EUROPEAN JOURNAL OF CANCER 47 (2011) 2182–2187

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Factors affecting treatment choices in paediatric palliative care: Comparing parents and health professionals

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ARTICLE INFO

Article history:
Available online 12 June 2011

Keywords:
Children
Parent
Healthcare professional
decision-making
Palliative
End-of-life
Chemotherapy
Supportive care
Factors

ABSTRACT

Study aim: When children with cancer are no longer curable, parents often need to decide between further aggressive treatments or symptom relief alone. Objectives were to: (1) Describe and compare factors influencing parent and healthcare professional (HCP) decision-making regarding the choice between chemotherapy versus supportive care alone in paediatric palliative care; and (2) Describe how these factors influence this choice.

Methods: Participants included parents of children with cancer without a reasonable chance of cure and health care professionals in paediatric oncology. Respondents were asked to indicate the preferred option and to report what factors affected their choice. Each factor was then rated on an importance visual analogue scale (VAS) ranging from 0 to 10. The importance scales were compared between parents and HCPs and the influence of importance ratings on preferred option was examined.

Results: A total of 77 parents and 128 health care professionals participated. For parents the median importance scores for hope, increased survival time and child quality of life were rated as most important (VAS score = 10). Parents rated these factors to be significantly more important than HCPs. Conversely, HCPs rated financial considerations more important than parents. For HCPs, stronger importance ranking for parent opinion was associated with stronger preference for aggressive chemotherapy.

Conclusion: Hope, increased survival time and child quality of life are all more important factors to parents when decision-making at end-of-life compared to HCPs. Conversely, HCPs place greater emphasis on the families' financial considerations than parents. Understanding these differences may aid in communication and improve end-of-life care for children with cancer.

1. Introduction

Despite the remarkable improvements in cure rates for children with cancer, a significant number of children will show resistance to conventional therapy and many will die.[1] Cancer remains the second most common cause of death for North American children between 1 and 14 years of age (after injuries).[2,3] Children who are refractory to conventional therapy eventually will be considered to no longer have a reasonable chance of cure and parents may be provided with an

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doi:10.1016/j.ejca.2011.04.038

opportunity to consider different therapeutic options.[4] Broadly, these parents often have to make decisions concerning approaches to palliative care with the possibility of accepting further aggressive treatments, or to accept symptom relief alone.[4]

Decision-making in health care and palliative care have been increasingly emphasised,[5–9] with more recent efforts attempting to gain insight to decision-making in the paediatric oncology setting.[10–15] Collaborative approaches to decision-making in cancer care between patients, parents and health care professionals (HCP) have also been highlighted.[6,16,17] The choice between therapeutic options available for children with cancer entering a palliative phase of disease presents one of the most difficult decisions for parents.[17] However, very little remains to be known about what factors are important to parents and HCPs, whether the importance of these factors differ between the two groups and how these factors influence parental preferences regarding aggressive treatment at the end-of-life.

The conduct of research and recruitment of participants for paediatric palliative care is often challenging[18] which have meant a dependence on retrospective reporting of palliative care.[19] Understanding the decision-making process during the palliative phase would help to target strategies that could make this process easier for parents. Prospective conduct of such research would ensure that recall bias did not influence the results. Therefore, our study investigated the prospective decision-making process for parents who may be in the position of choosing between supportive care alone or further aggressive chemotherapy.

The objectives were: (1) To describe and compare factors influencing parent and HCP decision-making regarding the choice between chemotherapy versus supportive care alone in paediatric palliative care; and (2) To describe how these factors influence the choice between chemotherapy versus supportive care.

2. Patients and methods

This was a cross-sectional study in which parents of children with cancer considered to have no realistic chance of cure and HCPs working in paediatric oncology were interviewed. This report was a component of a larger study that focused on strength of preference for aggressive treatment for children with cancer.[20,21]

