Parents' perceptions of the information provided to them about their child's leukaemia

Evangelia Patistea, Fotoula Babatsikou

Forty-one mothers and 30 fathers were interviewed to examine their perceptions of (a) the type and amount of information provided to them about their child's leukaemia; (b) their sources of information; (c) their level of satisfaction from the information given; and (d) additional information they needed to manage the stressful encounters associated with the disease. Study results showed that health-care professionals represented the main source of information for these parents. The information given was centred primarily on the bio-medical aspects of the child's condition. Parents, however, reported that they needed additional information related to the psychosocial ramifications of the situation. No statistically significant differences were found either between the two sexes or between the two spouses. Education and previous experience with cancer correlated both to perceived amount of information given and to parental satisfaction from it. Subjects' low satisfaction from the information offered to them seems to reflect their disappointment about (a) the limited effectiveness of current medical knowledge and treatment and (b) the bio-clinical focus of the Hellenic health-care system. © 2003 Elsevier Ltd. All rights reserved.

Keywords: information, parents, cancer, evaluation, satisfaction, sources

---

Wie Eltern Informationen ueber die Leukaemieerkrankung ihrer Kinder aufnehmen
In dieser Studie wurden 41 Muetter und 30 Vaeter interviewt. Die Befragung sollte: Aufschluss ueber die Art und Weise geben, wie Eltern Informationen aufnehmen, die sie ueber die Erkrankung ihrer Kinder an Leukaemie erhalten. Im Einzelnen handelte es sich um (a) Beschaffenheit und Menge der gegebenen Informationen, (b) die Informationsquellen, (c) zusaetzliche Informationen, die sie benoetigten, um mit den belastenden Begleiterscheinungen der Krankheit ihrer Kinder zurecht zu kommen. Die Ergebnisse der Untersuchung zeigten, dass Fachkraefte aus dem Gesundheitsbereich die Hauptquelle an Informationen fuer die betroffenen Eltem darstetten. Der Schwerpunkt der Informationen lag vor allem auf den biomedizinischen Aspekten der Verfassung des Patienten. Einige Eltem jedoch gaben dem Wunsch nach weiteren Informationen Ausdruck, die sie in Bezug auf die psychosozialen Komponenten der Situation fuer noetig hielten. Weder hinsichtlich des Geschlechts der Befragten noch hinsichtlich ihres Status als; Ehepartner ergaben sich statistisch signifikante Unterschiede. Bildungsniveau und vorhandene Erfahrung mit Krebserkrankung korrelierten sowohl mit der Faehigkeit zur Aufnahme der gegebenen Informationen als auch mit der Zufriedenheit ueber den danach verbesserten Kenntnisstand. Zeigte sich im Einzelfall ein geringerer Grad subjektiver Zufriedenheit mit dem Informationsangebot, so scheint diese Tatsache eine doppelte Enttaeuschung widerzuspiegeln; zum einen ueber die begrenzte Wirksamkeit gegenwaertigen medizinischen Wissens und entsprechender Behandlungsformen, und zum anderen ueber die bioklinische Orientierung des hellenischen Gesundheitssystems.

Evangelia Patistea, RN, BA, MSc, PhD Assistant Professor, Health, Visiting Department, Technological Educational Institution of Athens, Greece
Fotoula Babatsikou, RN, PhDc Assistant Professor, Nursing A' Department, Technological Educational Institution of Athens, Keas 80-82 Street, 11255 Athens, Greece. Tel.: +30(210) 2287 725; Fax: +30(210) 2284 994
Correspondence and offprint requests to: Fotoula Babatsikou

INTRODUCTION

During the course of childhood leukaemia, the family go through a number of critical and overlapping phases. In each phase, parents typically have many questions that need to be answered if they are to deal effectively with the multifaceted stressors associated with the disease and become informed carers of their child (Humphrey et al. 1996; Last and Grootenhius 1998; Patistea et al. 2000). Unfortunately, little research has been conducted in Greece concerning families of chronically ill children. Therefore, in an attempt to fill this research gap, the present study, which presents only a part of the results of a large-scale research (Patistea 1999), addresses

European Journal of Oncology Nursing 7(3), 172–181 © 2003 Elsevier Ltd. All rights reserved.
doi:10.1016/S1462-3889(03)00023-1

the type and amount of information provided to parents who have children with leukaemia. It also examines the sources that these parents use to increase their knowledge about the disease. Finally, it explores parental satisfaction from the explanations given to them about the medical condition of the child.

LITERATURE REVIEW

After the intense reactions to diagnosis, the search for information about the child's leukaemia and its treatment becomes a priority for the family. Unless they are health-care professionals, mothers and fathers have very limited and inaccurate information about the child's medical condition (Austin 1990). The seeking of information on the part of parents can be understood as a realistic attempt to learn as much as possible about childhood leukaemia in order to define their new situation and negotiate new arrangements. It is a powerful strategy for them because they find it reassuring to learn and practice new skills and to rehearse possible alternatives (Dale 1996; Maul-Mellott and Adams 1997).

