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Original Paper

Information About Diagnosis and Prognosis Related to Anxiety and Depression in Children with Cancer Aged 8–16 Years

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The aim of this study was to test the hypothesis that being openly informed about the diagnosis and prognosis benefits the emotional well-being of children with cancer. A stratified sample of 56 children with cancer aged 8–16 years and their parents participated. The parents were interviewed about the information they had given to their child. Self-report questionnaires were administered to the children measuring anxiety and depression. Children who received open information about their diagnosis and prognosis at the initial stage of the disease showed significantly less anxiety and depression. Our findings suggest that parents should be advised to inform their child with cancer openly and soon after the initial diagnosis. Physicians should offer help to the parents in dealing with the difficult task of confronting the child with the diagnosis, prognosis and treatment.

Key words: disease-related information, anxiety, depression, childhood cancer
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INTRODUCTION

THE RIGHT to be fully informed about the diagnosis and prognosis, including the benefits, side-effects and risks of treatment, is widely recommended nowadays as a principle in paediatric oncology. Not only informing the parents but also telling the child is an important guideline in patient care [1–3]. The first argument for open information given to the child is found in the concept of a child's 'basic right' to be informed and the physician's 'ethical duty' to give the child relevant information about the illness and the proposed treatment. Older children and adolescents in particular should be stimulated to be involved in decision-making about their treatment [3]. Although empiric research confirms that most children (over 8 years) prefer to be informed about their disease and treatment [4–6], they do not want to make decisions about their curative treatment themselves [7].

The second argument for giving information about the disease and treatment is that it benefits the child's well-being. Withholding information would isolate the child from communication which is meaningful in the situation. Knowing the facts increases the child's freedom to ask questions and to express worries about the disease, so that feelings of loneliness, alienation and isolation are prevented or reduced [2, 8].

Although contemporary opinion, at least in Anglo-Saxon countries, favours informing children about their cancer diagnosis, and one study shows that most doctors and or parents do [9], other recent studies demonstrate that many parents do not fully disclose medical information to their ill child, certainly not at first and especially not to younger (< 7–9 years) children [2, 6, 7]. A substantial part of parents and physicians either do not believe that open information is beneficial for the child or they are reluctant to put their ideas into practice. There is evidence that parents feel the issue of what and how to tell their child to be a very painful child-rearing dilemma [2]. Physicians also think it is difficult to speak with children about serious diagnoses because they lack knowledge of the cognitive skills of children in different age-groups and are afraid the child will become emotional at the moment the diagnosis is told [10]. Physicians frequently use metaphors when explaining diagnoses. Jankovic and colleagues [11], for example, developed a special information programme for children with leukaemia, using pictures of a garden with weeds as metaphor for leukaemia. Investigations do not show clear evidence that explaining illness by using metaphors results in better understanding than other types of explanations offered to the child [12, 13].

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An important reason for reluctance to tell the child openly about the diagnosis and prognosis could be found in a relative lack of empirical data proving the assumption that telling the child about the diagnosis and prognosis improves the child's well-being. Only a few studies have examined the effects of an open approach on the child's emotional functioning. With the exception of one study [6], in which the children were asked themselves what they were told about their illness, and in which no difference between poor and well-informed children could be found, the other studies have all demonstrated a favourable effect on emotional adjustment [14–16]. These findings are, nevertheless, not conclusive, because little attention has been paid to the reliability of the information measurements, and because of very small sample sizes [14, 15] or widely differing time-intervals since diagnosis in the patients [16].

We conducted a study on the relationship between communication and emotions among patients treated at the Paediatric Oncology Department of the University Hospital of Amsterdam [17]. In this article, we report our findings on children's anxiety and depression related to the information given to them by their parents about the disease. We asked the parents what they told the child because they have a key role in the information process. We also investigated the children's preferences for being informed about the illness.

PATIENTS AND METHODS

From the 67 eligible families, a total of 56 cancer patients and their parents, 56 mothers and 54 fathers, participated in the study. Almost all parents who refused to cooperate gave the reason that they do not want 'to drag everything up again'. Based on information we obtained from members of the hospital staff (nurse, medical doctor, social worker), who were close to the families, we found no indications that refusals were related to a certain communication style in the family. The characteristics of the stratified sample are represented in Table 1. On the basis of the doctor's evaluation of the child's survival chances, the prognosis was indicated as good when survival chances were estimated to be greater than 50% and poor when they were estimated to be lower. After the study was approved by the Hospital Ethical Committee and informed consent was obtained, children and both parents were interviewed and tested each individually at the family home. The interviews were carried out by experienced researchers.

