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Research Article

Physicians' Perceptions of Children's Right to Information and Decision-Making in Pediatric Oncology: Implications for Palliative Care in Cuba

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Abstract

Children's right to information in pediatric oncology represents a critical intersection of bioethics, clinical practice, and patients' rights. In Cuba, the normative framework—including the Constitution (2019), the Family Code (2022), and Public Health Law No. 165/2023—explicitly recognizes minors' right to information and participation in health decisions; however, the gap between normative recognition and clinical practice remains underexplored. This descriptive cross-sectional study aimed to describe physicians' assessments of patients' right to information in Cuban pediatric oncology from a bioethical perspective, and to identify gaps between normative recognition and clinical practice. A purposive convenience sample of 33 physicians working in Cuban pediatric oncology centers participated voluntarily. A structured questionnaire, designed and validated through expert judgment, was applied; descriptive statistical analysis was performed using absolute and relative frequencies. Results showed that 78.2% of physicians recognized children's and adolescents' right to receive information about their illness. Nevertheless, 56.5% reported giving more weight to parents' assessments of their children's quality of life than to patients' own views in medical decision-making. Moreover, 60.4% acknowledged that minors can offer assessments, although these are rarely considered when modifying treatments, and only 12.1% held postgraduate training in bioethics. These findings reveal the persistence of a paternalistic model in Cuban pediatric oncology and a clinically significant gap between normative recognition and professional practice. The results have direct implications for the integration of pediatric palliative care (PPC) and the development of shared decision-making competencies in PPC teams, underscoring the urgent need for institutional protocols and bioethics training in Cuba's eight reference pediatric oncology centers.

Keywords

Right to Information, Pediatric Oncology, Childhood Cancer, Bioethics, Medical Paternalism, Minor's Autonomy, Pediatric Palliative Care, Shared Decision-making

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1. Introduction

The right to information is an essential component of the physician-patient relationship and a fundamental guarantee recognized in contemporary clinical bioethics. In the specific context of pediatric oncology, this right acquires singular complexity: the patient is a minor whose ability to understand, process, and make decisions based on clinical information varies according to age, cognitive-emotional developmental level, and family context. This complexity places health professionals before high-frequency, high-impact ethical dilemmas that do not always find adequate responses in existing normative frameworks or available professional training [1, 12].

The World Health Organization (WHO) and the International Society of Paediatric Oncology (SIOP) explicitly recognize the right of children with cancer to be informed about their diagnosis, treatment, and prognosis in a manner adapted to their age and maturity. This right is grounded in the principle of progressive autonomy, recognized in the UN Convention on the Rights of the Child [2], ratified by Cuba, which establishes that the child has the right to express their opinion in all matters affecting them, with consideration given to their age and degree of maturity [6, 14, 23].

Scientific literature consistently documents the persistence of paternalistic relational models in pediatric oncology, particularly in Latin American countries. In these models, information flows preferentially toward parents or guardians, relegating the patient to a passive role in decision-making about their health, even in the case of adolescents with full cognitive capacity to participate actively [3, 4]. This practice not only violates minors' rights but may have negative consequences on quality of life, treatment adherence, and the emotional processing of illness [3, 5, 14, 20].

In Cuba, the current normative framework—including the Constitution of the Republic (2019), the Family Code (2022), and Public Health Law No. 165/2023 [13]—recognizes children's and adolescents' rights to information and participation in decisions about their health. However, the gap between normative recognition and daily clinical practice in Cuban pediatric oncology services remains empirically underexplored.

Within the framework of pediatric palliative care (PPC) specifically, the right to information and progressive autonomy are not merely ethical principles but operational dimensions of care quality: shared decision-making, advance care planning adapted to the child, and family communication constitute core competencies of any PPC team aligned with WHO standards [6]. Understanding the current state of physicians' attitudes toward these rights is therefore a necessary first step for designing effective PPC training and protocols in Cuba [22, 23].

This study aims to provide descriptive evidence on the assessments and attitudes of physicians working in Cuban pediatric oncology centers regarding patients' right to information, in order to identify gaps, guide bioethical training, and support the design of institutional protocols that guarantee the effective exercise of this right within the context of the National Pediatric Palliative Care Project 2025-2027 [7].

2. Materials and Methods

2.1. Design and Study Population

A descriptive cross-sectional study was conducted. The target population comprised physicians working in pediatric oncology services in Cuba. The purposive convenience sample included 33 physicians from different pediatric oncology centers across the country who voluntarily agreed to participate and provided informed consent.

2.2. Instrument

A structured questionnaire designed and validated by the researchers through the expert judgment method was applied. The instrument included: (a) sociodemographic and professional characterization data; (b) questions on recognition of children's and adolescents' right to information in cancer; (c) items on habitual practices in clinical decision-making regarding patient and parental assessments; and (d) items on effective respect for adolescents' opinions in treatment modification. Items related to attitudes and practices were formulated using an agreement/disagreement scale format.