Members of the health-care team, particularly physicians, represent the most significant source of information, especially during the initial phase of the disease. The information provided to parents is pertinent to the diagnosis, the pathophysiological changes of the bodily functions, the side effects of therapy, the treatment plans and options and the long-term biological consequences (Holaday 1984; Burr 1985; Pain 1999). Research findings show that the intellectual stress resulting from the sudden presentation of a great deal of new medical information is one of the most severe stressors of the diagnostic phase. As parents assert, this initial period is a particularly difficult time for them because, already numbed by the shock, they are expected to learn a whole new vocabulary of confusing medical terms and understand complicated drug therapy (Chesler and Barbarin 1987; Adams and Deveau 1988). There is no doubt that adequate and accurate medical information is essential for parents to obtain a realistic view of the situation and to help them move in a positive direction. However, several studies reveal that, during this period, much basic information either is not presented to parents or is presented in a highly technical fashion that further increases their confusion (Chesler and Yoak 1984; Chesler and Barbarin 1987). Furthermore, despite the emotional distress of all family members, additional information regarding the psychological implications of the disease is seldom incorporated even in the most orthodox intervention designs (Comaroff and MaGuire 1981; Dale 1996).

Parents frequently express their concerns regarding the way that medical personnel announce the diagnosis and inform them about the disease. According to the literature, sometimes physicians are too abrupt whereas, in other instances, they overwhelm parents with medical information and statistical data far in excess of what parents can understand. Traditionally, when informing parents, health-care professionals focus on complex medical issues, whereas, parents only want to deal with their intense feelings resulting from the diagnosis (Chesler and Barbarin 1987; Adams and Deveau 1988; Pain 1999). It is widely accepted, however, that physicians are in an extremely difficult position when they attempt to manage continuing communication with the parents of children who have cancer. This is so because the scientific problems inherent in the disease (such as the problem of complex risks and the ambiguous nature of the knowledge related to its course, cause and prognosis) do not allow them to provide bio-medical knowledge and guidelines with certainty (Comaroff and MaGuire 1981; Humphrey et al. 1996).

Research findings are contradictory in terms of reported parental satisfaction from information and other services provided to them and their families. Previous studies, for instance, reveal that mothers and fathers of chronically ill children are not satisfied with the amount of factual knowledge they receive regarding the progression of their child's illness (McKeever 1981). In contrast, more recent studies show that although parents are satisfied with the information given to them and the quality of care offered to their child at the secondary level of prevention, they consider health services at the primary and tertiary levels to be insufficient (Westbom and Koehler 1991). The literature states that the following reasons may account for the inadequacy of information given to parents concerning their child's cancer: (a) the fact that physicians are unavailable to answer questions; (b) the uncertain nature of the disease in terms of its course and its prognosis; (c) the confusing medical language used by health-care staff to explain aspects of illness; (d) the large number of health-related subspecialists involved in the care of the child; and (e) the poor organisation of the local health services (if they exist) (Comaroff and MaGuire 1981; Burr 1985; Hockenberry et al. 1989). In addition, there is evidence to support that parents are unable to internalise detailed information regarding the disease and its clinical course during the first few days after diagnosis (Chesler and Barbarin 1987; Maul-Mellott and Adams 1997). It usually takes a great deal of time before the family acclimatises to the drastic changes resulting from the diagnosis, and can more easily assimilate the information given (Swenson and Stewart 1987).

An overwhelming worry for their child's well-being, and their unanswered questions, make many parents search for information from sources other than the health-care personnel. The seeking of information from sources outside the hospital environment can also be seen as a consequence of the multiple uncertainties of the disease. As Comaroff and MaGuire (1981) point out, leukaemia comprises "a category of related clinical conditions with differing individual implications for treatment and outcome" (p 115). Theoretical and research accounts show that parents purchase newspapers and medical journals and textbooks in an attempt to increase their knowledge about the basic bio-chemical and physiological processes underlying the child's illness and newly acquired responsibilities. Other sources of information reported to be helpful include other parents of children similarly afflicted by cancer, self-help groups, and brochures and relevant books made available by associations representing childhood cancer (Holaday 1984; Medvene 1992; Lewis 1994; Pain 1999). Although parents are also informed about the child's condition by the extended family, friends and the lay literature, the information they receive from these sources is often perceived to be inaccurate, insufficient and not always useful (Burton 1975; Medvene 1992).

It is evident from the literature that health-care professionals should not underscore the importance of information when caring for a child with cancer. This is so because the vast majority of parents consider 'unanswered medical questions' as one of the major stressful factors they have to deal with throughout the course of the illness (Swenson and Stewart 1987; Maul-Mellott and Adams 1997). Based on their research with families experiencing childhood cancer, many authors conclude that those parents who are successfully involved in the long-term care of their children have adequate and detailed information about the disease. Furthermore, they have better psychological health in relation to emotional stability and integrity as well as to self-esteem and feelings of control (Adams and Deveau 1988; Tones and Tilford 1994). Finally, they use more effective decision making processes and problem-solving strategies (Holaday 1984; Chesler and Barbarin 1987; Dale 1996).

