

Γνώσεις και απόψεις γονέων για την ανακουφιστική φροντίδα των παιδιών με καρκίνο στην Ελλάδα

Abstract at the end of the article

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Parental knowledge and views regarding palliative care for children with cancer in Greece

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Introduction: Palliative care (PC) refers to interventions aimed to improve the quality of life (QoL) of children and their families by the prevention and relief of suffering. The purpose of this study was to explore the knowledge and views of parents of children with cancer regarding PC in Greece. **Methods:** A descriptive cross-sectional study was performed in a sample of 100 parents of hospitalized children in oncology departments and a bone marrow transplant unit of two pediatric hospitals in Attica, from February to June 2021. The “Evaluating Supportive Care for Children” tool was used. Data analysis was performed with SPSS v.23.0. All tests were performed at a statistical significance level of $p \leq 0,05$. **Results:** Only 19% of the participants know about PC while no one reports personal PC provision experience. Highest level of education and monthly income were statistically significantly correlated with the knowledge of PC, ($p=0,040$) and ($p=0,036$) respectively, and the positive parental attitude towards PC inclusion in the child’s care ($p=0,013$). The majority of parents rated the QoL of their children as good (46%) or very good (31%). Thirty two percent reported no or limited discussion with their child about their disease and treatment. Moreover, parents reported occurrence of pain in 95% of cases. **Conclusions:** It is clear that Greek parents are unaware of PC, they overestimate their children’s QoL, and there is a noticeable lack of adequate discussion regarding cancer and its treatment between parents and their children. Parents should be more informed about PC.

Λέξεις-εμπρηρίου: Palliative care, parents, paediatric nursing, oncology nursing, hospitalization, quality of life

Introduction

Pediatric palliative care (PPC) is the active holistic care of the child's body, mind and spirit that aims to the prevention and relief of suffering, support to the family and improvement of the quality of life (QoL) of children with cancer and their families.^{1,2,3} In a number of recent studies, parents of children with cancer state that provision of PC is beneficial for their children and family functioning,^{4,5} but there is a noticeable lack of knowledge regarding PC, its applications and its impact on child's care.⁶ In a number of studies was found that 34-43% of parents are partially aware of PC and/or its applications.^{6,7,8} There are several factors that influence the formation of parents' views on PC⁹ such as family centered care & family support.¹⁰

Parents of children with cancer desire supportive, timely, and effective communication with physicians focused on building relationships, sharing information, participation in decision-making process, managing uncertainty, responding to emotions, providing reassurance, and supporting hope.^{11,12,13} They also state several obstacles in this communication, such as paternalism in medicine, insufficient training in communication skills and limited support during bereavement.¹⁴ Parents report difficulty in making decisions, especially at the time of initial diagnosis, and that physicians are at the forefront of making such decisions. They argue that communication, information exchange, and participation in discussions about preferences, values, and ultimately care goals should be the basis for decision making.¹⁵

Parents of deceased children ex postly say they would prefer home death, non-aggressive care and ongoing anti-cancer treatment, programs/policies that could alleviate barriers that limit a family's time with a dying child, to prepare the family for death.¹⁶ At the same time, parents of children with end-stage cancer want better psychological support, better understanding of the decision-making process, secure sources of information, better communication with physicians, age-focused patient care.¹⁷

The vast majority of parents seem to avoid "bad news" discussions with their child, for example 60-70% of parents of children with end-stage cancer had not discussed impending death with their children.¹⁸ These parents also reported that PC in these children should focus on controlling symptoms, especially pain, enhance communication and guidance.¹⁹ On the other hand, children seem to be more willing to discuss about their condition, are more open to information and want not to be ex-

cluded from the "bad news" about their illness. Jalmseil et al. in their study concluded that children with cancer want to share their views and they want to be informed as positively as possible, allowing them to maintain their hope in words they could understand. They also want to be informed about "bad news" at the same time as their parents.²⁰

Despite the existing evidence²¹ the current views of parents on the needs of children with cancer for PC have not been clearly documented. The purpose of the study was to explore the views of Greek parents of children with cancer regarding PC.

Method

This is a descriptive cross-sectional study carried out from February to June 2021. The sample of the study (convenience sample) consisted of 100 parents of hospitalized children with cancer in two pediatric oncology wards and a bone marrow transplant ward in the two major public pediatric hospitals in Greece located in Athens. All the parents of the children treated for cancer during the study period in these units and met the inclusion criteria were approached and asked to sign informed consent in order to participate. In total, three parents were excluded due to language limitations or partial completion of the questionnaire and four parents did not agree to participate. The inclusion criteria were: parenting a child with cancer, hospitalized for at least 4 weeks, good knowledge of the Greek language, signed informed consent and full completion of the questionnaire. For each child one of the parents was asked to participate. All participants completed a form with demographic survey questions and the questionnaire "Evaluating Supportive Care for Children with Cancer"⁹ consisted of 44 questions (items) that surveys the needs, attitudes and perceptions of parents for PC. The questionnaire was used after permission was granted from authors.

The questionnaire was translated into Greek, the translation was performed independently by two experts and a qualitative review was conducted in order to ensure its clarity and conceptual adequacy along with the necessary language adaptation. Then a backward translation was performed by a native English speaker. Finally the research team reviewed each item independently in the consensus translation and approved the final translation for pilot testing in a sample of 30 subjects. The Cronbach's alpha internal consistency coefficient for the part "parents' views on the probability

Table 1. Demographic characteristics

Variables	Fathers (N=33)	Mothers (N=67)	Total (N=100)
Marital status			
Married	25	56	81
Unmarried	0	1	1
In dimension	3	1	4
Divorced	5	8	13
Widower	0	1	1
Total number of children			
1	9	23	32
2	19	34	53
3	5	8	13
4	0	2	2
Family members with whom the child lives			
Parents	8	24	32
Parents, brothers/sisters	14	28	42
Parents, brothers/sisters, grandparents	1	0	1
Father	2	0	2
Mother	8	15	23
Place of residence			
Athens	22	43	65
District town	10	21	31
Rural area	1	1	2
Island	0	2	2
Type of residence			
Department	26	47	73
Detached house	7	20	27
Educational level			
Secondary School	0	1	1
High School	7	13	20
Secondary Education	6	10	16
Higher Education	11	30	41
Master Degree	6	13	19
Doctoral Degree	3	0	3
Working condition			
Employee	30	50	80
Unemployed	2	9	11

Household	0	7	7
Retired	1	1	2
Average monthly family income (Euro)			
0-499	0	0	0
500-999	1	6	7
1000-1499	11	25	36
1500-1999	10	24	34
2000-2499	7	6	13
>2500	4	6	10
Parental health level			
Good	9	19	28
Very Good	13	36	49
Excellent	11	12	23

of cure and treatment" (N=13) was 0,726, for the part "parents' views on the symptoms after the first month of treatment" (N=22) was 0,760, for the part "parents' views on the QoL of children" (N=31) was 0,745 and for the part "parents' views on their participation in the study" (N=31) was 0,693.

