Bereaved parent's satisfaction with home-based pediatric palliative care: Finding from Poland

Aleksandra Korzeniewska-Eksterowicz^{1,2*}, Łukasz Przysław^{1,2}, Bogna Kędzierska^{2,3}, Małgorzata Cynker-McCarthy²,
Małgorzata Stolarska^{2,4} and Wojciech Młynarski⁴

¹Pediatric Palliative Care Unit, Department of Pediatrics, Oncology, Hematology and Diabetology, Medical University of Lodz, 36/50 Sporna str, 91-738 Łódź, Poland

²Gajusz Foundation – Pediatric Palliative Care Centre, Home Hospice for Children of Lodz Region, 17 Piotrkowska str, 90-406 Lodz, Poland.

³Institute of Psychology, University of Lodz 10/12 Smugowa str., 91-433 Lodz, Poland

⁴Department of Pediatrics, Oncology, Hematology and Diabetology, Medical University of Lodz, 36/50 Sporna str, 91-738 Łódź, Poland

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***Corresponding author:** Aleksandra Korzeniewska-Eksterowicz, Pediatric Palliative Care Unit, Department of Pediatrics, Oncology, Hematology and Diabetology 36/50 Sporna str, 91-738 Łódź, Poland, Tel: +48426177791, Fax: +48426177798, Email: aleksandra.korzeniewska-eksterowicz@umed.lodz.pl

Abstract

Background: Measurement of satisfaction with palliative care seems to be a tool evaluating quality of care, especially in pediatric population.

Objective: The aim of this study was the evaluation of care based on satisfaction measured among bereaved parents of patients of Home Hospice for Children of Lodz Region.

Methods: An anonymous questionnaire was posted to the parents of 51 children, who died under hospice care between years 2005-2010. Out of 36 questions 27 were divided into 5 domains: general care evaluation, communication with hospice staff, work of basic staff, conditions of social care, preparation for child's death. For standardization of results transformation of raw results in 100-point scale within 0-100 points was conducted.

Results: 42 completely filled questionnaires were returned and 37 were included in the analysis. The most frequently reason to use hospice care was the lack of possibility of further hospital care. Respondents asked about their fears connected with decision to use hospice care most frequently said that they wouldn't cope with home care. Main expectations connected with hospice care were minimizing the feeling of helplessness. Total value of children's families satisfaction with hospice care was classified as "very good". Average values in all domains excluding the level of preparation for child's death exceeded 75 points significantly. Among the domains which value was classified as "very good" general satisfaction with care and staff-family communication were top classified.

Conclusions: Measurement of satisfaction with palliative care key element which determines the strategy of organization development

Keywords: Pediatric palliative care, parents, bereavement, satisfaction

and requires planning and anticipatory guidance. [1-3] one of the models of PPC is home-based model, but unfortunately extremely little data are available on this topic [4-7].

Modern model of PPC includes monitoring and evaluation of that care but the basic problem in the evaluation of palliative care is finding proper criteria. Measurement of satisfaction with palliative care seems to be a tool evaluating quality of care, especially useful with reference to pediatric population [8,9] In PPC due to the patients' age, type of condition, limited possibilities of communication of patient "soft criteria" (evaluation of symptoms control, quality of life) could be difficult or impossible to apply. [10-12] Evaluation of patients' level of satisfaction with medical care raises the interest of Polish and foreign researchers. [4, 10-13]

In Poland PPC has been mainly provided by specialized palliative home care teams and that home-based model of care is called "home hospice". [11,14] Additional to planned physicians' and nurses' visits, patients have access for telephone consultation 24 - hours a day and intervention visits are always a response to the patient's health deterioration. Visits of psychologist, social worker, physiotherapist and chaplain are planned according to individual needs of each family. Home-based PPC, including medical equipments, in Poland is free of charge - all children are insured.

Home Hospice for Children of Lodz Region (HHChLR) was founded in 2005 and since then has been cared for over 180 children. In Lodz Region (over 2,5 mln inhabitants with 471000 children) there is only one more children hospice and the HHChLR looks after 80% of pediatric population classified for palliative care.

Due to controversy which PPC raises, there is a lack of literature on the satisfaction with that care, especially on home-

Introduction

Pediatric palliative care (PPC) is an interdisciplinary practice

based care. In Poland only one research on this topic has been done so far. [11]

Aim

The aim of this study is the evaluation of care based on satisfaction measured among bereaved parents of patients of HHChLR.

