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ORIGINAL ARTICLE

Facilitators and barriers perceptions to early referral to pediatric palliative care perceived

Percepción de facilitadores y barreras para la derivación a cuidados paliativos pediátricos

Annex 1. Measurement instrument

Pediatricians´ perceptions of barriers and facilitators for referrals to Pediatric Palliative Care in Chile

Section 1. Demographic data

For the next questions, answer only one of the following:

1.1 What is your age?

1.2 What is your gender?
Female
Male
Other

1.3 What is your pediatric specialty?
General Pediatrics
Children's Family Medicine
Pediatric Cardiology
Pediatric Pulmonology
Pediatric Neurology
Neonatology
Pediatric Intensive Care
Other (specify):

1.4 How many years have you been practicing as a pediatrician or pediatric subspecialist?

1.5 What clinical setting do you spend most of your working hours in?
100% of my working hours at an inpatient setting
> 50% of my working hours at an inpatient setting
100% of my working hours at an outpatient setting
> 50% of my working hours at an outpatient setting

1.6 On a scale from 0 to 10: How religious do you consider yourself? 0 being "Not religious" and 10 being "Very religious". Mark with an X.

0	1	2	3	4	5	6	7	8	9	10

1.8 On a scale from 0 to 10: How spiritual do you consider yourself? 0 being "Not spiritual" and 10 being "Very spiritual". Mark with an X.

0	1	2	3	4	5	6	7	8	9	10

Section 2. Pediatric Palliative Care in your clinical practice

2.1 Did you receive training in Pediatric Palliative Care during your specialty or subspecialty programme? (If your answer is YES, continue to question 2.2. If your answer is NO, skip to question 2.3)
Yes
No

2.2 If you received Pediatric Palliative Care training, how would you describe the impact on your clinical practice?
Very unhelpful
Unhelpful
Helpful
Very helpful

2.3 During your clinical practice as a pediatrician or pediatric subspecialty, have you directly taken care of patients with pediatric palliative care requirements?
Yes
No
I don't know

2.4 Is there a Pediatric Palliative Care team at your workplace?
Yes
No
I don't know

2.5 Have you ever referred any of your patients to a pediatric palliative care team?
Yes
No
Not to a pediatric team, but I have referred teenagers to an adult palliative care team.
I don´t have a pediatric palliative care team at my center.

Section 3. Perceptions of facilitators and barriers for referrals to Pediatric Palliative Care Teams

In the following section, a series of statements is next to a scale in accordance to your level of agreement as an interviewee. Mark only one option for each statement.

For the following statements, consider Pediatric Palliative Care as "an active total care of the body, mind and spirit of the child, as well as support to the family. It starts upon diagnosis and continues regardless of the child receiving treatment or not for his underlying condition." (WHO)

Strongly disagree
Disagree
Agree
Strongly Agree
I don´t know / I rather not answer

3.1 Patients with life-threatening diseases, regardless of their diagnosis or prognosis, can benefit from PPC

3.2 It is hard for me as a head physician to transfer the responsibility of care of my patients to another team.

3.3 An overlap between the head physician and PPC team could have a negative impact on the care of the patient.

3.4 Early referral to PPC could harm the relationship between the head physician and patient or family

3.5 Optimal care of the patient could be limited by the physician´s need to take control of every aspect of treatment.

3.6 My medical specialty does not promote PPC like other specialties.

3.7 PPC is not compatible with the active or curative treatment of my patients.

3.8 Early exposure to PPC will cause anxiety on parents and families.

3.9 PPC is perceived by patients and their families as a sign that the end-of-life is near

3.10 I perceive PPC as synonymous of end-of-life care or death

3.11 Early introduction of PPC teams could cause an extra burden to the parents

3.12 It is difficult for me to know at which stage during the course of the illness the patients can beneficiate from a referral to CCP

3.13 My emotional relationship with patients and their families influences what treatment options I could offer during relapse or disease progression.

3.14 My emotional relationship with patients and their families influences how I communicate treatment options during relapse or disease progression

3.15 As head physician, I tend to blame myself for patients' death, which in turn might influence my treatment decisions.

3.16 As head physician, I tend to be optimistic in the way I deliver information regarding experimental or 2nd-line treatment options.

3.17 As a pediatrician, it is hard for me to talk about death with my patients and their families.

3.18 During my clinical practice, I don't have enough time to discuss end-of-life care with my patients and families

3.19 Patients avoid reporting symptoms to their head physicians because they fear letting them down.

3.20 I think that parents fear that if they mention the possibility that their child might die, the clinical team can ´´give up´´ on their child.

3.21 It is necessary to produce clinical trials regarding early referral to PPC.

3.22 If PPC are included during the first month after the diagnosis of any life-threatening disease, the potential benefits could surpass the potential risks.