2.3. Statistical Analysis

Descriptive statistical analysis was performed with calculation of absolute and relative frequencies (percentages). Data were processed using SPSS version 25.0. No tests of statistical significance were applied given the descriptive nature of the study.

2.4. Ethics Approval and Consent to Participate

The study was approved by the Research Ethics Committee of the Cuban Ministry of Public Health (MINSAP). All procedures were conducted in accordance with the ethical standards established in the Declaration of Helsinki (1964) and its subsequent amendments. Participation was voluntary and anonymous. All participants signed informed consent prior to completing the questionnaire. Data were treated confidentially and used exclusively for research purposes.

3. Results

3.1. Sample Characterization

The sample comprised 33 physicians working in pediatric oncology services across different Cuban provinces. Table 1

presents participants' general characteristics. Notably, the majority (57.6%) reported no specific training in bioethics, and only 12.1% held a postgraduate degree or diploma in bioethics.

Table 1. Sociodemographic and professional characteristics of participants (n = 33).

Variable	Category	n (%)
Professional category	Specialist in pediatric oncology	21 (63.6%)
	Specialist in pediatrics	8 (24.2%)
	General practitioner / resident	4 (12.1%)
Years of experience	< 5 years	6 (18.2%)
	5-15 years	14 (42.4%)
	> 15 years	13 (39.4%)
Prior bioethics training	No specific training	19 (57.6%)
	Basic course (< 40 hours)	10 (30.3%)
	Postgraduate degree or diploma in bioethics	4 (12.1%)

3.2. Recognition of the Right to Information

78.2% of surveyed physicians (n = 26) recognized the right of children and adolescents to receive information about their diagnosis and disease process (Table 2). This recognition was higher among participants with prior bioethics training (90.0%) than among those without it (68.4%), suggesting that formal bioethical education influences professional attitudes toward patients' rights.

3.3. Weight of Patient Versus Parental Assessments

Despite this recognition, 56.5% of physicians (n = 19) stated that in clinical practice they give more weight to parents' assessments of their children's quality of life than to patients' own views in medical decision-making. Table 2 presents the full distribution of responses to the study's main items.

Table 2. Distribution of responses to main study items (n = 33). Percentages may not sum to 100% due to missing values on some items.

Item evaluated	Agree n (%)	Disagree n (%)
Recognizes children's and adolescents' right to information about their illness	26 (78.2%)	7 (21.2%)
In practice, gives more weight to parental assessments than to patient's own views in decision-making	19 (56.5%)	14 (42.4%)
Minors can offer assessments, but these are rarely considered for treatment modification	20 (60.4%)	13 (39.4%)
Adolescents' assessments are respected in routine clinical practice	19 (56.5%)	14 (42.4%)

3.4. Minor's Participation in Treatment Decisions

60.4% of physicians (n = 20) acknowledged that minors can offer their own assessments about their health status and quality of life, although they consider that such assessments are rarely taken into account for modifying established treatments. This reveals a clinically relevant paradox: the professional recognizes the minor's expressive capacity but does not systematically integrate their perspective into the decision-making process.

56.5% of participants reported that adolescents' assessments are respected in their routine practice. The coincidence of this percentage with that of those who affirm prioritizing parental assessments suggests the existence of ambivalent or

poorly differentiated interpretations of what "respecting" the opinion of the underage patient means in clinical contexts.

4. Discussion

4.1. Medical Paternalism in Cuban Pediatric Oncology

The results of the present study are consistent with findings reported in Latin American and international literature on the persistence of the paternalistic model in pediatric oncology. [16, 19] The fact that more than half of surveyed physicians (56.5%) prioritize parental assessments over those of the patient in clinical decision-making—despite 78.2% theoretically recognizing the minor's right to information—precisely illustrates the gap between normative recognition and actual professional practice.

This gap is not exclusive to the Cuban context. Studies conducted in Spain, Brazil, and Mexico document similar patterns, with rates of 65-75% of physicians reporting systematically consulting parents before the pediatric patient, even for adolescents with full cognitive capacity [3]. In Latin America, the paternalistic medical model has deep historical and cultural roots, overlaid on a medical training system that has historically not incorporated bioethics as a core competency in undergraduate and postgraduate curricula [1].

However, it is important to note that benevolent paternalism in pediatrics is not equivalent to a violation of the right to information. The decision to mediate information through parents may, in some cases, respond to a legitimate assessment of the minor's capacity to process adverse prognostic information. The problem arises when this mediation becomes the automatic norm for all patients, regardless of their age, maturity, and expressed wishes [8].