Material and Methods

Survey addressed to the parents/carers of all (n=51) children, who died under HHChLR care between years 2005-2010 has been conducted. Anonymous questionnaire was constructed for the needs of this from a comprehensive literature search, review of validated tools, and clinical experience. A group of six families was convened to test face validity. These questionnaires were validated by checking the logical consistency of individual questions, and different wording was used if necessary. Questionnaire was posted to the recipients, enclosing addressed return envelope. In all the cases the time from child's death to the day of mailing the survey was longer than 3 months.

Questionnaire included 36 closed questions and the socio demographic data. Out of 36 questions 27 were divided into 5 domains: general care evaluation (5 questions), evaluation of communication with hospice staff [7], evaluation of work of basic staff – physician, nurse, social worker [6], evaluation of conditions of social care [5], evaluation of the level of preparation for child's death [4]. Job of a chaplain, psychologist, physiotherapist and volunteers required individual evaluation (4 questions) because of the fact that their service is optional. The remaining 5 questions referred to motivation, fears and expectations of families connected with hospice care. Answers to 31 questions evaluating different aspects of provided care were classified in a few-level scale where higher values referred to better evaluation.

Statistical analysis

For needs of comparative analysis of groups of questions standardization of results through transformation of raw results in 0-100 points scale was conducted, according to formula¹⁵:

$$TR = \frac{RR - Min}{Max - Min} \times 100$$

TR – Transformed result

RR – Raw result

Min – Minimal result possible to achieve in the scale

Max – Maximal result possible to achieve in the scale

In the 100-point scale 0 represented the lowest result, 100 the highest one. The range of points from 0 to 25 was classified as negative, the range from 26 to 50 as satisfactory, results between 51 and 75 points as good, and over 75 points as very good.

To compare study variables two-sided exact Fisher and Student's t-test were used. The result in 100-point scale was dichotomised in 75th point and included in the logistic regression analysis as dependent variable. P-values < 0.05 were considered to be significant. Data was presented as with mean with

95% confidence interval. All analyses were performed using STATISTICA for Windows release 6.0 software and SPSS 11.5.

This study was approved by the Medical Ethics Committee of the Medical University of Lodz (RNN/419/06/KB).

Results

Surveys were directed to parents/carers of all hospice patients who died during analysed period. Out of 51 posted questionnaires 42 (82%) were returned. Out of these 37 correctly completed questionnaires were included in the analysis.

Patients and respondents characteristics are showed in Table 1.

Respondents' motivation, fears and expectations connected with hospice care are shown in Table 2.

Total value of children's families/carers satisfaction with hospice care (the sum of questions in all domains) was classified as "very good". Mean values in all surveyed domains excluding the level of preparation for child's death significantly exceeded 75 points. Detailed results of value of particular domains are presented in Tables 3 and 4.

Out of 37 respondents 15 benefited from spiritual care, 18 of psychological help, 8 of physiotherapist service and 9 of volunteers' support. Almost 30% of families participated in bereaved support groups. Chaplain's job was evaluated as "good" by the 50% of respondents, psychologist's job was classified as "very good" by majority of respondents (67%). No significant relation between value of satisfaction with hospice care and surveyed socio demographic variables (with exception of a domain evaluating basic staff job, where level of satisfaction depended on who filled in the questionnaire) were presented. Evaluation on basic staff job done by grandmothers was more critical than by mothers.

Discussion

Transition to palliative care - especially when care is planned as home-based model - is the most difficult decision for child and their parents during long period of treatment. Presented study showed main fears connected with decision to be transferred to home hospice care. Results of other studies showed positive effects of hospice intervention and support for children with life-limiting illnesses [4,13,16-18]. In opinion of this study authors home-based model of care should be promoted as most suitable for children and their families, as well as cheaper than the inpatient model of care. This opinion accords with the international trends which emphasise the importance of home-based PPC, especially with psychological and social input. [2,19,20] Care and dying at home becomes more and more possible due to the fast development of the symptom management, development of medical techniques and the advancement of PPC [4,21,22]. Main expectations connected with hospice care indicated by respondents are similar to observations of other authors.[4,10,17,23] It is worth noting that in the domain assessing the work of the basic staff respondents evaluated highest effectiveness of the symptoms' management.

Table 1: Respondents and patients characteristics.