Research questions

The present study was designed to address the following questions:

1. What are the type and amount of information that health-care professionals provide to parents of children with leukaemia?
2. How satisfied are parents with the adequacy of the disease-related information they are given?
3. What additional sources do parents use to increase their knowledge about their child's leukaemia?
4. What are parents' perceptions of their needs regarding information other than that offered to them by health-care personnel?

METHODOLOGY

Sample-data collection procedure

A consecutively selected sample of 71 parents (41 mothers and 30 fathers) who had children with leukaemia constituted the study population. Twenty-nine of the mothers participated in the study with their spouses, i.e., 29 couples, the remainder of the sample being composed of one father and 12 mothers. The subjects were recruited from the oncology clinic of a large, university teaching paediatric hospital located in metropolitan Athens, Greece. Prior to data collection, the University Review Committee and the General Council of the hospital approved the study to ensure protection of all subjects' human rights. The oncology registered nurse assisted in identifying and recruiting the parents while they were waiting for their child to be seen by the physician on an out-patient basis. Within a 3-month period, all parents meeting the inclusion criteria were invited sequentially to participate in the study. All subjects were advised of the objectives of the research and of their right to choose not to participate in it. The 71 mothers and fathers who constituted the sample participated voluntarily, and there were no risks to their child, themselves or their family. Sixty-five parents (91.5%) were interviewed in the oncology clinic and six parents (8.5%) were interviewed in their own homes. A total of nine mothers and fathers (11.5%) refused to participate in the study. Data were gathered at a mean time of 28.57 (SD = 27.47, range = 3–96) months after the diagnosis of the child's leukaemia.

Data collection instruments

Two questionnaires were constructed by the researchers to facilitate data collection. The first questionnaire was composed of closed- and open-ended questions and gathered factual information about the parent, family and child-related sociodemographic data. Illness-related information was also collected. The development of this questionnaire was based on a thorough literature review, and it included variables that, according to research and common sense, might influence parental perceptions of the illness experience such as the information provided to them about the disease and their satisfaction from it.

The second questionnaire consisted of three parts. Part I included one close-ended question regarding parents' perceptions of the seriousness of the disease for the child's life. Part II was a 3-point Likert scale ('no information', 'little information', 'much information') and concerned with parents' perceptions of the amount of information given to them by the health-care staff about certain bio-medical aspects of the child's leukaemia. This study assessed the disease-related explanations offered in the following areas: causes of leukaemia, diagnosis and basic physiology, medical procedures and options, existing therapies, side effects of treatment regimen, prognosis of the disease, warning signs and symptoms that professional help is needed, and progress of the disease and variations in its course. Parental responses were scored so that 'No information' had a score of 0; 'Little information', 1; and 'Much information', 2. In addition, parents were asked to report their satisfaction from the adequacy of the information provided on a 4-point Likert scale ranging from 'Very satisfied' to 'Not satisfied'. Part III was made up of both closed- and open-ended questions. In the close-ended questions, parents were asked to report their sources of information and rank them in terms of the contribution of each to their knowledge about the child's disease and its consequences. Open-ended questions were employed to collect data on (a) additional information that health-care professionals gave to the mothers and fathers besides the bio-clinical information included in the previous part and (b) other information that the parents perceived to be helpful in managing the situation, but was not offered to them.

The face validity of the instruments was assessed by a psychologist and a paediatric nurse working with families and children in the community. A pretest of the data collection procedures and the questionnaires was carried out to reveal any unanticipated problems that might have hampered the study. The pilot-study took place in the hospital setting. Eleven parents (eight mothers and three fathers) were asked to evaluate the content and clarity of the questions. Besides a few minor changes in the wording of some items, no revisions of the instruments were required. Therefore, the investigators included the pretest subjects in the study population.

Data analysis

This study represents a combination of a descriptive correlational design and a descriptive qualitative analysis. Descriptive statistics were used to analyse (a) the sociodemographic characteristics of the parent, the family and the child, (b) parents' perceptions of the information they received as well as their evaluation of it and (c) parental sources of information. The Chi-Square (χ^2) test, Kruskal–Wallis 1-way ANOVA and Spearman bivariate correlation coefficient were employed to examine correlations between the variables. Finally, content analysis was performed to organise the data obtained from the open-ended questions based on which common themes and categories emerged. The Statistical Package for the Social Sciences (SPSS) was used to simplify the statistical analysis of the data. Tests of significance between the variables were done with an accepted level of $P \leqslant 0.05$.