Frequency, mean, standard deviation (SD), median and interquartile range (IQR) for the continuous variables and frequency and percentage for the categorical variables were used adequately. The Kolmogorov–Smirnov test and graphs (histograms and normal Q–Q plots) were used to assess the normality of the distribution of the continuous variables. Bivariate analyses between demographic characteristics and the questionnaire scores included independent samples t-test, analysis of variance and Pearson's correlation coefficient. Independent samples t-test was used to compare a continuous variable with a dichotomous one, whereas analysis of variance was used to compare a continuous variable with a nominal one. The χ^2 test was used to investigate the relationship between two categorical variables. The Mann-Whitney test was used to investigate the relationship between a quantitative variable that does not follow the normal distribution and a binary variable. Also, we used Pearson's correlation coefficient to find out the correlation between two continuous variables. IBM SPSS, v.23.0 was used to perform statistical analysis. The two-sided level of statistical significance was set to 0,05.

Results

The study involved 100 parents (33 fathers, 67 mothers) of children (59 boys, 41 girls) with cancer with mean age 41,94 years (SD=5,27). The demographic characteristics of the sample are presented in Table 1. The mean age of the fathers was 43,03 SD=5,47 years (IQR:34-55 years) and 41,40 SD=5,13 years (IQR:30-54 years) of the mothers. The mean age of the children was 9,24 SD=3,42 years (IQR:1-16 years) and their mean age at the time of diagnosis was 7,61 years (SD=3,70 IQR:1-14).

No statistically significant difference was observed between the sex and the type of cancer ($p=0,496$). The children in the sample suffered from leukemia (60%), brain tumors (12%), lymphoma (8%) and other tumors (20%). Parents rate their children's QoL as good (46%) or very good (31%) and 97% estimate that their children's QoL will improve.

The majority of parents report that the probability of cure is relatively high or very high (75-86%) while 7% report that the physician has not discussed the probability of cure with them. Moreover, the 67% of parents stated that their child believes that they have a relatively high or very high probability of cure.

Thirty two percent of parents report none or relatively limited discussion with their child about the disease prognosis. On the contrary, 40% stated that they had an in-depth discussion. Regardless of the degree of discussion, the majority (67%) characterize this discussion

Table 2. Intensity of symptoms of children with cancer during the first month of treatment

Intensity of symptoms	Nausea	Loss of appetite	Diarrhea	Constipation	Anxiety	Depression	Pain
	%						
Don't know	3	0	1	1	1	7	3
Not at all	7	9	37	38	6	21	7
Minimum	23	11	24	34	17	15	23
Enough	33	32	14	17	30	28	18
Very	13	26	10	6	20	19	31
Very much	21	22	14	4	26	14	18
Total	100						

as quite difficult or very difficult. Regarding their information, they state that they are informed regarding the effects of the treatment on the physical functioning of the child by 78%, on the emotional state by 63% and on child's QoL by 64%.

Parents report that the probability of cure (93%), the ability of their children to participate in daily activities (74%), the effects of treatment (76%), the length of hospital stay (54%) and total treatment time (61%) were important factors in making treatment decisions.

The participants were asked to rate the pain management during the first month after the enactment of treatment. They reported pain symptoms during the first month of treatment in 95% of cases (3 participants report zero pain while 2 reported that they do not know if there was pain or its intensity). Nearly one in two parents reported that their child has suffered much or too much during the first month of treatment. The average pain intensity was 6,73 (SD=2,42, Median (IQR)=7 (0-10)). Moderate pain was reported by 36% of parents and severe/intense pain by 45%. Summarizing, the vast majority of parents (95%) stated that they were more or less satisfied of the efforts of health professionals to alleviate their child's pain despite the fact that they rated its management as quite or very effective at 56%.

The severity of children's symptoms as was assessed by their parents during the first month of treatment is presented in Table 2. Parents report the intensity of health professional's efforts to manage children's symptoms and their satisfaction of these efforts as presented in Table 3.

Participants were asked to choose between the two following treatment options:

Treatment A: 80% probability of cure but leads to side

effects such as nausea, vomiting, diarrhea and pain.

Treatment B: 75% probability of cure but there are significantly fewer side effects and offers the child a better QoL during treatment, compared to treatment A.

Treatment A was selected by 64% of the participants (definitely A chose 41% of parents, probably A 23%). Treatment B was selected by 19% (probably B 16% and definitely B 3%), while 17% said they were unsure.

Participants were also asked to select between one of the following treatments:

Treatment A: 65% probability of cure but there are significantly fewer side effects and offers the child a better QoL during treatment, compared to treatment B.

Treatment B: 80% probability of cure but there are side effects such as nausea, vomiting, diarrhea and pain.

Treatment A was selected by 8% (definitely 3%, possibly 5%), treatment B by 76% (definitely 51%, probably 25%), while 16% said they were unsure. In both cases, the majority of parents choose the treatment with the highest probability of cure versus the treatment with impact on QoL or the onset of symptoms. Fathers choose treatment B more than mothers, who preferred treatment A ($\chi^2=10,267$, $df=4$, $p=0,036$). In contrast, mothers tended to choose treatment with the lowest probability of symptoms compared to fathers, but the difference was not statistically significant ($p=0,080$). Accordingly, parents with a higher level of education choose the higher survival even if it was accompanied by significant side effects, compared to treatment with fewer symptoms, but less probability of cure ($\chi^2=33,498$, $df=20$, $p=0,030$).