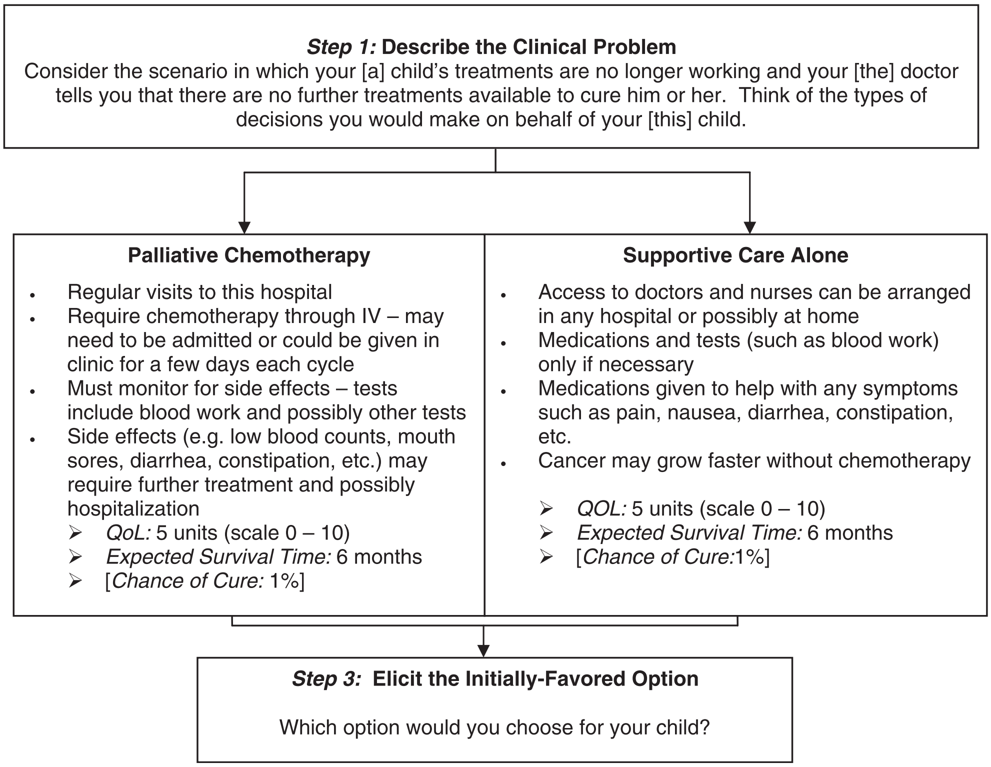
2.1. Study participants

Parents of children ($\leqslant$18 years of age) considered to have no reasonable chance of cure (<5% chance of long term survival) according to their attending physician, and who were not at a point of actual decision-making were evaluated for study eligibility. Inclusion criteria were the ability to speak and read English, and the provision of informed consent.

For HCPs, we included staff physicians practicing paediatric oncology, senior fellows with at least one year of dedicated paediatric oncology training, nurses and social workers who worked exclusively with children with cancer.

2.2. Overall study design

The Research Ethics Board at The Hospital for Sick Children approved this study, and written informed consent was obtained from all participants. A single research nurse (DT)



***Step 1:* Describe the Clinical Problem**

Consider the scenario in which your [a] child's treatments are no longer working and your [the] doctor tells you that there are no further treatments available to cure him or her. Think of the types of decisions you would make on behalf of your [this] child.

Palliative Chemotherapy

- Regular visits to this hospital
- Require chemotherapy through IV – may need to be admitted or could be given in clinic for a few days each cycle
- Must monitor for side effects – tests include blood work and possibly other tests
- Side effects (e.g. low blood counts, mouth sores, diarrhea, constipation, etc.) may require further treatment and possibly hospitalization
  - ➢ *QoL:* 5 units (scale 0 – 10)
  - ➢ *Expected Survival Time:* 6 months
  - ➢ [*Chance of Cure:* 1%]

Supportive Care Alone

- Access to doctors and nurses can be arranged in any hospital or possibly at home
- Medications and tests (such as blood work) only if necessary
- Medications given to help with any symptoms such as pain, nausea, diarrhea, constipation, etc.
- Cancer may grow faster without chemotherapy
  - ➢ *QOL:* 5 units (scale 0 – 10)
  - ➢ *Expected Survival Time:* 6 months
  - ➢ [*Chance of Cure:*1%]

***Step 3:* Elicit the Initially-Favored Option**

Which option would you choose for your child?

Fig. 1 – Setting up the threshold technique – parents' version [HCPs' version].

conducted all interviews, using kits with prepared scripts and visual aids that had been previously pilot-tested. The parent interviews were conducted in the inpatient or outpatient setting, or in the participant's home, according to their wishes. Responses from only one parent per child were included in this analysis as responses from two parents of the same child are not independent. Data from the 13 parents who both participated will be presented separately.