3.23 The head team – and not the PPC team – should manage symptoms related to treatments.

3.24 The head team – and not the PPC team – should manage symptoms related to the illness

3.25 Early referral to PPC of all patients with life-threatening diseases as a standard of care would reduce the anxiety related to referral during the illness' course

3.26 Early integration of PPC would generate less anxiety, in comparison to referral during illness' relapse or progression

3.27 The frequency of PPC team follow-up after the first evaluation should be determined by the head team and according to need.

3.28 Early referral to PPC would mean more detailed management of patient´s symptoms

3.29 Early referral to PPC of patients with potential life-threatening diseases would reduce suffering of patients and their families.

3.30 Quality of life is often not prioritized during curative treatment.

3.31 Early integration of PPC would improve interdisciplinary communication

3.32 Early integration of PPC would improve the patient's and their family´s understanding about their disease.

3.33 If the name of PPC was modified (for example, to Continuum Care) the patient's and family's perception would change.

3.34 Addressing potential misunderstanding from parents regarding the goals of PPC by education by the paediatrician in charge would result in higher CCP acceptance levels

3.35 In order to avoid misunderstandings by parents and their families and to improve referral acceptance, it would be beneficial if the PPC team educated healthcare professionals about the objectives of palliative care.

3.36 Better education of health professionals about PPC is a big step towards improving access to PPC.

3.37 It is hard to find appropriate PPC teams for my patients´ needs

3.38 There is a lack of funding for referral to PPC programs

Annex 2. Perception of statements associated with facilitators for referral to PPC in the group of specialities associated to PPC (n = 78)

Statements associated with facilitators for referral to PPC	Specialities associated to PPC. n (%)			Other specialities. n (%)			*p-value*
	Agree	Disa-gree	UK	Agree	Disa-gree	UK	
Patients with life-threatening diseases, regardless of their diagnosis or prognosis, can benefit from PPC	19 (95)	1 (5)	0 (0)	56 (96.6)	2 (3.4)	0 (0)	> 0.99
It is necessary to produce clinical trials regarding early referral to PPC.	17 (85)	0 (0)	3 (15)	49 (84.5)	4 (6.9)	5 (8.6)	0.6
If PPC are included during the first month after the diagnosis of any life-threatening disease, the potential benefits could surpass the potential risks.	16 (80)	1 (5)	3 (15)	43 (74.1)	5 (8.6)	10 (17.2)	> 0.9
Early integration of PPC would improve interdisciplinary communi-cation	16 (80)	1 (5)	3 (15)	50 (86.2)	3 (5.2)	5 (8.6)	> 0.9
Early integration of PPC would improve the patient's and their family´s understanding about their disease.	15 (75)	3 (15)	2 (10)	48 (82.8)	8 (13.8)	2 (3.4)	> 0.9
If the name of PPC was modified (for example, to Continuum Care) the patient's and family's perception would change.	15 (75)	3 (15)	2 (10)	51 (87.9)	4 (6.9)	3 (5.2)	0.17
Addressing potential misunderstanding from parents regarding the goals of PPC by education by the paediatrician in charge would result in higher CCP acceptance levels	17 (85)	1 (5)	2 (10)	54 (93.1)	2 (3.4)	2 (3.4)	> 0.9
In order to avoid misunderstandings by parents and their families and to improve referral acceptance, it would be beneficial if the PPC team educated healthcare professionals about the objectives of palliative care.	17 (85)	1 (5)	2 (10)	54 (93.1)	2 (3.4)	2 (3.4)	> 0.9
Better education of health professionals about PPC is a big step towards improving access to PPC.	17 (85)	1 (5)	2 (10)	54 (93.1)	2 (3.4)	2 (3.4)	> 0.9
Early referral to PPC of all patients with life-threatening diseases as a standard of care would reduce the anxiety related to referral during the illness' course	14 (70)	1 (5)	5 (25)	42 (72.4)	7 (12.1)	9 (15.5)	> 0.9
Early integration of PPC would generate less anxiety, in comparison to referral during illness' relapse or progression	18 (90)	1 (5)	1 (5)	48 (82.7)	3 (5.2)	7 (12.1)	> 0.9
Early referral to PPC would mean more detailed management of patient´s symptoms	17 (85)	1 (5)	2 (10)	45 (77.6)	6 (10.3)	7 (12.1)	0.8
Early referral to PPC of patients with potential life-threatening diseases would reduce suffering of patients and their families.	17 (85)	1 (5)	2 (10)	47 (81.0)	4 (6.9)	7 (12.1)	> 0.9

PPC: Pediatric palliative care, UK: unknown.

