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Healthcare professionals face ethical challenges in managing care for neurodevelopmental disorders: a qualitative study in Lebanon

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ABSTRACT

Objectives This study aimed to explore the ethical challenges faced by healthcare professionals (HCPs) in managing children and adolescents with neurodevelopmental disorders (NDDs) in Lebanon. The primary research question addressed how HCPs navigate ethical dilemmas related to patient autonomy, surrogate decision-making and communication in the context of severe cognitive impairments.

Design Qualitative, cross-sectional study using semi-structured interviews. Thematic analysis was applied to identify key ethical challenges in clinical practice.

Setting Participants recruited from a range of healthcare specialties, including paediatric neurology, general paediatrics and psychiatry, and registered with the Lebanese Order of Physicians.

Participants Sixteen HCPs, including paediatric neurologists and psychiatrists, participated in the study. Participants were selected based on their experience in treating children and adolescents with NDDs. There were no exclusion criteria based on gender, ethnicity or years of experience.

Interventions No formal interventions were applied. Participants were interviewed about their experiences and ethical challenges in managing patients with NDD.

Primary and secondary outcome measures The primary outcome was the identification of ethical dilemmas faced by HCPs in clinical decision-making with patients with NDD. Secondary outcomes included insights into the strategies employed by HCPs to balance patient autonomy with surrogate decision-making and the communication challenges they face with patients' families.

Results Thematic analysis revealed several key ethical challenges, including (1) balancing patient autonomy with the need for surrogate decision-making, (2) tailoring healthcare to individual cognitive abilities and (3) navigating the complexities of communication with patients and their families. Participants emphasised the importance of assessing decision-making capacity on a case-by-case basis. The study also highlighted the need for specialised, patient-centred approaches that respect autonomy while considering the practical limitations imposed by severe cognitive impairments.

Conclusions This study provides critical insights into the ethical considerations faced by HCPs in managing children and adolescents with NDDs. Further research is needed to develop training programs for HCPs that address these ethical challenges and promote patient-centred decision-making.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Semi-structured interviews allowed for a detailed exploration of healthcare professionals' lived experiences with ethical challenges in managing children and adolescents with neurodevelopmental disorders (NDDs).
- ⇒ Inclusion of healthcare professionals from a range of specialties provided a well-rounded understanding of the ethical complexities in treating patients with NDD across different fields of practice.
- ⇒ Interview guide was developed following an extensive literature review and refined through input from field experts, ensuring that the questions addressed key ethical issues specific to NDD care.
- ⇒ Conducted exclusively in Lebanon, the study's findings may not fully reflect the ethical challenges faced by healthcare professionals in countries with different healthcare systems, resource availability, or cultural practices surrounding NDD care.

INTRODUCTION

Disabilities and impairments are prevalent health issues among children and adolescents, affecting approximately 12.5% of children and adolescents aged 5–17 years.[1] In Lebanon, there is a notable absence of reliable data on the prevalence of neurodevelopmental disorders (NDDs). Existing studies have primarily focused on autism spectrum disorder (ASD), revealing a national prevalence of 1.48% in children aged 16–48 months,[2] being much higher than the global median ASD prevalence of 0.72%.[3]

NDDs represent a group of chronic disorders that lead to impaired brain or central nervous system growth, early in child development,[4] ultimately producing a functional, quantitative or qualitative deficit, in one or more areas of development; these areas include motor, behavioural, social, communication and daily life activities.[5] Several types of conditions fall into the category of NDD, such as attention deficit hyperactivity disorder (ADHD), ASD, epilepsy, intellectual disabilities, specific learning disabilities and hearing, visual and motor impairments among cerebral palsy (CP).[6 7]

Children and adults with NDDs, specifically aged between 5 and 18 years old, often experience stigma, discrimination and a lack of decision-making power, which negatively affects their access to healthcare (HC).[8 9] Patients with NDDs are often stereotyped as cognitively disabled and unable to participate in decision-making, which can damage the patient–physician relationship and limit patients' autonomy.[10] Moreover, children and adolescents with NDDs require unique management that goes 'beyond the traditional boundaries of healthcare' with a need for healthcare professionals (HCPs) to 'take a more active role in the management of children with functional limitations'.[11]