Parents were presented with the following: 'Consider the scenario in which your child's treatments are no longer working and your doctor tells you that there are no further treatments available to cure him or her. Think of the types of decisions you would make on behalf of your child.' It was emphasised that all presented information was hypothetical. HCPs were asked to consider a hypothetical situation in which they were caring for such a patient.

Next, the two relevant therapeutic options, palliative chemotherapy and supportive care alone, were outlined (see Fig. 1). We understand that types of palliative chemotherapy can vary considerably; here, we defined palliative chemotherapy as cytotoxic medications administered intravenously, because we were most interested in aggressive therapies. We listed for both options two (for parents) or three (for HCPs) therapeutic attributes. The *anticipated level of child QoL* was set at five for both options, and illustrated on a 0-cm (worst possible) to 10-cm (best possible) visual analogue scale (VAS). The *expected duration of survival time* was set at 6 months for both options, and illustrated on a 0-month to 12-month VAS. The *probability of cure* was only illustrated for HCPs and was set at 1% for both options. It was represented using a figure of a 'gumball machine' containing 99 black gumballs and one white gumball (see Fig. 2). The decision to not show this attribute to parents was based upon the results of a focus group that included parents who had lost a child to cancer.[22]

The respondent was asked to indicate which treatment option he or she would favour if actually faced with this decision. Respondents were also asked to report the factors that affected their choice of the initially-favoured option by being shown a list of potential factors. Each of these reported factors had earlier been derived from the focus group of parents who had lost a child to cancer.[22] Each factor was ranked and then rated on an importance 10-cm VAS which ranged from 0 = 'least important' to 10 = 'most important'. Respondents were also asked to add any factors that they considered relevant that were not included on our list.

2.3. Statistics

Importance VAS were described for factors influencing parent and HCP decision-making regarding the choice between chemotherapy versus supportive care alone for children who are unlikely to be cured of cancer. These values were compared using the Wilcoxon rank sum test. In order to determine how these factors influence the choice between chemotherapy versus supportive care, univariate logistic regression analysis was conducted. All statistical analyses were performed using the SAS statistical programme (SAS-PC, version 9.1; SAS Institute Inc., Cary, NC). All tests of significance were two-sided, and statistical significance was defined as $P < .05$.

Fig. 2 – Gumball machine illustration used to represent chance of cure. Black ball represents percentage of chance of cure (1%).

3. Results

Between June 1, 2005 and October 22, 2009, 115 potentially eligible parents were identified. Fourteen children died before a parent could be approached. Two children were considered too medically unstable, eight families were considered too emotionally overwhelmed, and one child was transferred to another hospital before the parent could be approached. Twelve families refused to participate. At the start of one interview, the child became unwell and the parent was unable to continue, leaving 77 parents who participated.

Distributions of age, gender, or diagnosis did not differ between participants and non-participants (data not shown). Amongst the 77 interviews, 31 were conducted in the inpatient setting, 43 in the outpatient setting and three were conducted in the family's home. For HCPs, 129 were approached; one refused, leaving 128 who participated.

Table 1 describes the attributes of the parents and their children. The majority of parents were female (77.9%). Almost half of the children had received intravenous chemotherapy within 4 weeks of the interview. For HCPs, 19/128 (14.8%) were male and the median age was 34.2 (interquartile range (IQR) 28.9, 41.4) years. They had been working with children with cancer for a median of 7.0 (IQR 3.0, 14.0) years. Of these, 13 (10.2%) were staff physicians, 12 (9.4%) were senior fellows, 97 (75.8%) were nurses and 6 (4.7%) were social workers.

Table 2 describes the factors that influenced decision-making regarding chemotherapy versus supportive care alone as measured on the importance VAS. Parents had median VAS scores of importance of 10 (maximum possible) for factors of hope (IQR 8.7, 10.0), increased survival time (IQR 9.0, 10.0) and their child's quality of life (QoL) (IQR 9.8, 10). The highest HCP

Table 1 – Characteristics of parents of paediatric palliative care patients.

	N = 77
Parent characteristics	
No. male (%)	17 (22.1%)
Median age in years (IQR)	40.0 (35.7, 45.3)
No. married (%)	65 (84.4%)
No. maximum education (%)	
High school	23 (29.9%)
College/university	42 (54.6%)
Professional/graduate degree	12 (15.6%)
Child characteristics	
No. male (%)	48 (62.3%)
Median age in years (IQR)	8.6 (6.2, 13.3)
Median years since diagnosis (IQR)	1.6 (0.8, 2.6)
No. with following cancer diagnoses (%)	
Leukaemia	18 (23.4%)
Lymphoma	3 (3.9%)
Solid tumour	32 (41.6%)
Brain tumour	24 (31.2%)
No. relapse (%)	56 (72.7%)
No. treatments last 4 weeks (%)*	
Intravenous chemotherapy	34 (44.2%)
Oral chemotherapy	19 (24.7%)
Inpatient chemotherapy	16 (20.8%)
Radiation	13 (16.9%)

Abbreviations: IQR – interquartile range.