More than nine to ten participants (93%) believe that health professionals should focus on issues that determine the QoL of the child. Almost one in two parents (47%) stated that health professionals supported as

Table 3. Intensity of health professional's efforts to manage children's symptoms and parents' satisfaction

	Symptoms						
	Nausea	Loss of appetite	Diarrhea	Constipation	Anxiety	Depression	Pain
Intensity of efforts	%						
Don't know	1	0	0	1	0	1	0
Not at all	0	3	1	1	1	2	0
Little hard	5	12	14	19	15	16	0
Enough hard	40	29	28	19	26	21	58
Very hard	48	47	24	26	50	36	37
Parents' satisfaction	%						
Don't know	1	1	1	0	0	0	5
Not at all	0	14	2	4	4	4	0
Little	17	16	16	14	12	13	18
Fairly	51	33	29	29	31	26	42
Very much	22	11	11	14	12	9	14

much as they should the QoL of their children and mainly interventions that enhanced children participation in daily activities and enjoy their daily life (29% very much and 18% enough).

The parents in our study expressed their need for additional information in specific areas such as: a) regarding the management of the child's physical symptoms (80%), b) emotional support (60%), c) enhancement of child's QoL (100%) and family's QoL and functioning (36%) and d) management of the child at the end stage of the disease (26%).

Respectively, the topics for discussion mentioned by the parents as the main ones for the information of the children themselves concern the management of their emotional disorders (52%), the management of physical symptoms and pain (78%) and less their effect on the function of the family and in everyday life.

Only 19% of parents report knowledge of the term PC and 18% associate it with improving the QoL of the child with cancer and 9% associate it with the management of the child during the end stage of the disease. None of the participants reported personal experience of PC. This is expressed by the reduced positive attitude of the participating parents (19%) towards PC, as 68% state that they are not aware of its content and associ-

ated interventions. However, 45% believe that the PC group would be helpful in managing the symptoms of cancer and its treatment. Only 18% believe that this group would be helpful in making initial treatment decisions but a higher percentage (38%) state that adding it would be beneficial for the overall care of the child. Reduced is the belief that it would assist strengthen the relationship between parents and the care team since only 15% reported this aspect of PC. On contrast, 3-7% of the participants stated that provision of care by the PC team would have a negative effect on their hope for cure or effective treatment. Despite the limited knowledge about the PC team and its role, 47% stated that they would definitely like to meet with its members from the time of diagnosis and 25% that they probably would. But there is a 4% who stated that they probably or certainly would not like to apply it at diagnosis because they believe that it is not necessary. The 60% of the parents reported that wanted the initiation of PC from the initiation of the treatment of their child, the 8% when pain or a symptom is a problem, the 4% when the disease worsens or relapses, and the 21% didn't know.

Participants were asked their views regarding the probability of no cure for their child. Fathers and parents with highest level of education stated that they

Table 4. Parents' views on palliative care correlated to education level and monthly income

Variables	Higher level of education			Higher average monthly income		
	χ^2	df	P	χ^2	df	P
Limited discussion	55,410	20	0,001	44,751	16	0,001
Difficult discussion	43,759	20	0,002	32,806	16	0,008
Length of hospitalization was very helpful in decision making	33,887	20	0,027	26,573	16	0,046
Total treatment time was very helpful in decision making	46,403	20	0,001	32,290	16	0,009
Effective management of pain	42,411	25	0,016	18,153	15	0,255
Effective management of nausea	29,706	20	0,075	28,575	16	0,027
Effective management of diarrhea	28,458	20	0,099	30,598	16	0,015
Greater knowledge of palliative care	11,639	5	0,040	10,274	4	0,036
Positive attitude on palliative care	26,500	10	0,003	19,313	8	0,013

would like health professionals to have discussed more about the probability of no cure, compared to mothers ($\chi^2=12,984$, $df=1$, $p=0,001$) and parents with lower educational level ($\chi^2=10,380$, $df=4$, $p=0,034$). Moreover, fathers tend to report less effectiveness in managing their children's symptoms than mothers. A statistically significant difference was found in the management of physical symptoms, such as nausea ($\chi^2=10,380$, $df=4$, $p=0,034$), constipation ($\chi^2=12,794$, $df=5$, $p=0,025$), loss of appetite ($\chi^2=9,504$, $df=5$, $p=0,041$) and psycho-emotional disorders (anxiety, depression) ($\chi^2=10,529$, $df=4$, $p=0,032$). Respectively, parents with higher average monthly incomes evaluate the efforts of health professionals to deal with physical symptoms such as nausea ($\chi^2=28,575$, $df=16$, $p=0,027$), or diarrhea ($\chi^2=30,598$, $df=16$, $p=0,015$) to a higher degree compared to lower income parents (Table 4).

Parents with a higher level of education and a higher monthly income tend to characterize the degree of discussion with their child about the disease as more limited and express a desire for a greater degree of discussion ($\chi^2=55,410$, $df=20$, $p=0,001$) and ($\chi^2=44,751$, $df=16$, $p=0,001$), respectively, and characterize the content of the discussion as difficult ($\chi^2=43,759$, $df=20$, $p=0,002$) and ($\chi^2=32,806$, $df=16$, $p=0,008$), respectively (Table 4).

Parents with a higher level of education and those with a higher average monthly income stated that length of stay in the hospital and the total time of treatment were very helpful in making decisions about the

child's treatment plan, in contrast to the parents with a lower level who found the residence time less helpful ($\chi^2=33,887$, $df=20$, $p=0,027$) and ($\chi^2=26,573$, $df=16$, $p=0,046$), respectively, as well as the total treatment time ($\chi^2=46,403$, $df=20$, $p=0,001$) and ($\chi^2=32,290$, $df=16$, $p=0,009$), respectively. Higher level of education was associated with greater satisfaction with pain management ($p=0,016$) (Table 4). The level of education was not associated with statistically significant differentiation regarding the effectiveness of management of other physical symptoms.

The concept of PC is better known to parents with a higher level of education ($\chi^2=11,639$, $df=5$, $p=0,040$) and therefore their attitude is more positive ($\chi^2=26,500$, $df=10$, $p=0,003$). Respectively, parents with higher average monthly income declared knowledge of the concept of PC compared to them with lower income ($\chi^2=10,274$, $df=4$, $p=0,036$) and respectively their attitude was more positive ($\chi^2=19,313$, $df=8$, $p=0,013$).