Studies have shown that engaging children in healthcare decisions and asking their preferences are becoming a crucial value in most professional societies even when they cannot act as fully autonomous individuals.[12] This exposure to assent is considered a fundamental first step towards full respect of patients' ethical values, decreasing therefore transition problems from paediatric to adult healthcare in patients with NDD, as well as the adherence of HCPs to ethical principles by Beauchamp and Childress. Patients' rights in the fourth article of 'The right to medical attention' in the Lebanese law clearly states that 'Minors shall be provided with information about the necessary medical examinations and procedures for their health status, according to their age, and their ability to understand, regardless of the information'.

In Lebanon, some patients describe HCPs as 'lacking humanity' and reducing the patient–physician relationship to a 'business relationship'.[13 14] This raises questions about the experiences of this specific group of patients with NDDs, and how they are treated in healthcare settings. While addressing the complex needs of patients with NDD, doctors may struggle with balancing clinical practice with the emotional and ethical aspects of patient care, potentially leading to difficulties in fostering meaningful, humane doctor–patient relationships. Given the significant impact of NDDs on individuals, families and healthcare systems, ethical considerations and questions arise.[15] HCPs must strive to understand and adhere to ethical values and principles when caring for patients with NDDs.[10] We have identified overlapping attitudes towards adherence to and application of ethical principles in the clinical care of patients with NDDs in the literature. Ethical challenges in the clinical care of patients with NDDs involve a delicate balance between respecting patient autonomy and ensuring beneficence. Clinicians face dilemmas in interventions like transcranial electrical stimulation; the overprescription of psychotropic medications, often lacking sufficient justification, raises significant ethical issues; respect for autonomy is essential, especially when patients have limited decisional capacity; and shared decision-making is recommended to improve care quality.[16 17]

In this study, we focus on the lived experiences of HCPs as they manage the care of patients with NDD. Through these experiences, we explore the ethical challenges that arise in the context of providing care to this unique patient population. As HCPs navigate complex clinical decisions, communicate with patients and their families and tailor specialised care to meet the diverse needs of patients with NDD, they encounter a range of ethical dilemmas. By examining these lived experiences, we aim to shed light on the ethical complexities that define the care landscape for patients with NDDs, offering insights into the moral considerations that guide HCPs in their clinical practice.

MATERIAL & METHODS

The objective of this study was to explore the lived experiences of HCPs in managing the care of children and adolescents aged 5 to 18 years with NDDs. Through qualitative interviews, we aimed to gain insights into the ethical challenges these professionals encounter and their approaches to addressing the complex health and social needs of this patient population.

Study design

This study was conducted over a 6-month period. Considering the intricate ethical challenges inherent in caring for patients with NDDs and the limited availability of specialised practitioners, we employed semi-structured interviews as the primary method for data collection. This qualitative approach enabled HCPs to share their lived experiences in detail, offering rich, nuanced insights into the moral complexities they navigate in their practice. This qualitative approach allowed HCPs to articulate their perspectives in depth, providing rich and nuanced data.

Study questionnaire

The semi-structured interview guide was meticulously developed following an extensive literature review on ethical issues related to NDDs and previous research in the field. The guide was divided into three key sections: (1) demographic information of participants, (2) their understanding and awareness of medical ethics and (3) their attitudes and approaches towards addressing the health and social needs of children and adolescents with NDDs, particularly focusing on ASD, CP and ADHD. To ensure that the questions captured the complexity of the respondents' views, the guide was refined with input from two experts in the field, alongside the principal investigator. The initial questionnaire was crafted in Arabic and subsequently translated into English using a rigorous process that included back-translation to maintain accuracy and reliability. This translation process was led by the principal investigator with the assistance of an Arabic grammar specialist. The accuracy of the translation was