	Respondents' characteristics (n=37)	
	n	%
Degree of consanguinity with child		
Mother	27	73
Father	5	13
Grandmother	5	13
Level of education		
Elementary	0	0
Vocational	14	39
Secondary	21	55
Academic	2	6
Place of living		
Village	15	40
Town	8	21
City	14	39
Died patients' characteristics (n=37)		
Cause of death	n	%
Cancer	27	73
Neurologic disorder	8	22
Other life-limiting illness	2	5
Age at the moment of admission to the hospice	Range (min – max)	Mean±SD
	2 months - 18 years	10,27±6,2 years
Duration of hospice care	2 weeks - 31 months	7,13 ±5,4 months

Table 2: Respondents' motivation, fears and expectations connected with hospice care.

Questions and answers' options	Number and percentage of respondents (n=37)	
	n	%
Source of information about hospice		
Physician	20	54
Parents of other ill children	8	22
Acquaintances	1	3
Mass-media	3	8
Internet	5	13
Fears connected with decision to apply hospice care*		
Child will not to be treated	6	14
Child will die faster	8	22
Child would discover the truth about his disease	10	27
Strangers will come to our home		
We wouldn't cope with home care	15	40
Hospice introduces gloomy mood in our home	1	3
Family/friends/neighbors will have a bad opinion about us	5	13

Causes of decisions about applying hospice care*		
Child wanted to stay home	6	14
Awareness of the lack of possibility of further hospital care	16	43
Difficult conditions of stay in hospital ward	4	11
Chance of being close to the child with family in home	13	37
Others	3	8
Expectations connected with hospice care*		
Expectation of limiting child's suffering	14	38
Expectation of child's ensuring their sense of safety	13	37
Minimizing the feeling of helplessness	17	45
Receiving medical help	16	43
Receiving psychological support	10	27
Receiving spiritual support	7	20
Receiving financial support	4	11
Expectation of help connected with settling formalities connected with child's death	7	20
Others	5	13

* Multi choice question – respondents could indicate two options of answers.

Table 3: Detailed results of hospice care satisfaction domains.

Domains	Questions	Answers and evaluation in 0-4 points scale (raw results)					Mean results after transformation to the 100-points scale.
		0	1	2	3	4	
General care	Was the care of child a big organisational load for your family?	yes	rather yes	on average	rather no	no	90,16
	Are you satisfied with hospice care of child?	no	rather no	on average	rather yes	yes	95,36
	Did you receive sufficient information about the care of child?	I didn't receive	I was not interested in	information was sketchy	information were sufficient	information were exhaustive	91,12
	Were there any decisions made by physicians or other hospice team members difficult to accept or inconsistent with yours expectations?	yes	no	-	-	-	90,76
	Was arranging of care caused difficulty for you?	yes	no	-	-	-	88,65
Communication	How do you assess first conversation with hospice team?	information were incomprehensible	my anxiety increased	I was very nervous and I don't remember this conversation	I calmed down	information were comprehensible	89,15
	Did you satisfied with communication with hospice team?	no	rather no	on average	rather yes	yes	92,65
	Was the number of conversations with hospice team sufficient?	no	rather no	on average	rather yes	yes	87,13

	Did you receive sufficient information about child's diagnosis?	I didn't receive	I was not interested in	information were sketchy	information were sufficient	information were exhaustive	89,97
	Did you receive sufficient information about child's disease course and prognosis?	I didn't receive	I was not interested in	information were sketchy	information were sufficient	information were exhaustive	90,48
	Did you receive sufficient information about the best for your child lifestyle?	I didn't receive	I was not interested in	information were sketchy	information were sufficient	information were exhaustive	86,62
	Did you receive sufficient information about child's treatment?	I didn't receive	I was not interested in	information were sketchy	information were sufficient	information were exhaustive	89,24
Work of basic staff	How do you assess effectiveness of symptoms' management?	child often suffered because management of the symptoms was not at all effective	child suffered most of the time and the management brought relief only for a short period of time	child rare suffered and exacerbations of symptoms were able to control after the drugs administration	child was not suffer because of fully effective management	-	90,17
	How do you assess support provided by physicians?	poor	fair	good	very good	excellent	88,40
	How do you assess support provided by nurses?	poor	fair	good	very good	excellent	87,12
	How do you assess support provided by social worker?	poor	fair	good	very good	excellent	86,04
	Did you receive enough of a smile, kindness and courtesy on the part of hospice team?	no	rather no	on average	rather yes	yes	85,35
	Was the frequency of hospice team visits sufficient?	no	rather no	on average	rather yes	yes	85,64
Preparation for child's death	Did you talk with your child about the death?	no	yes	-	-	-	50,00
	Did you feel prepared for child's death?	no	rather no	on average	rather yes	yes	54,67
	How do you assess attendance of hospice team during the last moments of child's life? (if applicable)	was helpful	was embarrassing	I didn't need that	-	-	65,85
	How do you assess assistance from hospice staff in completing the formalities after the death of a child?	negatively	positively	-	-	-	59,52
Conditions of social care	Could the child stay without any embarrassment in a separate room (whenever she/he desires)?	no	rather no	on average	rather yes	yes	83,24
	Was the home equipment facilitated the care of child?	no	rather no	on average	rather yes	yes	87,45
	Did you able to maintain proper cleanliness of the premises?	no	rather no	on average	rather yes	yes	88,34

