



Article scientifique

Article

2023

Appendix

Open Access

This file is a(n) Appendix of:

Palliative care services in paediatric oncology centres across Europe: A
cross-sectional survey

Pedraza, Eddy Carolina; Raguindin, Peter Francis; Hendriks, Manya Jerina; Vokinger, Anna Katharina;
De Clercq, Eva; Rüesch, Katja; Hjorth, Lars; Von Bueren, André; Tinner, Eva Maria; Bergstraesser, Eva;
Wiener, Lori; Michel, Gisela

This publication URL:

<https://archive-ouverte.unige.ch/unige:181648>

Publication DOI:

[10.1016/j.ejcped.2023.100125](https://doi.org/10.1016/j.ejcped.2023.100125)

Online Appendix

Appendix A: Questionnaire	2
Appendix B: Sensitivity analyses	2
Appendix C. Total number of probable institutions eligible for participation, number of institutions approached and number of responses	3
Appendix D. Association of participants' occupation and perceived availability of palliative care services.....	5
Appendix E. Association of participant's occupation and perceived matching of services.....	5
Appendix F: Characteristics of HCPs per participant centre	6
Appendix G: Characteristics of the paediatric oncology centre and other services	7
References:.....	8

Appendix A: Questionnaire

See separate document (PDF)

Appendix B: Sensitivity analyses

We determined the response rate using the respondents' affiliation (numerator) and the reported paediatric oncology centres according to EU report (denominator) [1]. Furthermore, to detect respondent bias, we performed logistic regression on (a) the availability of paediatric palliative care services (dependent variable) and (b) respondents' characteristics (profession and length of service). We also determined the association of hospital characteristics (dependent variable) with the availability of paediatric palliative care services.

We determined the association of (1) the time of paediatric palliative care introduction and the presence of trigger diagnosis (dependent variables) and the (2) frequency, capacity, number of referrals, and length of service of paediatric palliative care (independent variables). In addition, we performed multinomial logistic regression (trigger diagnosis) and multivariate logistic regression (time of palliative care introduction) using penalized maximum likelihood estimation to account for empty cells in the analyses. We performed list-wise deletion for incomplete responses and missing data.

We used the number of paediatric oncology facilities from the EU report to determine the population and describe the overall response rate (**Appendix C**). We estimated a response rate of 49.7% from approximately 318 eligible paediatric oncology centres from the EU [1]. There was a wide disparity among response rate across different regions, with Northern Europe at 85.7%. Western Europe at 62.8%, Eastern Europe at 31.1%, and Southern Europe at 37.2%. No responses were obtained from 4 countries (13% of eligible states).

We reported that 64.5% centres had specialized PPC, but if we include all the paediatric facilities in Europe, then at least 32.8% have specialized PPC in their oncology units. Thus, the true availability of specialized palliative care facilities should be between 30-60% in our region.

We observed no association between the professional profile of the respondents and the response/outcome (**Appendix D**). In addition, we found no association between professional profile and the perception of service capacity (**Appendix E**). As such, we presumed response bias is unlikely.

Appendix C. Total number of probable institutions eligible for participation, number of institutions approached and number of responses

Region	Country	Total Number of institutions contacted (e-mails sent) ^a	Responding institutions	EU and SIOp e-report's paper [1]	Response rate (e-report SIOPe [1])	Palliative Care Service							
						Specialised PPC service ^b		Adult PC ^c		Paediatric PC Provider		No PC for children	
British Isles		n	n	n	%	n	%	n	%	n	%	n	%
	Ireland	1	1	1	100	1	100	0	0	0	0		
	UK	Mailing list	10	20	50.0	8	80	0	0	2	20		
Total			11	21	52.4	9	81.8	0		2	18.2		
Northern Europe		n	n	n	%	n	%	n	%	n	%	n	%
	Denmark	4	3	4	75.0	3	100	0	0	0	0		
	Estonia	Mailing list	0	3									
	Finland	5	2	5	40.0	2	100	0	0	0	0		
	Iceland	Mailing list	0	-									
	Latvia	Mailing list	1	1	100	1	100	0	0	0	0		
	Lithuania	2	1	2	50.0	1	100	0	0	0	0		
	Norway	10	6	-	-	3	50	0	0	3	50		
	Sweden	6	5	6	83.3	1	20	3	60	1	20		
Total			18	21	85.7	11	61	3	16.6	4	22.2		
Southern Europe		n	n	n	%	n	%	n	%	n	%	n	%
	Croatia	Mailing list	2	4	50.0	0	0	0	0	2	100		
	Cyprus	1	1	1	100	1	100	0	0	0	0		
	Greece	Mailing list	5	7	71.4	0	0			5	0		
	Italy	Mailing list	9	~50	18.0	3	33.3	1	11.1	4	44.4	1	11.1
	Malta	1	1	1	100	0	0	0	0	1	0		
	Portugal	4	4	4	100	4	100	0	0	0	100		
	Slovenia	1	1	1	100	1	100	0	0	0	0		
	Spain	40	21	~50	42.0	16	76.1	1	4.7	4	19		
Total			44	~118	37.2	25	56.8	2	4.5	16	36.4	1	2.3
Western Europe		n	n	n	%	n	%	n	%	n	%	n	%
	Austria	5	4	7	57.1	3	75.0	0	0	1	25.0		
	Belgium	8	6	7	85.7	4	66.6	0	0	2	33.3		
	France	Mailing list	10	~30	33.3	4	40	1	10.0	5	50.0		
	Germany	Mailing list	41	~58	70.6	29	70.7	0	0	11	26.8	1	2.4
	Luxembourg	Mailing list	0	1									
	Netherlands	1	1	1	100	1	100	0	0	0	0		
	Switzerland	9	9	9	100	7	77.7	0	0	2	22.2		
Total			71	113	62.8	48	67.6	1	1.4	21	29.5	1	1.4