RESULTS

Sociodemographic and illness-related characteristics

The sample ranged in age from 26 to 52 years ($M = 40.55$, SD = 6.23) and represented a range of socioeconomic levels. The frequency distributions and the percentages of the mothers and fathers according to level of education, employment status and place of residence are presented in Table 1. The same table also describes the frequency distributions and the percentages of the children with leukaemia according to sex and type and stage of the disease. The mean of the children's present age in months was 107.71 (SD = 53.65). The 42 families that participated in the study consisted of one to six children and provided a spectrum of developmental stages in the life cycle. Only one-fifth ($n = 13$, 18.3%) of the parents had a previous experience with cancer from relatives, friends or job. The percentage of mothers and fathers who considered the child's medical condition to be very serious was as high as 70.5 ($n = 50$). Fourteen parents (20%) perceived the disease as being somewhat serious whereas two parents thought of it as not representing a threat to the child's life. The remaining five parents (7.5%) said that they were uncertain about the seriousness of their child's illness.

Type and amount of factual information given

Table 2 describes the subjects' mean scores of all perceived explanations offered to them about the various aspects of the child's leukaemia. With a possible range of 0–16 on the scale, it was found that the mothers' mean score was slightly higher than that of the fathers ($M = 10.85$, SD = 3.03, range = 5–11 and $M = 10.66$, SD = 3.27, range = 3–15, respectively). The mean score for the total sample was 10.77 (SD = 3.11,

Table 1 Demographic data of the parents (*N*=71) and the children with leukaemia (*N*=42)

	Mothers		Fathers	
Characteristics of the parents	***n***	**%**	***n***	**%**
Level of education				
Elementary school	12	29.2	10	33.3
High school	20	48.8	10	33.3
College	4	9.8	3	10.0
University/postgraduate studies	5	12.2	7	23.4
Professional status				
Self-employed	4	9.8	13	43.3
Clerks	9	22.0	16	53.3
Housewives	28	68.3	–	–
Retired	–	–	1	3.4
Place of living				
< 10 000	17	41.5	12	40.0
10 000–1 000 000	19	46.3	13	43.3
> 000 000	5	12.2	5	16.7
Characteristics of the children with leukaemia		n	%	
Sex				
Boys		18	42.8	
Girls		24	57.2	
Type of leukaemia				
Acute lymphocytic		37	88.0	
Acute myelocytic		5	12.0	
Stage of disease				
Continuous remission		30	71.4	
Relapse		12	28.6	

Table 2 Mean scores of all disease-related explanations provided to parents (*N*=71)

	Mothers		Fathers		Sample	
Aspect of the disease	***M***	**(SD)**	***M***	**(SD)**	***M***	**(SD)**
Diagnosis and basic physiology	1.83	(0.54)	1.72	(0.66)	1.78	(0.60)
Causes of the disease	0.75	(0.70)	0.67	(0.67)	0.71	(0.68)
Medical procedures and options	1.62	(0.71)	1.69	(0.77)	1.66	(0.65)
Existing therapies	1.81	(0.54)	1.67	(0.56)	1.74	(0.54)
Side effects of treatment regimen	1.60	(0.54)	1.70	(0.46)	1.65	(0.51)
Prognosis of the disease	0.79	(0.62)	0.79	(0.55)	0.79	(0.59)
Warning signs/symptoms for help	1.56	(0.86)	1.60	(0.82)	1.58	(0.84)
Course and progress of the disease	0.89	(0.64)	0.82	(0.55)	0.86	(0.58)

range = 3–15). The two bio-medical areas in which most respondents perceived that they were given the most information were the diagnosis/basic physiology and the existing therapies. In contrast, the disease-related issues on which the majority of the participants reported that they were given the least information included the causes, course and prognosis of the disease (Table 2).

In the relevant open-ended question, less than half of the parents ($n = 30$, 42.2%) commented that they were given some additional information besides that associated with the clinical aspects of the disease. This information included the following: (a) guidelines to obtain fringe benefits for the child and the family ($n = 8$, 11.3%); (b) other sources of information about the child's condition ($n = 8$, 11.3%); (c) stress and behaviour management for the sick child ($n = 6$, 8.4%); (d) the existing self-help associations which could offer emotional and practical support ($n = 5$, 7%); and (e) the management of family conflicts ($n = 3$, 4.2%). Forty-one parents (57.8%) said that the hospital personnel did not provide them with information other than that concerning the pathophysiology of illness.

Sources of information

As is evident from Table 3, the most significant source of information was the members of the medical team, especially physicians. Informal sources of information included relatives, friends, books, medical journals, television and other parents in the same situation. It is apparent from this table that a remarkably high percentage of parents used only two sources to increase their knowledge about childhood cancer and its implications.