Table 1. *Demographic characteristics of patients*

	n	(%)
Patients	56	
Age at survey		
8–12 years	32	(57)
13–16 years	24	(43)
Gender		
Female	26	(46)
Male	30	(54)
Time since diagnosis		
4 months	14	(25)
1 year	14	(25)
2 years	14	(25)
3–3.5 years	14	(25)
Prognosis		
Good	35	(63)
Poor	21	(38)
Diagnosis		
Leukaemia	11	(20)
Lymphoma	18	(32)
Brain tumour	1	(2)
Other solid tumour	26	(46)
Phase of disease		
In treatment	17	(30)
Off therapy	39	(70)
Relapsed	5	(9)
Palliative	2	(4)

Parents

A structured interview for the parent included detailed closed-ended questions about the kind of information the parent and/or the doctor in the presence of the parent had given to the child about the diagnosis and prognosis. Post-hoc analyses resulted in two reliable subscales. The subscale 'information about the diagnosis' has five items with questions about the information one or both parents has given the child about the diagnosis at the initial stage (before discharge) or at a later stage, i.e. the seriousness, the duration, the medical term (tumour/growth/leukaemia), the term cancer and the possibility of a relapse or recurrence (score range 0–10). This subscale has a reliability coefficient (Chronbach's α) of 0.73. The subscale 'information about the prognosis' has two items with questions about the information the parent(s) has given about the prognosis in the initial stage or at a later stage, i.e. the possibility that the child will not get better and the possibility that the child will die of the disease (score range 0–4). The intercorrelation between these two items is 0.93. The parents were also interviewed about their reasons to inform their child or withhold information from the child.

Children

Medical and biographical data was obtained from the medical records. The child's anxiety was measured with the Dutch version of the State-Trait Anxiety Inventory for Children developed by Spielberger and associates [18]. Both trait and state anxiety was assessed. Depression was measured with the Dutch Depression Questionnaire for children developed by de Wit [19].

The reliability and validity of both instruments were proven to be satisfactory. From the nine subscales of the depression questionnaire, we used the total depression score and the scores of three subscales: negative self-esteem, negative evaluation of social environment and negative expectations for the future. In order to be able to estimate the effect of the child's defensive attitude while reporting emotional reactions, the Defense Scale for Children [20] was administered. In this scale, defense is defined as the denial of anxiety and other unpleasant emotions and experiences which everyone has or has had at some time and which concern general and social situations.

Finally, an Information Questionnaire for Children (IQC) was administered, asking questions on the sources of information (i.e. persons) available to the child, on problems the child experiences when trying to obtain information and on the child's need to get information about the disease.

Analysis

For each couple, individual itemscores on the information scales were converted into new itemscores. When both parents had an identical itemscore (i.e. both parents gave the same information at the same time) their scores were added and divided by two. When parental itemscores differed (i.e. the parents did not give the same information at the same time), the highest itemscore of one of the parents was used. It was reasoned that the child received specific information from at least one parent. Itemscores were then added up into sumscores.

Pearson correlations have been calculated to determine the relationship between the variables. The type of scales used and the frequency distributions as well as the scatterplots did not indicate any contra-indication for using this statistic. Partial correlations were calculated to remove the effect of the child's defensiveness. We only assigned significance to the relationships when the number of significant correlations was greater than the 5% which can be expected by chance.

RESULTS

Anxiety and depression related to information about the disease

Table 2 presents the partial correlations between the anxiety and depression variables of the child and the information given by one or both parents. It was found that the child's defensiveness correlated significantly with a number of emotion variables and slightly with the information variables (Table 3). Partial correlations indicate the relationship between information and emotion variables after the effect of the child's defensiveness has been removed. The correlations were not high but all in the same direction, showing that children who had received more information about the diagnosis and prognosis from their parents during the initial stage of the disease were significantly less anxious and less depressed than children who had received less information and/or information at a later stage.

The mean defence score

The mean score on the children's defence scale (mean = 7.23; S.D. = 4.78) did not differ significantly from the mean score of a reference group of healthy peers (mean = 7.44; S.D. = 4.21).

Table 2. Partial correlations (r) *between the communication variables 'information about the diagnosis' and 'information about the prognosis' and the anxiety and depression variables of the child*

		Information given by the parents:	
		about the diagnosis	about the prognosis
Emotional variables of the child	*n*	*r*	*r*
Anxiety-trait	56	−0.28*	−0.35†
Anxiety-state	56	−0.04	−0.81
Depression	56	−0.18	−0.29*
Negative self-esteem	56	−0.24	−0.24
Negative evaluation of social environment	56	−0.28*	−0.24
Negative expectation for the future	56	−0.01	−0.22

* $P < 0.05$. † $P < 0.01$.