Parents with a lower level of education associate the onset of PC with the removal of hope for cure ($\chi^2=15,910$, $df=4$, $p=0,003$). The mothers considered that the PC group would be a positive addition to the overall care of the child to a greater extent, compared to fathers ($\chi^2=4,186$, $df=1$, $p=0,041$).

Discussion

It was clear from the data analysis that participants' knowledge regarding PC was quite limited since just

only one in five stated that knows the term and the content of PC. It is widely believed that PC is referred only to end-stage patients and that is why very often is referred as “care before death”, pain relief, and peaceful death.⁸ In accordance to our findings, level of parents’ education and older age were positively associated with knowledge of PC, however many parents had a misconception about its role.^{7,22,23} Parents believe that the goal of PC is to support the family (90,6%), to provide social, emotional support (93,4%) and to manage pain and other symptoms (95,1%), but the majority of them have not realized the role of nurses in the provision of PC.²⁴ Parents who knew the meaning of the term point out its importance in management of care from diagnosis to treatment and cure or end-stage care, according to the prognosis of the disease.¹⁰

The term of PC was familiar to parents with a higher level of education. Parents’ educational level has been strongly associated with knowledge of PC.^{7,24} Parents with a lower level of education associate the start of PC with the removal of the hope of cure, while mothers believe that the PC team would make a more positive contribution to care than fathers. In a previous similar study, none of the parents had a negative attitude toward PC and even in relation to early integration of PC in pediatric oncology patients in USA. The parents, after being informed, wanted to have met the PC team at the time of diagnosis. Pediatric patients stated that for them was more necessary to include PC early in the care plan to relieve their symptoms in comparison to their parents.⁹ Other parents report that although they hoped the child would recover, despite knowing that the cancer was incurable.²¹ In literature is argued whether early PC integration in pediatric oncology patients and families might be beneficial and not a barrier.^{9,21}

In our study, despite parents’ limited knowledge regarding PC, almost one in two believes that it would be helpful. On contrary, another study claims that most parents described that they had limited expectations about what support the PPC team could provide them.²⁵ In a study on the needs, attitudes and views of parents and children with cancer for early initiation of PC, it was found that few children and parents expressed opposition, while children considered PC more necessary than parents.⁹ Virbun et al. in a recent systematic review focused on the elements of optimal pediatric PC. They concluded that this type of care should be flexible, responsive and tailored to the needs of children and their families, targeting to the management of suffering.²⁶

In the present study, the majority of parents rated the QoL of children as good or very good in contrast to previous studies which found that mothers reported that their QoL and child’s QoL to be significantly lower than population norms. In the same study, mothers who rated their own QoL as poor rated the child’s QoL to be low as well.²⁷ In an older study in Greece, parents of children with cancer underestimated the QoL of children compared to the one reported by them, especially in the domains regarding emotional and social domains.²⁸ These differences in the assessment of children’s QoL, may reflect in a point, the parental fear, worry and anxiety. Educational level, good communication with health professionals and the child and good family functioning seem to limit these differences.^{9,27,28}

In accordance to previous studies, almost all parents reported that health professionals should focus more on the QoL of the child. However, the impact to QoL from symptoms related to the disease or the treatment is acknowledged by the parents. The symptoms management is a desired milestone in pediatric oncology care for both children and their parents.^{29,30} Therefore, the early integration of PC is argued. Mack & Wolfe noted this element. In their study, parents stated that early integration of PC allows for improved symptom management, parental adjustment and preparation for the end-of-life care period. Those families were more likely to believe that their care has been of high quality. In addition to information about what to expect, parents valued sensitive and caring communication from the physician and health professionals.³¹ The existing evidence supports that access to specialist care, such as PC is considered crucial for parents³² and there is a need for support related to relief of their children from suffering and especially symptoms that cause extreme burden to children such as pain.²⁶

The majority of parents reported that the chance of cure is high, however almost one in ten parents stated that he/she had not discussed the prognosis of the disease with the physician. According to a study of parents’ expectations for curing children with cancer, the majority significantly overestimated the chance of cure, with 24% of parents reporting that their child had >90% chance of being cured. It is noticeable that only 26% of parents recognized that the chance of cure was less than 25%. When asked to choose a single most important goal of care, approximately 72% chose cure, 10% chose longer life, and 18% chose better QoL.³³ It is widely acknowledged that there is a considerable delay

in parental recognition of bad prognosis or poor cure outcomes. However, earlier recognition of this prognosis may be associated with interventions targeting to the relief from suffering and greater integration of PC. Wolfe et al. in their study with 103 parents of children who died of cancer, found that the majority of parents during the parent defined end-of-life period, continued to report that the primary goal of cancer-directed therapy was to extend life (34%), to cure the child (28%), to support hoping (13%), to have done everything (10%), or to extent life without hope of cure (15%).³⁴ In accordance, parents of children with cancer tend to report better QoL than the children themselves.³⁵ Another study supports parental optimism as an internal coping mechanism in a way. Personal intuition had been an important source of prognostic information, and the parent coping styles of disengagement and reliance on emotional support from others were associated with decreased parent-physician agreement about cure and increased parent optimism.³⁶

Fathers and parents with a higher level of education stated that they wanted better information about the chance of non-cure, a finding consistent with the results from previous studies.²³ Information level regarding disease prognosis and consequences from both disease and treatment options impacts on parental coping.