Table 3 Sources of information in relation to their contribution to parental understanding of the child's illness (*N*=71)

Source of information	First source		Second source		Third source	
	n	%	*n*	%	*n*	%
Medical staff	69	97.2	3	4.2	–	–
Nursing staff	2	2.8	8	11.3	3	4.2
Psychologists	–	–	19	26.8	6	8.4
Social workers	–	–	13	18.3	7	9.9
Informal sources (books, TV, friends, other parents)	–	–	12	16.9	16	22.5
No response	–	–	16	22.5	39	55.0

Level of satisfaction—additional information needed

As far as parental evaluation of the information offered is concerned, the frequency distributions and percentages of the subjects by levels of satisfaction are depicted in Table 4. Approximately 1/3 of the subjects expressed a good deal of satisfaction. Only a few parents reported high levels of satisfaction whereas about half of them ($n=34$, 48%) were found with low levels ('slightly satisfied' or 'not satisfied'). One more question was developed to identify what supplementary information would be helpful to the parents in managing effectively the stressful event of having a child with leukaemia. Not all parents responded to this question, whereas others indicated more than one area in which they requested further knowledge. Although most parental responses focused on the cure and causes of the disease, the results of the study revealed that the participants desired to learn more about a wide spectrum of familial and psychosocial issues including the function and organisation of the health-care system (Table 5).

Correlations between the variables

Although there were variations in scores, statistical analysis did not reveal significant differences between the two genders on any of the variables examined. Therefore, correlations were calculated for the total sample. The findings of the study indicated that the mothers and fathers who lived in large cities (over 1 000 000 population) reported that they received more information as compared to those who resided in smaller cities, towns or villages (Kruskal–Wallis 8.6, $P=0.013$). In addition, it was found that the higher the parents' education level was, the less satisfied they were with the amount of information they were offered ($\chi^2=21.56$, $P=0.010$). Moreover, the χ^2 test showed that those of the participants who had a previous contact with cancer in their social or occupational environment reported higher satisfaction ($\chi^2=9.67$, $P=0.021$). Finally, it was shown that the mothers and fathers who said that they received more information about their child's leukaemia also had higher levels of satisfaction from it ($r_s=0.53$, $P<0.001$). No statistically significant relationships were observed between the respondents' perceptions of the seriousness of illness and (a) the amount of information they were given and (b) their evaluation of it. The stage of the disease (i.e., continuous remission or relapse) did not correlate with any of the dependent variables included in this analysis.

Table 4 Sample's frequency distributions and percentages by level of satisfaction (*N*=71)

	Mothers		Fathers		Sample	
Level of satisfaction	*n*	%	*n*	%	*n*	%
Very satisfied	7	17.1	5	16.7	12	16.9
Satisfied	15	36.6	10	33.3	25	35.2
Slightly satisfied	13	31.7	8	26.7	21	29.6
Not satisfied	6	14.6	7	23.3	13	18.3

In terms of the two spouses in each of the 29 couples examined in this study, the findings indicated that most parents were symmetrical (i.e., they agreed on) in their perceptions of the severity of the child's medical condition ($n=16$, 55%, respectively). There were no significant differences between the two spouses in relation to (a) the amount of information they reported that they received and (b) their satisfaction from it.

DISCUSSION

The parents who participated in this study reported that they received adequate information on issues on which medical practitioners had accurate knowledge that they felt they could convey, such as the pathophysiology of the disease, existing therapies, medical signs and the symptoms and side effects of treatment. As became apparent from this study, the Hellenic medical staff dealt mainly with the bio-physical aspects of the disease. Although this trend has been altered to some extent in the North American medical context (Adams and Deveau 1988; Maul-Mellott and Adams 1997), in several European countries including Greece, clinicians avoid discussing with parent the psychological

Table 5 Topics in which parents perceived that additional information was needed to manage successfully the stressful situation[a]

	Mothers		Fathers		Sample	
Areas of information needed	*n*	%	*n*	%	*n*	%
1. Treatment of the disease (more details)	21	51.2	12	38.7	33	46.5
2. Causes of the child's illness	15	36.6	9	30.0	24	33.8
3. Telling and disciplining healthy siblings	11	26.8	10	33.3	21	29.6
4. Operational routine of the health-care system	6	14.6	7	23.3	13	22.2
6. Discipline of the child with leukaemia	8	19.5	4	13.3	12	17.0
5. Management of own emotional reactions	7	17.0	5	16.7	12	17.0
6. Family planning	3	7.3	4	13.3	7	9.8

[a] The figures in this table do not add up to 100% because some parents reported more than one issue whereas others did not respond.

and social dimensions regarding their child's leukaemia (Papadatou and Anagnostopoulos 1986; Sontag 1990). This tendency can be attributed to the bio-clinical model that still constitutes the core philosophy of the Hellenic National Health Care System.