East Europe		n	n	n	%	n	%	n	%	n	%	n	%
	Bulgaria	Mailing list	0	3									
	Czech Republic	2	1	2	50.0	1	100	0	0	0	0		
	Hungary	9	5	7	71.4	2	40.0	1	20	0	0	2	40
	Poland	25?	2	18	11.1	1	50.0	0	0	1	50.0		
	Romania	Mailing list	3	12	25.0	2	66.6	0	0	0	0	1	33.3
	Slovak Republic	3	3	3	100	3	100	0	0	0	0		
Total			14	45	31.1	9	64.2	1	7.1	1	7.1	3	21.4
Total			158	~318	49.7	102		7		43			

Appendix D. Association of participants' occupation and perceived availability of palliative care services

	Beta coefficient (95% CI)	P value
Specialised paediatric palliative services	Ref	Ref
With adult palliative services	-0.97 (-3.25, 1.29)	0.398
With paediatric palliative care professional	-0.18 (-1.61, 1.25)	0.803
None	11.69 (-1205, 1228)	0.985

Multinomial logistic regression. Betas represent the probability of non-MD (social worker, psychologist nurse) with response compared with MDs (general practice, paediatricians, PC specialists) in logit scale.

Appendix E. Association of participant's occupation and perceived matching of services

	Beta coefficient (95% CI)	P value
Capacity significantly higher	-0.61 (-2.18, 0.96)	0.448
Capacity somewhat higher	-0.20 (-1.50, 1.09)	0.757
Capacity matches	Ref	Ref
Capacity somewhat lower	-0.69 (-1.44, 0.05)	0.070
Capacity significantly lower	-0.33 (-1.66, 0.98)	0.617

Multinomial logistic regression. Betas represent the probability of non-MD (social worker, psychologist nurse) with response compared with MDs (general practice, paediatricians, PC specialists) in logit scale.

Appendix F: Characteristics of HCPs per participant centre

	n	%
Total number of participants	158	100
Profession*		
Paediatric oncologist	133	84
Palliative care specialist	58	37
Paediatrician	38	24
Other	6	4
Social worker	2	1
Psychologist	1	1
Nurse	1	1
General practitioner	1	1
Gender		
Male	65	41
Female	93	59
Experience in Paediatric Oncology		
No experience	3	2
< 1 year	2	1
1-5 years	5	3
6-10 years	20	13
11-15 years	27	17
16-20 years	23	15
> 20 years	78	49
Experience in Paediatric Palliative Care		
No experience	5	3
< 1 year	3	2
1-5 years	21	13
6-10 years	27	17
11-15 years	35	22
16-20 years	23	15
> 20 years	44	28

HCPs: Healthcare providers. *Multi-responses possible

Appendix G: Characteristics of the paediatric oncology centre and other services

	n	%
Transition of PPC to adult service		
Yes	58	38
No	85	56
Do not know	8	5
Availability of pain service		
Yes, the pain service is part of the PPC service	52	33
Yes, but the pain service is separate from PPC service	87	56
No dedicated pain service	15	10
Do not know	1	1
PPC Guidelines		
Yes	85	56
No	65	42
Do not know	3	2
Type of PPC Guideline		
Internal (within hospital)	47	55
Regional	16	19
National	15	18
International	5	6
Other, please specify	2	2
Training for PPC team		
Yes	98	63
No	53	34
Do not know	4	3
<i>If yes, which type of training is offered? *</i>		
Lecture(s)	61	63
Workshop(s)	46	47
Webinars	43	44
Grand rounds presentations	41	43
Other	18	19
Congress	4	4
Postgraduate degree/master degree	7	7
Provision of compassion fatigue to the staff		
Yes	72	47
No	69	45
Do not know	12	8
<i>If yes, which strategies does your cancer centre offer? *</i>		
Group debriefings	52	74
Psychological counselling	48	69
Peer-to-peer discussions	39	56
Spiritual counselling	19	27
Employee's wellness programs (e.g. yoga)	18	26
Educational programs	18	26
Other	9	13
Supervision/mentoring	3	4

PPC: Paediatric Palliative Care. * Multi-responses possible. Some participants might not have answered certain questions such that numbers do not always add up to the total N of 158.

References:

[1] Joint Action on rare cancer. Report summarizing recommendations to facilitate referral of children to trial centers offering innovative medicines. 2019.
<https://ec.europa.eu/research/participants/documents/downloadPublic?documentIds=080166e5c3a66334&appId=PPGMS>