The children that are less informed, face more problems and suffering in relation to children that are well informed. Even in end-of-life care for pediatric cancer patients, information and communication with family members and health professionals plays a key role in their overall experience and QoL.³⁰ Fathers of children with cancer experienced uncertainty and fear when professionals did not communicate effectively or involve them in the decision-making.³⁷ At the same time, parents reported not preparing those around them for the possibility of the child's death.³⁸

Parents with a higher level of education and income reported limited discussion with the child. Lövgre et al. examined how families in pediatric oncology experienced illness-related information and communication with professionals and within the family. The study revealed that parents reported the lowest levels of family communication, followed by siblings. Parents, ill children, and siblings all scored low scores on the item related to sharing "bad news" to one another. Four of 25 ill children, could talk with someone in the family about the illness but only 2 of 25 ill children and 4 of 33 siblings had questions about the illness that they did not dare

ask their family. Sixty-eight percent of the parents reported that they did not share their thoughts or feelings with their families.³⁹ Although the effect of parents' educational attainment and income on limited communication with children with cancer has not been adequately investigated, lower receptivity to PC was associated with having a lower household income.⁴⁰

Almost one in three parents reported that the communication with their child was quite limited. Similar studies have identified variability in parents' reports of how information was shared with their children and how the child was involved in the treatment decision making process.⁴¹ It has been reported that some parents desire to become more "hands on" and involved with their parenting as well as experiencing increased intimate communication or feelings of establishing and maintaining a closer, more open and emotionally supportive relationship with each other since the cancer diagnosis,⁴² while some maintain good communication in the final stages of the disease.⁴³

Kars, Grypdonck & van Delden tried to explore parents' experiences when caring for their child with incurable cancer. The parents experience a variety of stressors that threaten their parenting role and decrease their ability to acknowledge the child's needs. Communication in such cases becomes difficult and parents avoid discussing about cure at a time when a child's health is deteriorating near the end of life.^{43,44} Nurses play a key role in assisting parents to deal with the realistic prognosis and their child's condition and alter their role accordingly, such as by providing information and alternative perceptions that are closer to the child's pragmatic needs. For example, there is widely accepted that cancer treatment is responsible for a variety of symptoms and adverse events. However, many parents still seem to be less prepared for the long-term effects of treatment than for acute ones. These findings indicate that the acute effects of treatment are discussed more by physicians and long terms effects less, indicating a lack in parental information.^{45,46,47}

Parents express the need for information about the emotional support of the child and the treatment of physical symptoms. In a similar study, parents and patients reported that the most significant effects were caused by emotional distress, fatigue, nutrition, and pain.⁴⁸ Consistent with our results, other researchers have shown that the majority of parents believed that it was important to receive information about the day-to-day care of the child.⁴⁵ Parents report a significant need for information

and psychosocial support after diagnosis.⁴⁹

In our study pain was the most common symptom, reported by the 95% of the participants. In a similar study, 50% of the parents stated that the child experienced severe pain. Parents of children receiving treatment reported significantly more severe pain than those whose children had completed treatment.⁵¹ However, other studies report that parents are unaware of their children's pain, and some parents overestimate pain in their children. Haraldstad et al. for example concluded that the level of agreement between parents and children regarding pain intensity is quite low.⁵¹ Despite the occurrence of pain symptoms in pediatric cancer, evidence from previous studies indicates that parents were pleased with the health professionals' efforts to manage physical symptoms and to alleviate the child's pain. On contrary, they were less satisfied with the emotional support offered to them and their children with cancer.⁵² However, the level of satisfaction from overall cancer care remains moderate.⁵³ A study with families receiving PC at home in children with end-stage cancer showed a significant improvement in their QoL and a significant relief related to their symptoms.⁵⁴ Higher level of education was statistically significantly correlated with satisfaction with pain management. Recent studies have shown that better parenting education for pain management can help them cope with the pain of children with cancer.^{55,56} Based on our results, fathers tend to report less effectiveness in managing symptoms than mothers. Despite advances in pain management techniques, children with cancer still have to deal with intense pain and this causes distress to their parents along with misconceptions about pain management.⁵⁷ However, cancer, such as other chronic diseases may lead to a number of symptoms other than pain along with fatigue and inadequate patient care.^{58,59}

Our analysis revealed that fathers are more willing to choose a treatment that leads to a better QoL compared to the mothers. Instead, mothers choose a treatment with the least chance of symptoms. Accordingly, the parents with the highest level of education choose the treatment with the highest survival. In a study of parents of deceased children, the parents preferred their child to receive treatment regardless of its side effects. Parents with higher educational attainment and income reported that the criterion for choosing treatment was the chance of cure. When asked to retrospectively consider what the goal of treatment might be, they reported lessening suffering.⁶⁰ Fathers tended to report feeling more

pressure from others and reported more uncertainty about the optimum choice than did mothers. Parents with prior knowledge of pediatric cancer treatments, particularly the mothers, preferred more involvement from their child's oncologist.⁶¹

Parents report that the chance of cure influences treatment decisions. It has been argued that the high risk of delayed treatment outcomes has influenced the treatment choices of parents and physicians. In other study, both parents and physicians accepted a high risk of infertility (parents, a 137% increased risk; physicians, an 80% increased risk) in exchange for a 10% greater chance of cure.⁶² These findings are consistent with those of Huang et al. study that most parents wanted information on their children's QoL (95%), followed by chance of recovery (88%), and pain relief (84%).⁶³ Unfortunately, as argued earlier, parents often are unwilling to accept the reality and force health professionals to enact treatments such as chemotherapy, even when the chance of cure is relatively low.⁶⁴ In another study, when parents were asked to choose a single treatment goal, 72% chose the cure, 10% chose a longer life expectancy, and 18% chose a better QoL.³³

The parents with the highest level of education and income stated that the time spent in the hospital and the total time of treatment, helped them in making treatment decisions. However, another study reported that length of hospitalization significantly increased parental anxiety levels, unrelated to education level.⁶⁵ Other researchers have shown that the majority of parents with a high level of education wanted a participatory decision-making process without correlation with education, gender, race, or treatment chance. The same study identifies information provision and communication as key elements of effective decision making process.⁶⁶

Study Limitations

This is a sample of convenience in a limited period of study for all parents who met the admission criteria. The provision of PC in our country is in the development stage, therefore the degree of information of the parents is small, as well as the organized PC services. Measures to prevent the transmission of the COVID-19 pandemic to the hospitals where the data were collected led to barriers to communication with parents and time delays.

Conclusions

Our analysis revealed the great lack of information

regarding PC among parents of children with cancer in our country. This is more stressed since no one reported experience of PC provision to their child in any of the cancer treatment stage. Parents assessed their children's QoL as high despite the increased reference of pain and other symptoms. Moreover, a great lack regarding information and communication was exposed and parents do not discuss adequately about cancer illness with their child. These results could contribute to the development of better care practices in children with cancer and to the widespread information among children and parents regarding PC. In the frames of family centered care and patient oriented experience, emphasis should be posed towards lessening suffering and early integration of PC. We have to keep in mind that although parents intend to act beneficially toward their child, their limited knowledge, lack of adequate information and fear losing their child,

can impede their ability to act in the child's best interest and stand as a barrier to effective enactment of PC.