Parents need to know more about their child's medical condition, and these findings showed that they have additional queries which health-care providers should address. For instance, the subjects requested more information about the aspects of the disease in which little progress has been done such as its cause, course and prognosis. These results are in conformity with the literature supporting that parents of children with cancer often perceive to be less informed about the previously cited aspects of the disease for which little is known (Comaroff and MaGuire 1981; Pizzo and Polack 1993; Miller et al. 1995). Nevertheless, nurses and other health caregivers should evaluate parental requests for detailed medical information in terms of what underlying needs mothers and fathers are attempting to fulfil. This is so because earlier and more recent literature maintains that some parents may demand information from, and seek the advice of, other doctors in order to confirm their suspicions of a mistaken diagnosis (Swenson and Stewart 1987; Fitzgerald-Miller 2000).

This study identified a number of other problem areas in the education of parents of children with cancer that require some attention on the part of health-care professionals. Awareness of additional information that is essential to parents could be used to determine the content of structured teaching sessions aimed at assisting parents of children with life-threatening illness. Study results showed that the familial issues in which the parents needed specific guidelines included discipline methods for the sick child and the healthy siblings, family planning and the management of their own strong emotions that the announcement of diagnosis aroused. The findings thus confirmed other investigations which reveal that parents of chronically ill children are not well educated in many areas such as the management of the leukaemic child's and healthy siblings' development, of intra-familial conflicts and tensions as well as of the practical problems of everyday life (Wallace et al. 1984; Moyer 1989; Pain 1999). What and how to tell siblings about the child's disease was also a major concern for the respondents who should be advised to maintain open communication lines in their family and share information based on each member's needs.

Study results reaffirmed those of Chesler and Barbarin (1987) suggesting that parents of children with cancer are not educated about the location and bureaucratic functions of health and social services required for the holistic care of the child. Similarly, the subjects in this research indicated that they needed assistance in learning how to negotiate the Hellenic health-care delivery system, social services and ancillary agencies on which their family depends. Nurses and social workers can educate parents about the structure of the hospital, the routine of the clinic and the rotation of the staff because these issues were found to be among the difficulties that these parents faced after the diagnosis (Patistea et al. 2000).

In spite of technological advances in the field of electronic communication, the mothers and fathers who participated in this study restricted their search of information to traditional sources. Because (a) cancer is a field of continuous research and (b) parents seek information mainly from doctors, nurses, psychologists and social workers, it is necessary that health-care professionals stay informed of the progress of related studies reported in the scientific literature. They also need to keep abreast of what is being presented in the lay press and the mass media since these findings showed that the subjects used non-scientific sources to learn about the child's cancer. Such sources frequently convey inaccurate information that negatively affect parental fears and concerns (Moyer 1989; Ruccione et al. 1994).

Although the involvement of many disciplines is essential for the provision of comprehensive care to the child with cancer and his/her family, it might create problems in that some information may not be provided at all whereas other information may be duplicated. Therefore, the health-care team along with the parents should identify a particular professional who would synchronise the communication not only among the staff and the family but also among the members of the staff. It is proposed that, regardless of the intervention level of the caring services they provide, nurses have much to offer in such a coordinated approach (Swenson and Stewart 1987; Fitzgerald-Miller 2000).

These study results indicated that the Hellenic nursing staff were a source of information for a few parents only. This is not surprising, taking into account the centralised bureaucratic structure of the Hellenic National Health Care System (which has been developed to serve the beliefs, benefits and values of medicine) and the vague legislative regulation concerning the nature and practice of nursing. These regulations frequently suit policymakers', organisations', administrators' and physicians' convenience, resulting in the dominance of physicians in the Hellenic health industry. Physicians, through legislation, have managed not only to institute their right to perform many of the advanced interventions declared to be the domain of nursing, but also to determine officially the level of each individual's monetary compensation.

Additional explanations can be traced to (a) the culturally determined stereotypes which define nursing in terms of manual skills and the provision of physical care, and view its professionals as 'physicians handmaidens', (b) the medical philosophy of nursing curricula which makes Hellenic society reluctant to recognise the scientific knowledge and qualities of nurses and (c) the fact that the nursing profession has not yet earned the right and the responsibility to govern its own affairs and regulate its professionals. Because of the long-term imperialism of medicine at their profession's expense, Greek nurses themselves do not feel confident enough and/or authorised to provide medical information about the disease and the condition of the child to young patients, families and relatives. The causes and effects of the traditional public perspectives on nurse caring in Greece are described analytically elsewhere in the literature (Patistea and Vardaki 2001).

The subjects who lived in one of the two (Greek) largest cities (Athens or Thessalonica) were found to be better informed than those whose families inhabited towns, villages or smaller cities. This is reasonable since most paediatric hospitals and oncology clinics as well as other health-related and social services are located in these two cities. Thus, those parents who reside in or close to these large urban areas have easier access to hospital staff and to other resources such as libraries, research centres and self-help agencies. When working with families of children with cancer in hospital or community settings, nurses need to facilitate parents' access to information and, as other investigators (Hockenberry et al. 1989; Pain 1999) recommend, offer them written instructions and other published materials (e.g., books, brochures etc.). This is particularly advisable for those families who live in areas in which sources of knowledge are limited.

