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ORIGINAL ARTICLE

Clinical complexity and need for palliative care in non-oncological patients with special health care needs

Complejidad clínica y necesidad de cuidados paliativos en pacientes no oncológicos con necesidades especiales de atención en salud

Supplementary Material 1. PaPaS scale[7,8]

Domain and item number	Item	Characteristic	Score
Domain 1: Trajectory of disease and impact on daily activities of the child			
1.1	Trajectory of disease and impact on daily activities of the child (in comparison with the child's own baseline) (with reference to the last 4 weeks)	Stable	0
		Slowly deteriorating without impact on daily activities	1
		Unstable. With impact on and restriction of daily activities	2
		Significant deterioration with severe restriction of daily activities	4
1.2	Increase of hospital admissions, (> 50% within 3 months, compared to previous periods)	No	0
		Yes	3
Domain 2: Expected outcome of treatment directed at the disease and burden of treatment			
2.1	Treatment directed at the disease, (does not mean treatment of disease related complications, such as pain, dyspnoea or fatigue)	…is curative	0
		...controls diseases and prolongs life with good quality of life	1
		...does not cure or control but has a positive effect on quality of life	2
		...does not control and has no effect on quality of life	4
2.2	Burden of treatment, (Burden means side effects of treatment and additional burdens such as stay in hospital in the patient's or family's view)	No or minimal burden or no treatment is envisioned.	0
		Low level of burden	1
		Medium level of burden	2
		High level of burden	4

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Domain 3: Symptom and problem burden			
3.1	Symptom intensity or difficulty of symptom control (over the last 4 weeks)	Patient is asymptomatic	0
		Symptom(s) are mild and easy to control	1
		Any symptom is moderate and controllable	2
		Any symptom is severe or difficult to control (unplanned hospitalization or outpatient visits, symptom crises)	4
3.2	Psychological distress of patient related to symptoms	Absent	0
		Mild	1
		Moderate	2
		Significant	4
3.3	Psychological distress of parents or family members related to the child's symptoms and distress	Absent	0
		Slight	1
		Moderate	2
		Significant	4
Domain 4: Preferences/needs of patient or parents Preferences of health professional			
4.1	Patient/parents wish to receive palliative care or formulate needs that are best met by palliative care	No	0 (please answer 4.2)
		Yes	4 (do not answer 4.2)
4.2	You/your team feel that this patient would benefit from palliative care	No	0
		Yes	4
Domain 5: Estimated Life Expectancy			
5.1	Estimated life expectancy	Several years	0 (please answer 5.2)
		Months to 1–2 years	1 (please answer 5.2)
		Weeks to months	3 (do not answer 5.2)
		Days to weeks	4 (do not answer 5.2)
5.2	"Would you be surprised if this child were to suddenly die in 6 months time?"	Yes	0
		No	2
		Total score	

Supplementary Material 2. Complexity Guideline for the Comprehensive Management of CYSHCN Technical Guidance 2023. "Short Version"

Low-complexity CYSHCN	
Score: 1-8 points	CYSHCN who are generally stable, and their families have tools that allow them to be self-sufficient in care. This group includes children or adolescents, without significant alterations in their functionality, who may need support or supervision in activities of daily living. The team accompanies and coordinates the different instances of health care, links to support networks, promotes health and detects early intercurrences or deterioration of the underlying condition. The focus is primarily on Primary Health Care (PHC), with one or two follow-up specialists in secondary care.
Medium complexity CYSHCN	
Score: 9-15 points	CYSHCN that are stable but require specific permanent or frequent care to carry out activities of daily living or to overcome situations of disability. The care of this group requires a specialized and multidisciplinary team to solve complex needs. In the current structure of our public health system, care should be located at the secondary health level: a therapeutic diagnostic center, or a health reference center, in charge of a pediatrician or family doctor who centralizes decision-making, in agreement with the family and the child or adolescent.
High complexity CYSHCN	
Score: 16 or more points	CYSHCN with extreme frailty and severe and permanent functional limitations. They frequently require hospitalization due to decompensation of their underlying condition, temporarily or permanently. This group remains in the care of a team for a long time in tertiary care, in neonatology services, pediatrics, critical patient unit, chronic care hospitals or home hospitalization. Multiple medical specialties and other health professionals participate in its care. This group of CYSHCN requires a periodic assessment of their needs to allow the level of care to be flexible when complexity varies, with the aim of maximizing the use of the benefits of the health network.

Three main dimensions: need for complex care, need for respiratory support, and need for technical aids. Each item receives a specific score, and the total sum allows the level of complexity of the patients to be defined as low (≤ 8 points), medium (9-15 points), and high (≥16 points).