Table 3. Pearson correlations between the defence scale for children and the emotion variables of the child or communication variables of the parents

	Defence scale
Emotion variables of the child:	
Anxiety-trait	−0.59*
Anxiety-state	−0.22
Depression	−0.52*
Negative self-esteem	−0.41*
Negative evaluation of social environment	0.01
Negative expectations for the future	−0.38*
Communication variables of the parents:	
Information about the diagnosis	−0.07
Information about the prognosis	−0.16

* $P < 0.01$.

Information given by the parents

Table 4 lists the information given by the parents in the two different age groups, the 8–12-year-old and the 13–16-year-old children. With the exception of information about the seriousness and duration of the illness, the information given by the parents to the child about the diagnosis and prognosis clearly increased with age. The term cancer for example was concealed from one third of the children aged 8–12 years and approximately one fifth of the children aged 13–16 years old.

Reasons most often reported by the parents for giving information were to preserve the child's trust in them, to promote the child's acceptance of the illness and treatment, and to respect the child's right to be informed. Twenty per cent of the parents stated they were forced to tell after classmates or children in the neighbourhood had confronted their child with remarks such as: "You have cancer and you are going to die, aren't you?" Another 9% of the children had first learned the facts of their illness from fellow patients. The most important reason to withhold information was that parents thought their child to be too young to burden him/her with such frightening serious facts. None of the parents mentioned withholding information because their child was anxious or depressed.

Table 4. Proportion of children in different age groups who were informed about the disease by one or both parents

	Age groups	
Information given by one or both parents about the:	8–12 years (*n* = 32) %	13–16 years (*n* = 24) %
Diagnosis		
Seriousness	97	100
Long period of illness	97	92
Tumour/growth/medical term	88	92
Cancer	66	79
Possibility relapse or recurrence	69	88
Prognosis		
Possibility of not getting better	72	88
Possibility of dying	69	83

Information needs, sources and obstacles

The data from the IQC scale is presented in Table 5. With regard to the subscale information needs, two thirds of the children wanted to know everything about their disease and one third as little as possible. A number of children (26%) expressed ambivalence and answered both questions in this subscale in the negative or affirmative. When asked whether both answers were correct they made the following type of replies. "What I want to know, I ask about. At least that way you end up knowing what you should. But if you find out too much, that isn't good either." Another child said: "It isn't very nice to hear that you have a tumour and that I will die, eh... It isn't nice if you don't know anything and if you do know, it isn't nice either."

The children who have received more information about the diagnosis in the early stages of the disease experience a significantly greater availability of sources of information ($r = 0.29$; $P = <0.05$). The child's information obstacles and information needs were not related to the information about the diagnosis or prognosis they received. As the child experienced a greater availability of sources of information, the child reported significantly less trait anxiety ($r = -0.43$; $P = <0.01$), less depression ($r = -0.45$; $P = <0.01$) and less negative self-esteem ($r = -0.48$; $P = <0.01$). As the child experienced more obstacles to get information, he/she reports signficantly more trait anxiety ($r = 0.42$; $P = <0.01$), more depression ($r = 0.33$; $P = <0.05$) and more negative self-esteem ($r = 0.29$; $P = <0.05$). There was no relationship between the child's information needs and the way parents gave information about the disease, nor was there a significant relationship between information needs and the child's emotional reactions.

Table 5. Distribution of scores on the children's scale 'sources of information', 'information obstacles' and 'information needs' (n = 56)

Items	Yes %	No %
Sources of information:		
If I ask questions about my illness, I usually get an honest answer	95	5
If I have questions about my illness, I always have someone to turn to	86	14
I feel I've been able to ask enough questions about my illness	86	14
I usually ask questions when I want to know something about my illness	82	18
I have someone I can talk to about my illness	73	27
Information obstacles:		
I find it difficult to ask questions about my illness	39	61
I find it difficult to talk about my illness	30	70
Information needs:		
I want to know everything about my illness	64	36
I want to know as little as possible about my illness	36	64

Correlation between biographical and disease characteristics and information given by the parents

Sex and age. No significant relationship was found between the child's sex and the information about the disease given by the parents. Significant relationships were found between the child's age and the information about the diagnosis ($r = 0.43$; $P = <0.01$) and about the prognosis ($r = 0.39$; $P = <0.01$) given by one or both parents. It indicates that older children were given significantly more information about the diagnosis and prognosis in the initial stage of the disease.