* Children may have received more than one type of therapy.

importance scores were for the child's QoL with a median score of 9.8 (IQR 9.5, 10.0). Parents rated hope, increased survival time and child's QoL significantly more important in comparison to HCPs. Qualitatively, amongst the factors considered important by parents, the largest difference between parent and HCPs scores was seen with hope, in which HCPs rated its importance as 8.3 (IQR 6.9, 9.8). Conversely, HCPs rated financial considerations significantly more important than parents.

Similar to the importance ratings, we also examined the raw rankings of factors. For parents, the top ranked factors were hope (median rank of 2) and child QoL (median rank of 2) followed by increased survival time (median rank of 3). Conversely, for HCPs, the highest ranked factor was child QoL (median rank 1) followed by survival time (median rank 2). Both hope and other family QoL had a median rank of 4. Amongst HCPs, the opinion of the parent only had a median rank of 5.

The most common factors added by respondents, that had not been included on our original list, were 'child opinion' (HCP, *n* = 16; parents, *n* = 9) and 'religion/faith/spirituality' (HCP, *n* = 5; parents, *n* = 10). Other factors reported were duration of illness, previous experience of illness and experimental treatments.

The proportion of respondents who favoured chemotherapy was (42/77, 54.5%) for parents and (20/128, 15.6%; $P < .0001$) for HCPs. Table 3 illustrates the influence of these factors on the choice between palliative chemotherapy versus supportive care alone. In this Table, an odds ratio greater than one means that as the importance VAS increased (the factor was rated as more important to decision-making), the odds of choosing intravenous chemotherapy rather than supportive care alone increased. HCPs that placed greater importance on parent opinion were significantly more likely to choose aggressive chemotherapy.

4. Discussion

We found from parents' perspective that hope, increased survival time and child's QoL were the three most important factors considered in making the decision between aggressive chemotherapy and supportive care alone. We also found that all three factors were significantly more important to parents as compared to HCPs. In particular, hope was top ranked amongst parents whilst hope only ranked fourth in importance to HCPs.

We identified that hope was a key factor for decision-making amongst parents. Hope, often linked with both increased survival time and with enhancing QoL, has been reported in the literature as important for patients with cancer and for caregivers,[23,24] with patients and parents wanting to maintain a sense of hope despite acknowledging the terminal nature of their illness.[24,25] In concordance with our results, regarding hope in decision-making, parents have identified their role as bearers of hope when their child was dying.[10,26] Equally, others have reported that hope was seen by HCPs to contradict acceptance of the reality of the prognosis,[26] which may explain the lower ranking of this factor amongst HCPs in our study.

A descriptive study by Hinds and colleagues reported on decision-making factors considered by parents and HCPs in the care of children with cancer.[17] A total of 65 factors were identified by parents and 36 by HCPs. Hope was not cited as a factor, though only the top 13 rated as 'most important' were reported. Interestingly the two highest scoring factors

Table 2 – Factors influencing decision of intravenous chemotherapy versus supportive care as measured using an importance visual analogue scale.

	Median parents' scores (IQR) N = 77	Median healthcare providers' scores (IQR) N = 128	*P* values
Hope	10.0 (8.7, 10.0)	8.3 (6.8, 9.8)	<.0001
Increased survival time	10.0 (9.0, 10.0)	9.4 (8.6, 9.9)	.0002
Child quality of life	10.0 (9.8, 10.0)	9.8 (9.5, 10.0)	.006
Other family member quality of life	7.6 (5.1, 9.9)	8.4 (7.1, 9.2)	.222
Financial considerations	2.9 (1.0, 6.5)	5.8 (3.9, 7.2)	.0001
Parent opinion	–	7.8 (6.8, 9.0)	–
Healthcare provider opinion	8.0 (5.0, 9.8)	–	–

Table 3 – Influence of factors on choice between intravenous chemotherapy versus supportive care alone as measured using an importance visual analogue scale[a].