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Ethical Issues

This study approved from the Research Ethics Committee of the Children's Hospitals (7329/21-04-2021 and 22488/16-10-2020).

Conflict of Interest

No Conflict of Interest has been declared by the Authors.

ABSTRACT

Γνώσεις και απόψεις γονέων για την ανακουφιστική φροντίδα των παιδιών με καρκίνο στην Ελλάδα

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Εισαγωγή: Η ανακουφιστική φροντίδα (PC) αναφέρεται σε παρεμβάσεις που στοχεύουν στη βελτίωση της ποιότητας ζωής (QoL) των παιδιών και των οικογενειών τους μέσω της πρόληψης και ανακούφισης του πόνου.

Σκοπός της παρούσας μελέτης ήταν να διερευνήσει τις γνώσεις και τις απόψεις των γονέων παιδιών με καρκίνο σχετικά με την ανακουφιστική φροντίδα στην Ελλάδα.

Μέθοδοι: Πραγματοποιήθηκε περιγραφική συγχρονική μελέτη σε δείγμα 100 γονέων νοσηλευόμενων παιδιών σε ογκολογικά τμήματα και στη μονάδα μεταμόσχευσης μυελού των οστών, δύο παιδιατρικών νοσοκομείων στην Αττική, από Φεβρουάριο έως Ιούνιο του 2021. Χρησιμοποιήθηκε η κλίμακα «Evaluating Supportive Care for Children». Η ανάλυση των δεδομένων πραγματοποιήθηκε με το SPSS v.23.0. Όλες οι δοκιμές πραγματοποιήθηκαν σε επίπεδο στατιστικής σημαντικότητας $p \leq 0,05$.

Αποτελέσματα: Μόνο το 19% των συμμετεχόντων γνωρίζει την ανακουφιστική φροντίδα ενώ κανείς δεν αναφέρει προσωπική εμπειρία παροχής PC. Το υψηλότερο επίπεδο εκπαίδευσης και μηνιαίο εισόδημα συσχετίστηκαν

στατιστικά σημαντικά με τη γνώση της ανακουφιστικής φροντίδας ($p=0,040$) και ($p=0,036$) αντίστοιχα και με τη θετική στάση των γονέων στην ένταξη της στη θεραπεία του παιδιού ($p=0,013$). Η πλειοψηφία των γονέων αξιολόγησε την QoL των παιδιών τους ως καλή (46%) ή πολύ καλή (31%). Το 32% ανέφεραν καμία ή περιορισμένη συζήτηση με το παιδί τους σχετικά με την ασθένεια και τη θεραπεία του. Επιπλέον, οι γονείς ανέφεραν εμφάνιση πόνου στο 95% των περιπτώσεων.

Συμπεράσματα: Είναι σαφές ότι οι Έλληνες γονείς αγνοούν την PC, υπερεκτιμούν την QoL των παιδιών τους και υπάρχει αισθητή έλλειψη επαρκούς συζήτησης για τον καρκίνο και τη θεραπεία του μεταξύ των γονέων και των παιδιών τους. Οι γονείς θα πρέπει να είναι πιο ενημερωμένοι για την PC.

Key words: Ανακουφιστική φροντίδα, γονείς, παιδιατρική νοσηλευτική, ογκολογική νοσηλευτική, νοσηλεία, ποιότητα ζωής

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References

- Singer AE, Goebel JR, Kim YS, Dy SM, Ahluwalia SC, Clifford M, et al. Populations and Interventions for Palliative and End-of-Life Care: A Systematic Review. *Journal of palliative medicine* 2016; 19(9): 995–1008.
- Piette V, Beernaert K, Cohen J, Pauwels NS, Scherrens AL, van der Werff ten Bosch J, et al. Healthcare interventions improving and reducing quality of life in children at the end of life: a systematic review. *Pediatric Research* 2021; 89 (5): 1065-1077.
- Kaye EC, Weaver MS, DeWitt LH, Byers E, Stevens SE, Lukowski J, et al. The impact of specialty palliative care in pediatric oncology: a systematic review. *Journal of Pain and Symptom Management* 2021; 61 (5): 1060-1079.
- Snaman JM, Kaye EC, Baker JN, Wolfe J. Pediatric palliative oncology: the state of the science and art of caring for children with cancer. *Current Opinion in Pediatrics* 2018; 30 (1): 40-48.
- Zimmermann K, Bergstraesser E, Engberg S, Ramelet AS, Marfurt-Russenberger K, Von der Weid N, et al. When parents face the death of their child: a nationwide cross-sectional survey of parental perspectives on their child's end-of life care. *BMC Palliative Care* 2016; 15 (1): 1-14.
- Zhu Y, Enguídanos S. When patients say they know about palliative care, how much do they really understand? *Journal of Pain and Symptom Management* 2019; 58 (3): 460-464.
- Zawistowski CA, Black C, Spruill TM, Granowetter L. Parental Knowledge and Opinions on Palliative Care for Children. *Pediatrics* 2018; 141 (1_Meeting-Abstract): 385-385.
- Westerlund C, Tishelman C, Benkel I, Fürst CJ, Molander U, Rasmussen BH, et al. Public awareness of palliative care in Sweden. *Scandinavian Journal of Public Health* 2018; 46 (4): 478-487.
- Levine DR, Mandrell BN, Sykes A, Pritchard M, Gibson D, Symons HJ, et al. Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Pediatric Oncology. *JAMA Oncology* 2017; 3 (9): 1214–1220.
- Boonchuaylua P, Kongvattananon P, Somprasert C. Parental View of Palliative Care in Children with Cancer: Integrative Review. *The Bangkok Medical Journal* 2018; 14 (2): 101-107.
- Sisk BA, Friedrich A, Blazin LJ, Baker JN, Mack JW, DuBois J. Communication in pediatric oncology: a qualitative study. *Pediatrics* 2020; 146 (3): e20201193.
- Tenniglo LJA, Loeffen EAH, Kremer LCM, Font-Gonzalez A, Mulder RL, Postma A, et al. Patients' and parents' views regarding supportive care in childhood cancer. *Supportive Care in Cancer* 2017; 25 (10): 3151-3160.
- Sisk BA, Schulz GL, Blazin LJ, Baker JN, Mack JW, DuBois JM. Parental views on communication between children and clinicians in pediatric oncology: a qualitative study. *Supportive Care in Cancer* 2021; 29 (9): 4957-4968.
- Singh RK, Raj A, Paschal S, Hussain S. Role of communication for pediatric cancer patients and their family. *Indian Journal of Palliative Care* 2015; 21 (3): 338-340.
- Badarau DO, Ruhe K, Kühne T, De Clercq E, Colita A,

