [23]. In this regard, the satisfaction level with our intervention was rated as "very good" or "excellent" by most of the parents, who admitted feeling more confident in relating with their children once they fully understood the reasons behind their children's reactions. As a result, they felt they could ask for help more freely without blaming themselves for being inadequate parents. They also disclosed that they felt less alone because there was more cohesion in their families and they could ask MDT for help if they were experiencing difficulties or having doubts. They also stated that by feeling more confident in their parenting role, they felt more positive about the effectiveness of their cancer therapy ahead. Most parents were also satisfied with the intervention because they no longer had to hide their illness and emotional state from their children, which gave them more tranquility and peace of mind.

This study has some limitations that need to be considered and taken into account for further research. First, the findings are based on a not huge size sample and, therefore, have to be interpreted with caution because the results may not be generalizable. Second, during the compilation of the self-reported questionnaire, the parents may have been influenced by a social desirability bias or may have failed to recognize some psychological problems in their children. Third the parents group is not balanced and female represents a large proportion. Lastly, the study only includes a post-intervention evaluation, and the analyses were just limited to a few items of the questionnaire.

Future investigations should provide above all pre- and post-intervention assessments by means of an easier and shorter questionnaire. The instrument used in this study was in fact too long—the average time taken to fill it out was 40 min—and some parents were confused when completing it.

5. Conclusion

This intervention further supports the importance of communicating openly and effectively with children about their parent’s cancer diagnosis to help the whole family cope with this trying situation, as described previously [3,18,24]. In particular, this intervention recognizes the right of children to be directly engaged in the explanation of their parent’s illness because they are an integral and active part of the family. Furthermore, it highlights the many benefits of this direct involvement in terms of family cohesion and mutual understanding. The lesson we have learned from this study is that the emotions and thoughts of children must be taken into account and fully understood.

The intervention also underscores the importance of a multidisciplinary approach to foster an easy-to-understand, coherent and inclusive communication among family members. As more and more families are affected by cancer, it is essential that we create a framework of healthcare professionals ready to step in to support cancer patients and their families, especially children who need help to understand their parent’s cancer and manage their emotions.

In this scenario, clinicians may represent an important guide for parents with cancer to help them improve their family atmosphere and their parental competence in recognizing their children’s needs. They may also be a safe harbor for children that wish to be informed about their parent’s cancer and need some help in managing their emotions.

Overall, we strongly believe that this type of psychosocial support offered by clinicians to the families of cancer patients should be considered an ethical responsibility of the pediatrician.

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