Education and socio-economic status of the parent. There did not appear to be any relationship between education or socio-economic status of the parents and the information they gave to their child about the disease.

Disease characteristics. The nature of the diagnosis (tumour or leukaemia), and the prognosis (good or poor), did not have any effect on the way parents gave information about the disease to their child.

Correlation between biographical and disease characteristics and emotion variables of the child

Sex and age. There were no significant differences between boys and girls on the anxiety and depression variables. The factor age clearly influenced the children's emotional reactions. Significant negative correlations were found between the child's age and the child's anxiety trait ($r = -0.33$; $P = <0.05$), depression ($r = -0.27$; $P = <0.05$) and negative self-esteem ($r = -0.30$; $P = <0.05$) showing that younger children were more anxious, more depressed and had a lower self-esteem.

Disease characteristics. Of all the disease characteristics, only the variable 'time since diagnosis' was significantly correlated with the child's negative self-esteem ($r = 0.31$; $P = <0.05$), indicating a more negative self-esteem the longer a child was diagnosed with the disease.

DISCUSSION

The results of our study support the hypothesis that open information about the diagnosis and prognosis is beneficial to the child's emotional well-being. The children in our sample who initially received open information about the diagnosis from their parents, i.e. who were told that they had a tumour or leukaemia, and had cancer, and who were offered open information about the prognosis, i.e. who were told there was a possibility they would not get better and die, were significantly less anxious and less depressed 3 months to 3 years later, than children who received less open information and/or information at a later stage of their disease. Our data support previous findings and are possibly even more reliable, because we tested the hypothesis that open information benefits the child's emotional functioning in a substantial large and stratified sample of children with cancer using reliable and valid instruments.

Also in agreement with other studies, we demonstrated that the majority of the children preferred to be fully informed about their disease. Nevertheless, quite a number of the children showed ambivalence in answering the questions about their preference to know or not to know the facts about diagnosis and prognosis. A proportion of the children clearly expressed their wish to know as little as possible about their disease. However, parents appeared to disregard their child's wishes, because there was no relationship between the way they informed their child and the child's need to be informed.

A remarkable finding was that the children with cancer did not appear to be more defensive than healthy children. In the literature, it is often suggested that they use more denial and under-report painful emotions [21, 22].

A few shortcomings associated with the design of our study should be mentioned. Firstly, the parents were interviewed retrospectively about the information they have given to their child. This might have produced a certain bias based on memory distortions, although most parents said that they had a vivid remembrance of the moment they sat down with their child and talked about the diagnosis. Also, a number of parents who were not able to share the diagnosis with their child stated spontaneously that they will never forget the moment they attempted to tell the child but found it too painful.

Furthermore, it is not impossible that the child's emotional state before or at the diagnosis determined the parents communication style, in the sense that they refrained from giving painful information because their child was already anxious or depressed. An argument against this is that all parents in our study who gave their child minimal information about the disease explained their behaviour by saying they thought the child to be too young or they did not want to burden the child with such serious facts. None of the parents mentioned their child's anxiety or depression as a reason for withholding information. However, we cannot rule out the possibility that parents did not inform their child because they judged their child to be too anxious or sensitive.

On the basis of our research, we recommend the following clinical policy regarding informing children with cancer. Immediately after diagnosis, it is important to advise parents to tell the child as soon as possible about the nature and possible implications of the disease, including the word cancer and the possibility of dying from the disease. Explicit use of these terms is important because many children in our study learned these facts for the first time from peers, who told them bluntly what was wrong with them. If correct information is passed on to the child straight after diagnosis, it can be combined with a message of hope. Emphasising hope is realistic when explaining the possiblities for treatment. The advice of giving open information to the child will certainly encounter resistance among some parents, because they are afraid that their child will become highly emotional or will lose courage. It is important to understand these feelings, but the doctor can reassure the parents that openly informing the child will not have harmful effects. In our study, we observed that the doctor performs an important role model function in the communication about the disease between child and parents. In the few cases in which the doctor had openly discussed cancer and the survival chances in the presence of the child, the parents reported they had initially been shocked by this frankness. However, they had not noticed any harmful effects to their child and it had facilitated their own communication about the illness with the child. When the provision of information is incorporated in the doctor's protocol, the other hospital staff will have to help the child assimilate this information, and to support the child and parents in their attempts to gain psychological control of their situation.

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