The statistical analysis indicated that the parents who had higher education and a previous experience with cancer received a greater amount of information and evaluated it more positively. Such characteristics may increase parents' understanding of the explanations provided allowing them to ask specific questions. These study results are similar to those of Chesler and Barbarin (1987) suggesting that limited education and lack of previous experience with the disease create problems with communication and comprehension on the part of parents. These findings underscore the importance of two professional interventions being employed during the education of parents about their child's leukaemia. It is essential that health-related staff (a) tailor initial discussions to the level of understanding of each of the family members, and (b) assess their comprehension of the explanations offered.

The absence of significant differences between the spouses is indicative of the establishment of successful communication patterns in the couples who participated in the study. As the mother is closer to the sources of information because the task of regular visits to the hospital with the leukaemic child usually falls on her, she acts as a 'liaison' between her family and the health-care delivery system, sharing knowledge with her husband and other family members about the child's health condition, treatment and progress (Friedman 1992; Patistea and Siamanta 2000). Since parents determine the family's emotional environment and thus the way in which it will deal with the situation, community and paediatric nurses must ensure effective communication between the two spouses.

Overall, the present study confirmed other research (McKeever 1981; Humphrey et al. 1996) showing that parents who face the stressful event of childhood chronic illness are not very satisfied with the adequacy of factual information they receive about their child's cancer. Nevertheless, the observed dissatisfaction of several respondents seems to reflect their disappointment with the ambiguous nature of the scientific knowledge concerning the unpredictability of the disease's course and outcome, rather than their lack of confidence in professional capability or honesty.

This is obvious in that the subjects (a) reported being well informed on issues on which accurate knowledge is available but less informed on aspects of the disease for which little is known, and (b) did not spend much of their time and energy in seeking additional information from several sources outside the hospital environment. The present findings thus appear to sustain Stacey's (1991) writings according to which what lay people do not appreciate in medical science is that knowledge does not automatically lead to power to cure. There is no doubt that health-care personnel, especially physicians are, indeed, in a hazardous position when talking about and explaining issues of childhood leukaemia that are in dispute or for which understanding is not yet clear. Nevertheless, when parents do ask questions, they expect much fuller information than the medical staff is prepared or able to give. Professional responses indicating ignorance or lack of certainty are not easily accepted when 'the stake' (i.e., the child's life) is so important.

The findings of this study indicated that the areas of knowledge important for caring for children with cancer reflected a wide spectrum of parental needs and concerns. Increased emphasis thus should be placed on training health-related professionals in using a multidisciplinary approach to provide coordinated and comprehensive care for families experiencing childhood chronic illness, including cancer. As mentioned above, traditionally, the Greek health education is based on a strong medical philosophy centring on the physiology of the body and the mechanisms and treatment of disease. Although it provides basic knowledge about the rudiments of cognitive and social development of the human being, both nurses' and physicians' theoretical and clinical training lack breadth and depth. Nonetheless, as this study revealed, physicians and nurses need to have a good understanding of various personal, familial and social factors influencing the child's illness and parental coping patterns.

LIMITATIONS OF THE STUDY

This study provided valuable data concerning the topic under investigation. Nevertheless, it has certain limitations that should be addressed. First, although the sample appears to be representative and thus can permit generalisations to other populations of parents having children with leukaemia, the retrospective nature of the study might have influenced the subjects' ability to recall past events. Therefore, self-report data may be inaccurate due to perceptual biases. Second, other studies are needed to verify or reject the finding that the parents who inhabited large urban areas were better informed than those who resided in smaller cities or villages. This result may be biased because of the low number of subjects on which it was based. Third, due to the design of the instrument used, it was impossible to discern whether the parents chose to use a limited number of sources to increase their knowledge or did so because they had no opportunity to make use of other resources. Finally, this research did not explicitly examine the reasons for the subjects' low levels of satisfaction with the information given. Further research is required to explore whether parents of children with cancer are dissatisfied due to lack of comprehension, incomplete explanations or insufficient clinical knowledge.

CONCLUSION

The seeking of information can be thought of as a crisis-meeting resource that reduces parental stress and uncertainty. Health caregivers should educate parents about all aspects of their child's illness, including both medical and psychosocial issues. As was evident from this study, Greek paediatric nurses in the oncology field need to become more active in providing information. Because physicians often give a hurried explanation to parents, it is their responsibility to answer parental questions and to provide comfort and support. Attempts to educate parents, however, need to acknowledge existing technological and scientific limitations. This is so because the effective management of the disease and its psychosocial consequences are based on a sincere and trusting relationship between the family and the health-care team.