- Elger BS, et al. Decision making in pediatric oncology: Views of parents and physicians in two European countries. *AJOB Empirical Bioethics* 2017; 8 (1): 21-31.
16. Johnston EE, Molina J, Martinez I, Dionne-Odom JN, Currie ER, Crowl T, et al. Bereaved parents' views on end-of-life care for children with cancer: Quality marker implications. *Cancer* 2020; 126: 3352-3359.
 17. Juárez-Villegas LE, Altamirano-Bustamante MM, Zapata-Tarrés MM. Decision-Making at End-of-Life for Children With Cancer: A Systematic Review and Meta-Bioethical Analysis. *Frontiers in Oncology* 2021; 11: 739092.
 18. van der Geest IMM, van den Heuvel-Eibrink MM, van Vliet LM, Pluijm SMF, Streng IC, Michiels EMC, et al. Talking about death with children with incurable cancer: perspectives from parents. *The Journal of Pediatrics* 2015; 167 (6): 1320-1326.
 19. Kuan GL, Low WY. Parents' perspectives on the important aspects of care in children dying from life limiting conditions: a qualitative study. *Med J Malaysia* 2015; 70 (5): 295-299.
 20. Jalmsell L, Lövgren M, Kreicbergs U, Henter JI, Frost BM. Children with cancer share their views: tell the truth but leave room for hope. *Acta Paediatrica* 2016; 105 (9): 1094-1099.
 21. Tan AJN, Tiew LH, Shorey S. Experiences and needs of parents of palliative paediatric oncology patients: A meta-synthesis. *European Journal of Cancer Care* 2021; 30 (3): e13388.
 22. Huo J, Hong YR, Grewal R, Yadav S, Heller IW, Bian J, et al. Knowledge of palliative care among American adults: 2018 health information national trends survey. *Journal of Pain and Symptom Management* 2019; 58 (1): 39-47.
 23. Motlagh ME, Mirzaei-Alavijeh M, Hosseini SN. Information needs assessment among parents of children with cancer. *Asian Pacific Journal of Cancer Prevention: APJCP* 2019; 20 (6): 1865-1870.
 24. Boakye EA, Mohammed KA, Osazuwa-Peters N, Lee MJ, Slomer L, Emuze D, et al. Palliative care knowledge, information sources, and beliefs: Results of a national survey of adults in the USA. *Palliative & Supportive Care* 2020; 18 (3): 285-292.
 25. Verberne LM, Schouten-van Meeteren AY, Bosman DK, Colenbrander DA, Jagt CT, Grootenhuis MA, et al. Parental experiences with a paediatric palliative care team: a qualitative study. *Palliative Medicine* 2017; 31 (10): 956-963.
 26. Virdun C, Brown N, Phillips J, Luckett T, Agar M, Green A, et al. Elements of optimal paediatric palliative care for children and young people: an integrative review using a systematic approach. *Collegian* 2015; 22 (4): 421-431.
 27. Eiser C, Eiser JR, Stride CB. Quality of life in children newly diagnosed with cancer and their mothers. *Health and Quality of Life Outcomes* 2005; 3 (1): 1-5.
 28. Matziou V, Perdikaris P, Feloni D, Moshovi M, Tsoumakas K, Merkouris A. Cancer in childhood: Children's and parents' aspects for quality of life. *European Journal of Oncology Nursing* 2008; 12 (3): 209-216.
 29. Abu-Saad Huijer H, Sagherian K, Tamim H, Naifeh Khoury M, Abboud MR. Quality of palliative care in children with cancer in Lebanon. *J Med Liban* 2013; 61 (4): 228-36.
 30. Saad R, Huijer HAS, Noureddine S, Muwakkit S, Saab R, Abboud MR. Bereaved parental evaluation of the quality of a palliative care program in Lebanon. *Pediatric Blood & Cancer* 2011; 57 (2): 310-316.
 31. Mack J, Wolfe J. Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis. *Current Opinion in Pediatrics* 2006; 18 (1), 10-14.
 32. Noyes J, Edwards RT, Hastings RP, Hain R, Totsika V, Bennett V, et al. Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar. *BMC Palliative Care* 2013; 12 (1): 1-17.
 33. Mack JW, Cronin AM, Uno H, Shusterman S, Twist CJ, Bagatell R, et al. Unrealistic parental expectations for cure in poor-prognosis childhood cancer. *Cancer* 2020; 126: 416-424.
 34. Wolfe J, Klar N, Grier HE, Duncan J, Salem-Schatz S, Emanuel EJ, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA* 2000; 284 (19): 2469-2475.
 35. Yeh CH, Chang CW, Chang PC. Evaluating quality of life in children with cancer using children's self-reports and parent proxy reports. *Nursing Research* 2005; 54 (5): 354-362.
 36. Mack JW, Cook EF, Wolfe J, Grier HE, Cleary PD, Weeks JC. Understanding of prognosis among parents of children with cancer: parental optimism and the parent-physician interaction. *Journal of Clinical Oncology* 2007; 25 (11): 1357-1362.
 37. Fisher V, Fraser L, Taylor J. Experiences of fathers of