	Parents (*N* = 77)			Healthcare professionals (*N* = 128)		
	OR	95% CI	*P*	OR	95% CI	*P*
Hope	1.339	(0.96, 1.86)	0.083	1.259	(0.94,1.68)	0.117
Increased survival time	0.868	(0.61, 1.24)	0.432	0.863	(0.61,1.23)	0.417
Child quality of life	0.596	(0.25, 1.40)	0.235	0.744	(0.36, 1.53)	0.423
Other family member quality of life	0.967	(0.82, 1.14)	0.679	0.869	(0.68, 1.10)	0.251
Financial considerations	0.901	(0.78, 1.04)	0.152	1.223	(0.97, 1.54)	0.085
Parent opinion				1.883	(1.22, 2.92)	0.005[b]
Healthcare provider opinion	1.070	(0.92, 1.24)	0.380			

[a] An odds ratio greater than one means that as the importance VAS increased (the factor was rated as more important to decision-making), the odds of choosing aggressive chemotherapy rather than supportive care alone increased.

[b] HCPs who said parent opinion was more important to them were significantly more likely to choose chemotherapy.

for parents were ‘recommendations received from HCPs’ and ‘things my child said about continuing or not continuing treatment’. The preference of the child was not included in our initial list of potential factors as this was not identified as a potential factor affecting treatment choices in our original focus group of parents. Also, only 9 parents and 16 HCPs added the factor of ‘child’s opinion’ to the original list during this study. In contrast, we found, in our larger study, that child’s opinion was of high importance in palliative care decision-making.[21] It is possible that parents in our study incorporate their child’s preference with their own preference in decision-making.

Financial considerations were thought to be more important by HCPs than parents. However, parents of children who had died of cancer suggest that they were affected greatly by financial concerns.[22,27,28] Similarly, it is interesting that our original focus group identified financial considerations, such as depletion due to out-of-work, trips to hospital etc., as an important factor contributing to treatment choices whilst parents enrolled on our study did not believe financial considerations to be very important. It is possible that financial considerations is an issue that only becomes fully appreciated following a child’s death as opposed to prospectively, whilst receiving treatment. In other words, retrospective reporting may assign higher importance to financial concerns, when parents whose child has died of cancer have had time to reflect on the process. This hypothesis may also explain why HCPs considered the families’ financial considerations more important than parents themselves. Our prospective reporting, when a child is receiving palliative care, suggests that parents are not focused on financial concerns at that time. However, if both prospective and retrospective results are considered together, they suggest that whilst parents may not request financial assistance during the palliative phase, system processes that reduce financial strain may have long-term benefit for the family.

Understanding the factors that parents consider important in making end-of-life decisions can facilitate communication and may help to understand why differences in opinion between parents and HCPs may occur. Whilst it is well recognised that parents need to remain hopeful, the HCP is facing the challenge to allow hope whilst presenting realistic prognostic information about QoL and survival time.

Limitations of our study include the potential for selection bias, since only 76 of 114 identified families participated. However, characteristics of age, gender or diagnosis did not differ between participants and non-participants. Our study also may have issues with generalisability since participants were recruited from a single Canadian centre, although it is situated in a large urban multicultural city. Furthermore, although the participating families in our study had a child with no reasonable chance of cure, we presented hypothetical decision-making situations for parents to consider. This may have a different effect for parents than if they were to decide in reality. However, we believe that the respondent stated preferences still provides insight into the decision-making process.

Future, prospective studies should focus on decision-aids to assist families in clarifying the factors important to them in decision-making. Additionally, perspectives of older children themselves are an important issue to examine.

In conclusion, we found that parents consider hope, increased survival time and child quality of life most important and more important than HCPs when deciding between palliative chemotherapy and supportive care alone for children with no realistic chance of cure. Consequently, we suggest that HCPs explicitly address hope, survival and QoL during the decision-making process and help families appreciate how both parents value these factors when arriving at treatment decisions. We believe honest communication, implementing these important aspects during a difficult decision process, will result in more satisfactory informed decisions for parents and HCPs in the interest of the child. Decision-aids to help parents clarify which attributes are most important to them may facilitate decision-making.

Conflict of interest statement

None declared.

Acknowledgements

This research is funded by a Canadian Cancer Society (grant #016388). In addition, LS is supported by a New Investigator Award from the Canadian Institutes of Health Research (Grant no. 87719). The study sponsor has no responsibility for this manuscript.

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