REFERENCES

Adams D, Deveau E (1988) Coping with childhood cancer: where do we go from here? Kinbridge Publications, Ontario

Austin J (1990) Assessment of coping mechanisms used by parents and children with chronic illness. American Journal of Maternal and Child Nursing 15(2): 98–102

Burr CK (1985) Effects of chronic illness on children, families, and communities. In: Hobbs N, Perrin JM, Ireys HT (Eds) Chronically ill children and their families. Jossey-Bass, San Francisco

Burton L (1975) The family life of sick children. Routledge & Kegan Paul, Boston

Chesler M, Barbarin O (1987) Childhood cancer and the family: meeting the challenge of stress and support. Brunner/Mazel Publishers, New York

Chesler M, Yoak M (1984) Self-help groups for families of children with cancer: patterns of stress and social support. In: Roback H (Ed) Helping patients and their families in coping with medical problems. Jossey-Bass, San Francisco

Comaroff J, MaGuire P (1981) Ambiguity and the search for meaning: childhood leukaemia in the modern clinical context. Social Science and Medicine 158: 115–123

Dale N (1996) Working with families of children with special needs: partnership and practice. Routledge, London

Fitzgerald-Miller J (2000) Coping with chronic illness: overcoming powerlessness, 3rd Edn. F.A. Davis, Philadelphia

Friedman MM (1992) Family nursing: theory and practice, 3rd Edn. Appleton & Lange, Norwalk

Hockenberry MJ, Herman SB, Schultz WH, Falletta JM (1989) Cancer in children. In: O'Quinn AN (Ed) Management of chronic disorders of childhood. G.K. Hall, Boston

Holaday B (1984) Challenges of rearing a chronically ill child. Nursing Clinics of North America 19(2): 361–368

Humphrey G, Skeel J, Boon C (1996) Uncertainty: a conceptual model applied to parental stress associated with prognostic uncertainty in pediatric oncology. International Journal of Pediatric Hematology/Oncology 3: 47–51

Last B, Grootenhius M (1998) Emotions, coping and the need for support in families of children with cancer: a psychosocial model. Patient Education and Counseling 33(2): 169–179

Lewis FM (1994) Strengthening family supports: cancer and the family. Cancer 65(3): 752–759

Maul-Mellott SK, Adams JN (1997) Childhood cancer: a nursing overview. Jones and Bartlett, Boston

McKeever PT (1981) Fathering the chronically ill child. Maternal and Child Nursing Journal 6: 124–128

Medvene L (1992) Self-help groups, peer helping and social comparisons. In: Spacaman S, Oskamp S (Eds) Helping and being helped. Sage, Newbury Park, CA

Miller R, Joung J, Novakovic B (1995) Childhood cancer. Cancer (Suppl) 75(1): 395–405

Moyer A (1989) Caring for a child with diabetes: the effects of specialist nurse care on parents' needs and concerns. Journal of Advanced Nursing 14(7): 536–545

Pain H (1999) Coping with a child with disabilities from the parents' perspective: the function of information. Child: Care, Health and Development 25(4): 299–312

Papadatou D, Anagnostopoulos F (1986) Psychological approach to patients with cancer. Floga, Athens, Greece

Patistea E (1999) Parental coping strategies in childhood leukaemia. Unpublished Doctoral Dissertation, Faculty of Nursing, University of Athens

Patistea E, Makrodimitri P, Panteli V (2000) Greek parents' reactions, difficulties and resources in childhood leukaemia at the time of diagnosis. European Journal of Cancer Care 9: 86–96

Patistea E, Siamanta H (2000) Family life, two cultures and a serious childhood illness. Community Practitioner 73: 566–569

Patistea E, Vardaki Z (2001) Clients' and nurses' perspectives of caring as related to nursing leadership – the Hellenic dimension. Part one. Canadian Journal of Nursing Leadership 14(3): 28–39

Pizzo P, Polack D (1993) Principles and practice of pediatric oncology, 2nd Edn. J.B. Lippincott, Philadelphia

Ruccione K, Waskerwitz M, Buckley J, Perrin G, Hammond DG (1994) What caused my child's cancer? Parents' responses to an epidemiology study of childhood cancer. Journal of Pediatric and Oncology Nursing 11(2): 71–84

Sontag S (1990) Illness as metaphor and AIDS and its metaphors. Ancor Books, New York

Stacey M (1991) Concepts of health and illness and the division of labour in health care. In: Currer C, Stacey M (Eds) Concepts of health, illness and disease: a comparative perspective, 2nd Edn. Berg, New York

Swenson BJ, Stewart JL (1987) Patterns of impairment: childhood cancer. In: Rose MH, Thomas RB (Eds) Children with chronic conditions. Nursing in a family and community context. Grune & Stratton, Orlando

Tones K, Tilford S (1994) Health education, effectiveness, efficiency and equity, 2nd Edn. Chapman & Hall, London

Wallace M, Bake AH, Pendergrass T (1984) Coping with childhood cancer: an educational program for parents. Oncology Nursing Forum 11: 30–35

Westbom L, Koehler R (1991) Parental perceptions of health care of children with chronic illness: a population-based study in a Swedish primary care district. Scandinavian Journal of Primary Health Care 9(4): 285–291