- children with a life-limiting condition: a systematic review and qualitative synthesis. *BMJ Supportive & Palliative Care*. Epub ahead of print: 17 June 2021.
38. Al-Gharib RM, Abu-Saad Huijjer H, Darwish H. Quality of care and relationships as reported by children with cancer and their parents. *Ann Palliat Med* 2015; 4 (1): 22-31.
 39. Lövgren M, Udo C, Alvariza A, Kreichbergs U. Much is left unspoken: Self-reports from families in pediatric oncology. *Pediatric Blood & Cancer* 2020; 67 (12): e28735.
 40. Shalev A, Phongtankuel V, Kozlov E, Shen MJ, Adelman RD, Reid MC. Awareness and misperceptions of hospice and palliative care: a population-based survey study. *American Journal of Hospice and Palliative Medicine* 2018; 35 (3): 431-439.
 41. Kelly KP, Pyke-Grimm K, Stewart JL, Hinds PS. Hypothesis generation for childhood cancer communication research: results of a secondary analysis. *Western Journal of Nursing Research* 2014; 36 (4): 512-533.
 42. Williams LK, McCarthy MC, Eyles DJ, Drew S. Parenting a child with cancer: Perceptions of adolescents and parents of adolescents and younger children following completion of childhood cancer treatment. *Journal of Family Studies* 2013; 19 (1): 80-89.
 43. Kars MC, Grypdonck MH, van Delden JJ. Being a parent of a child with cancer throughout the end-of-life course. *Oncology Nursing Forum* 2011; 38 (4): E260-E271.
 44. Viola A, Taggi-Pinto A, Sahler OJZ, Alderfer MA, Devine KA. Problem-solving skills, parent-adolescent communication, dyadic functioning, and distress among adolescents with cancer. *Pediatric Blood & Cancer* 2018; 65 (5): e26951.
 45. Greenzang KA, Cronin AM, Mack JW. Parental preparedness for late effects and long-term quality of life in survivors of childhood cancer. *Cancer* 2016; 122 (16): 2587-2594.
 46. Kaye E, Mack JW. Parent perceptions of the quality of information received about a child's cancer. *Pediatric Blood & Cancer* 2013; 60 (11): 1896-1901.
 47. Ramirez LY, Huestis SE, Yap TY, Zyzanski S, Drotar D, Kodish E. Potential chemotherapy side effects: what do oncologists tell parents? *Pediatric Blood & Cancer* 2009; 52 (4): 497-502.
 48. Pöder U, Ljungman G, von Essen L. Parents' perceptions of their children's cancer-related symptoms during treatment: a prospective, longitudinal study. *Journal of pain and symptom management* 2010; 40 (5): 661-670.
 49. Carlsson T, Kukkola L, Ljungman L, Hovén E, von Essen L. Psychological distress in parents of children treated for cancer: An explorative study. *PloS One* 2019; 14 (6): e0218860.
 50. Tutelman PR, Chambers CT, Stinson JN, Parker JA, Fernandez CV, Witteman HO, et al. Pain in children with cancer. *The Clinical Journal of Pain* 2018; 34 (3): 198-206.
 51. Haraldstad K, Sørnum R, Eide H, Natvig GK, Helseth S. Pain in children and adolescents: prevalence, impact on daily life, and parents' perception, a school survey. *Scandinavian Journal of Caring Sciences* 2011; 25 (1): 27-36.
 52. Al-Gamal E, Long T, Shehadeh J. Health satisfaction and family impact of parents of children with cancer: a descriptive cross-sectional study. *Scandinavian Journal of Caring Sciences* 2019; 33 (4): 815-823.
 53. Keiza EM, Chege MN, Omuga BO. Assessment of parents' perception of quality of pediatric oncology inpatient care at Kenyatta National Hospital. *Asia-Pacific Journal of Oncology Nursing* 2017; 4 (1): 29-37.
 54. Groh G, Borasio GD, Nickolay C, Bender HU, von Lütichau I, Führer M. Specialized pediatric palliative home care: a prospective evaluation. *Journal of Palliative Medicine* 2013; 16 (12): 1588-1594.
 55. Hockenberry M, Haugen M, Slaven A, Skeens M, Patton L, Montgomery K, et al. Pediatric Education Discharge Support Strategies for Newly Diagnosed Children With Cancer. *Cancer Nursing* 2021; 44 (6): E520.
 56. Tiozzo E, Fondi S, Biagioli V, Piccinelli E, Alibrandi F, Gawronski O, et al. Electronic Assessment and Tracking of Pain at Home: A Prospective Study in Children With Hematologic or Solid Tumors. *Journal of Pediatric Oncology Nursing* 2021; 38 (2): 82-93.
 57. Twycross A, Parker R, Williams A, Gibson F. Cancer-Related Pain and Pain Management: Sources, Prevalence, and the Experiences of Children and Parents. *Journal of Pediatric Oncology Nursing* 2015; 32 (6): 369-384.
 58. Molloy MA, DeWitt ES, Morell E, Reichman JR, Brown DW, Kobayashi R, et al. Parent-Reported Symptoms and Perceived Effectiveness of Treatment in Children Hospitalized with Advanced Heart Disease. *J Pediatr* 2021; 238: 221-227.

59. Donnelly JP, Downing K, Cloen J, Fragen P, Gupton AW, Misasi J, et al. Development and assessment of a measure of parent and child needs in pediatric palliative care. *Journal of Pain and Symptom Management* 2018; 55 (4): 1077-1084.
60. Mack JW, Joffe S, Hilden JM, Watterson J, Moore C, Weeks JC, et al. Parents' views of cancer-directed therapy for children with no realistic chance for cure. *Journal of Clinical Oncology* 2008; 26 (29): 4759-4764.
61. McKenna K, Collier J, Hewitt M, Blake H. Parental involvement in paediatric cancer treatment decisions. *European Journal of Cancer Care* 2010; 19 (5): 621-630.
62. Greenzang KA, Al-Sayegh H, Ma C, Najafzadeh M, Wittenberg E, Mack JW. Parental considerations regarding cure and late effects for children with cancer. *Pediatrics* 2020; 145 (5): e20193552.
63. Huang IC, Kenzik KM, Sanjeev TY, Shearer PD, Revicki DA, Nackashi JA, et al. Quality of life information and trust in physicians among families of children with life-limiting conditions. *Patient Related Outcome Measures* 2010; 1: 141-148.
64. Tomlinson D, Bartels U, Gammon J, Hinds PS, Volpe J, Bouffet E, et al. Chemotherapy versus supportive care alone in pediatric palliative care for cancer: comparing the preferences of parents and health care professionals. *CMAJ* 2011; 183 (17): E1252-E1258.
65. Commodari E. Children staying in hospital: a research on psychological stress of caregivers. *Italian Journal of Pediatrics* 2010; 36 (1): 40.
66. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Parents' roles in decision making for children with cancer in the first year of cancer treatment. *Journal of Clinical Oncology* 2011; 29 (15): 2085-2090.