Did your child have easy access to the toilet?	no	yes	-	-	-	75,30
How do you access your financial costs incurred in connection with the care of a child at home?	The costs exceed our capacity, appropriate care was not possible (despite of the support from the hospice)	The costs exceed our capacity but appropriate care was possible by support from the hospice	The costs did not exceed our capacity	-	-	91,42

Table 4: Evaluation of hospice care satisfaction presented in the 100-points scale result significantly above 75 points.

Domains and range of points in 100-point scale		Number of respondents (%) N=37	Mean±SD (points)	Minimal-maximum results (points)
General care evaluation	Satisfactory (26-50)	1 (2,7)	91,21*±13,80	47-100
	Good (51-75)	2 (5,3)		
	Very good (76-100)	34 (92)		
Evaluation of communication with hospice staff	Good (51-75)	2 (5,3)	89,32*±9,48	65-100
	Very good (76-100)	35 (94,7)		
Evaluation of work of basic staff	Good (51-75)	5 (13,5)	87,12*±11,02	53-97
	Very good (76-100)	32 (86,5)		
Evaluation of conditions of social care	Good (51-75)	7 (18,9)	85,15*±12,23	52-100
	Very good (76-100)	30 (81,1)		
Evaluation of the level of preparation for child's death	Negative (0-25)	2 (5,3)	57,52±20,13	21-98
	Satisfactory (26-50)	13 (35,1)		
	Good (51-75)	15 (40,7)		
	Very good (76-100)	7 (18,9)		
All domains			83,45*±10,76	21-100

High level of satisfaction with hospice care, presented in this study is in accordance with other authors' observations, however, there are small number of studies concerning PPC at home. [4,10,15,18] Respondents highly evaluated communication with hospice staff, what is similar to results of the research conducted previously among staff of HHChLR. [24] Many studies showed that family-staff communication issues are the central aspects of palliative care and a measurement of its is an integral part of complex evaluation of palliative care quality.[4,25-28] Results of other authors' studies showed that parents have emphasized the importance of receiving complete and honest information and having continuous and open access to staff.2. [29-31]

The loss of a child is one of the most stressful life events possible and it is controversial that care provided during the process of dying in comparison with other evaluated domains received low scores. On the one hand it is hard to expect full family preparation for child's death, on the other hand it is duty of hospice team to prepare family for premature and inevitable death of their child. [4,32-33] Nevertheless a positive observation is the high evaluation of attendance of hospice team during the child's death.

The definition of palliative care includes social support for patients. In presented study domain which evaluated conditions of social care received the lowest score among domains classified as "very good". It should be emphasized that social support is not covered by medical insurance and must be funded from other sources - often with the hospice's own resources. Katz et al [34] stated that parents of children with cancer feel more satisfied with social support than parents of chronically ill children, but in this study such relationships were not observed.

Contact with the child's family can not finish at the moment of child's death because it is the most difficult and painful time for them. Many studies identified contact with staff and with other parents who lost child as important for bereaved parents. [18, 25, 26, 28] According to results of this study two fifths of families took part in support groups organized by the hospice.

The limitations of presented survey include lack of comparison with other models of palliative care as the home-based care is dominant in Poland and a small number of participants. However the survey was addressed to all bereaved parents of HHChLR.

Conclusion

Results of presented study are the key element which determines the strategy of hospice development. Specifics of PPC require particular attention to the needs of terminal, incurable patients and people supporting them.

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