4.2. Progressive Autonomy of the Minor: A Principle Pending Implementation

The concept of progressive autonomy, introduced into pediatric bioethical debate from the Convention on the Rights of the Child [2] and subsequently developed by Alderson and Montgomery [9] and Hinds et al. [10], recognizes that the child's capacity to participate in health decisions increases gradually with age and experience, and that this capacity must be evaluated individually, not assumed based on chronological age. This approach has been adopted by SIOP as a reference for clinical relationships in pediatric oncology.

For adolescents, the literature is particularly compelling: qualitative studies with cancer patients aged 12-18 show that the vast majority wish to be informed directly about their diagnosis and treatment, and that informational exclusion generates feelings of distrust, loss of control, and greater anxiety [10]. The finding of this study that 60.4% of physicians acknowledge that adolescents' assessments are rarely used to modify treatments is, in this context, particularly concerning from an ethical standpoint [16-18].

4.3. Weight of Parents in Decisions: Protection or Substitution

The prevalence of parents in clinical decision-making in pediatric oncology partly responds to a legitimate justification: parents are the minor's legal representatives and have the duty to ensure their wellbeing. However, bioethical literature clearly distinguishes between legitimate representation (in which the representative decides according to the represented person's values and wishes) and substituted judgment (in which the representative imposes their own assessments, displacing the minor's perspective) [11, 17].

The results of this study suggest that a substituted judgment model may frequently operate in Cuban clinical practice, given that the minor's perspective rarely influences treatment decisions. This dynamic may be exacerbated by the absence of institutional protocols guiding the health team on how and when to incorporate the pediatric patient's perspective into decision-making.

4.4. Implications for Palliative Care Training and Practice

The study's findings have direct implications for three intervention domains within the framework of PPC development in Cuba. First, bioethical training of health personnel in pediatric oncology must explicitly and practically incorporate the concept of progressive autonomy, minor's assent, and age-adapted communication skills as part of the mandatory undergraduate and specialization curriculum. The fact that only 12.1% of participants had postgraduate bioethics training is, in itself, an indicator of urgent formative gap [16, 21].

Second, the development of institutional protocols for information communication and shared decision-making in pediatric oncology is a need identified by this study. Such protocols must establish the process for evaluating the minor's capacity, criteria for assent according to age and maturity, and mechanisms to document and integrate the patient's perspective in the clinical record [20, 22].

Third, the results strongly support including training in pediatric patient rights and adapted clinical communication in the training plan of the National Pediatric Palliative Care Project 2025-2027, which already contemplates training more than 240 professionals in Cuba's eight pediatric oncology reference centers [7]. The ethical competencies examined in this study are not peripheral to PPC quality—they are central to it [15, 23].

4.5. Limitations

The data collection instrument has not been validated in

populations other than the Cuban one and its reproducibility requires confirmation. The cross-sectional design prevents establishing causal relationships or temporal trends. Future studies should expand the sample to a nationally stratified representation, incorporate the perspective of patients themselves and their families, and employ mixed methodology to deepen professionals' narratives.

5. Conclusions

Although there is a tendency among Cuban pediatric oncology physicians to recognize the right to information of children and adolescents with cancer, this recognition has not been consolidated as systematic professional practice. The prioritization of parental assessments over those of the patient, the minimal influence of the minor's opinions on treatment decisions, and the ambiguity in defining what "respecting" the adolescent's will means demonstrate the persistence of a paternalistic model in the physician-patient relationship in Cuban pediatric oncology.

These findings are consistent with Latin American and international literature, and reflect the need for specific educational and organizational interventions to advance toward a care model that guarantees the effective exercise of the right to information and the progressive participation of the minor in decisions about their health, in accordance with Cuba's normative framework, the principles of clinical bioethics, and the international standards of pediatric oncology.

We recommend:

(1) incorporating clinical bioethics and the progressive autonomy approach as mandatory competencies in the training of pediatric oncology and pediatrics specialists;
(2) developing institutional protocols for communication and shared decision-making in Cuba's eight pediatric oncology reference centers;
(3) including the pediatric patient's perspective as a care quality indicator in the National Pediatric Palliative Care Program monitoring system; and
(4) promoting qualitative research with patients and families to complement the evidence provided by this study.

Abbreviations

PPC	Pediatric Palliative Care
WHO	World Health Organization
SIOP	International Society of Paediatric Oncology
MINSAP	Ministerio De Salud Publica (Cuban Ministry of Public Health)
SPSS	Statistical Package for the Social Sciences

Author Contributions

Mariuska Forteza Saez: Conceptualization, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing

Maria del Carmen Llanta Abreu: Conceptualization, Supervision, Writing – review & editing, Data curation

Yolainy Romero Rodriguez: Data curation, Formal analysis, Writing – original draft, Writing – review & editing

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Conflicts of Interest

The authors declare no conflicts of interest.

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