Annex 3. Perception of statements associated with barriers to referral to pediatric palliative care (PPC) in specialities associated to PPC (n = 78)

Statements associated with barriers to CPP referral	Specialities associated to PPC. n (%)			Other specialities. n (%)			*p- value*
	Agree	Disa-gree	UK	Agree	Disagree	UK	
The head team – and not the PPC team – should manage symptoms related to treatments.	5 (25)	13 (65)	2 (10)	27 (46.6)	23 (39.7)	8 (13.7)	0.09
The head team – and not the PPC team – should manage symptoms related to the illness	12 (60)	5 (25)	3 (15)	26 (44.8)	23 (39.7)	9 (15.5)	0.33
Early exposure to PPC will cause anxiety on parents and families.	5 (25)	15 (75)	0 (0)	18 (31)	36 (62.1)	4 (6.9)	0.69
PPC is perceived by patients and their families as a sign that the end-of-life is near	17 (85)	3 (15)	0 (0)	49 (84.5)	7 (12.1)	2 (3.4)	> 0.9
The frequency of PPC team follow-up after the first evaluation should be determined by the head team and according to need.	14 (70)	6 (30)	0 (0)	33 (56.9)	20 (34.5)	5 (8.6)	0.74
Quality of life is often not prioritized during curative treatment.	11 (55)	9 (45)	0 (0)	39 (67.2)	19 (32.8)	0 (0)	0.47
It is hard to find appropriate PPC teams for my patients´ needs	13 (65)	6 (30)	1 (5)	32 (55.2)	16 (27.6)	10 (17.2)	> 0.9
There is a lack of funding for referral to PPC programs	13 (65)	2 (10)	5 (25)	34 (58.6)	7 (12.1)	17 (29.3)	> 0.9
It is hard for me as a head physician to transfer the responsibility of care of my patients to another team.	9 (45)	11 (55)	0 (0)	15 (25.9)	42 (72.4)	1 (1.7)	0.2
An overlap between the head physician and PPC team could have a negative impact on the care of the patient.	4 (20)	16 (80)	0 (0)	16 (27.6)	42 (72.4)	0 (0)	0.72
Early referral to PPC could harm the relationship between the head physician and patient or family	4 (20)	16 (80)	0 (0)	5 (8.6)	50 (86.2)	3 (5.2)	0.37
Optimal care of the patient could be limited by the physician´s need to take control of every aspect of treatment.	10 (50)	9 (45)	1 (5)	26 (44.8)	29 (50)	3 (5.2)	0.89
My medical specialty does not promote PPC like other specialties.	2 (10)	18 (90)	0 (0)	17 (29.3)	38 (65.5)	3 (5.2)	0.11
PPC is not compatible with the active or curative treatment of my patients.	1 (5)	18 (90)	1 (5)	6 (10.3)	50 (86.2)	2 (3.4)	0.85
I perceive PPC as synonymous of end-of-life care or death	5 (25)	15 (75)	0 (0)	24 (41.4)	34 (58.6)	0 (0)	0.29
Early introduction of PPC teams could cause an extra burden to the parents	3 (15)	16 (80)	1 (5)	19 (32.8)	36 (62.0)	3 (5.2)	0.21
It is difficult for me to know at which stage during the course of the illness the patients can beneficiate from a referral to CCP	11 (55)	9 (45)	0 (0)	42 (72.4)	14 (24.1)	2 (3.4)	0.16
My emotional relationship with patients and their families influences what treatment options I could offer during relapse or disease progression.	4 (20)	15 (75)	1 (5)	29 (50)	27 (46.6)	2 (3.4)	0.03*
My emotional relationship with patients and their families influences how I communicate treatment options during relapse or disease progression	5 (25)	15 (75)	0 (0)	26 (44.8)	30 (51.7)	2 (3.4)	0.15
As head physician. I tend to blame myself for patients' death. which in turn might influence my treatment decisions.	2 (10)	18 (90)	0 (0)	15 (25.9)	40 (68.9)	3 (5.2)	0.19
As head physician. I tend to be optimistic in the way I deliver information regarding experimental or 2nd-line treatment options.	4 (20)	15 (75)	1 (5)	18 (31.0)	35 (60.3)	5 (8.6)	0.45
As a pediatrician. it is hard for me to talk about death with my patients and their families.	7 (35)	13 (65)	0 (0)	27 (46.6)	31 (53.4)	0 (0)	0.52
During my clinical practice. I don't have enough time to discuss end-of-life care with my patients and families	7 (35)	13 (65)	0 (0)	23 (39.6)	32 (55.2)	3 (5.2)	0.79
Patients avoid reporting symptoms to their head physicians because they fear letting them down.	3 (15)	16 (80)	1 (5)	11 (19.0)	41 (70.7)	6 (10.3)	0.89
I think that parents fear that if they mention the possibility that their child might die. the clinical team can ´´give up´´ on their child.	10 (50)	10 (50)	0 (0)	27 (46.6)	26 (44.8)	5 (8.6)	> 0.9

*Significant

PPC: Pediatric palliative care. UK: unknown.