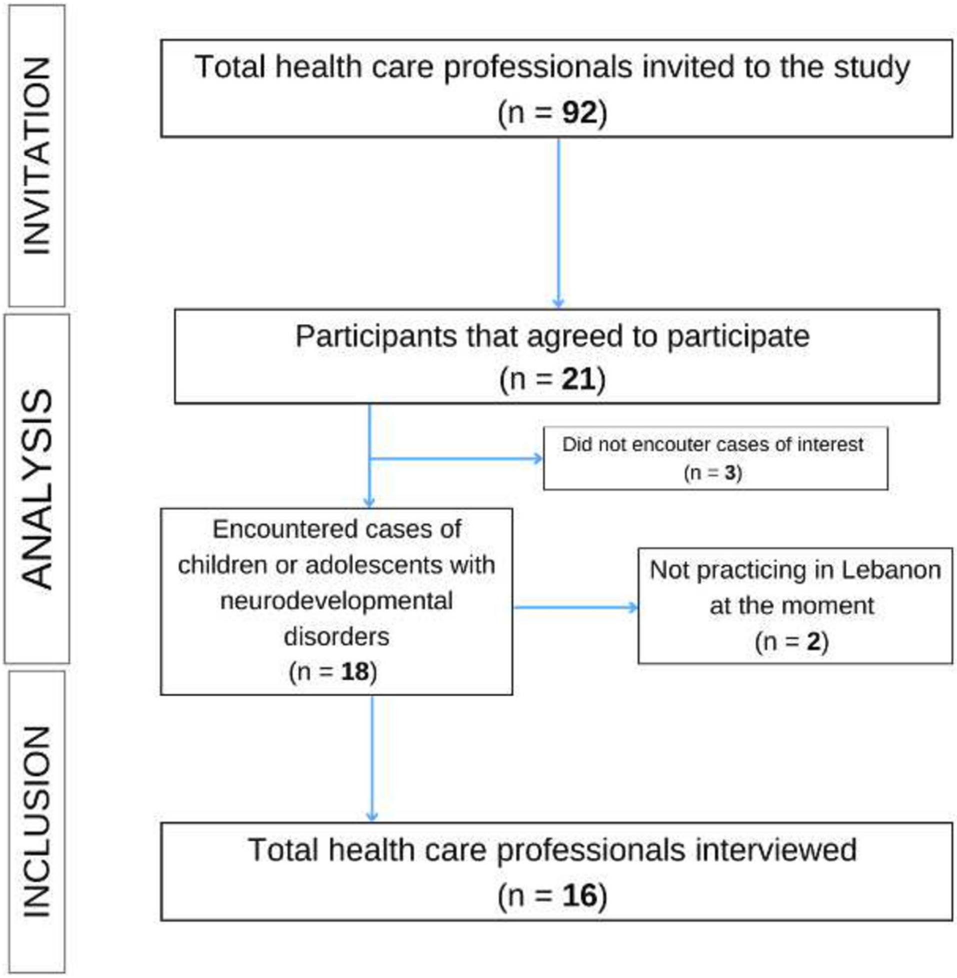

Figure 1 Flowchart of Lebanese Health Care Professionals recruitment to the study.

further validated through a pilot test conducted with two physicians, leading to minor adjustments to enhance the clarity and coherence of the interview guide.[10 18]

Study population

To capture a broad spectrum of perspectives, the study included HCPs from various specialties registered with the Lebanese Order of Physicians, a professional organisation that serves as the governing body for medical doctors in Lebanon. A total of 92 physicians specialising in neurology, paediatric neurology, general paediatrics and psychiatry were progressively invited to participate in online interviews via email or phone. Sixteen participants ultimately agreed to take part in the study and provided informed consent. The inclusion criteria were limited to HCPs who had treated children or adolescents aged 5–18 years with NDDs. The study's objectives were clearly explained to all participants before the interviews to ensure their understanding and voluntary participation (figure 1).

Data collection

All interviews were conducted by the first author, and each was audio-recorded, with sessions lasting between 20 and 35 min. The semi-structured interviews followed a predefined topic guide, yet maintained flexibility to explore emerging themes as the interviews progressed. This iterative process allowed for the refinement of the interview guide and the continuous addition of relevant topics based on the insights gained from previous interviews. Data collection continued until theoretical saturation was achieved, ensuring that the research objectives were comprehensively addressed.

Data analysis

The semi-structured interview data were thematically analysed using NVivo V.12, following the principles of grounded theory. Initial line-by-line coding was performed by two coders to identify and understand participants' perspectives, followed by focused coding to organise these codes into broader themes for a structured analysis. After each independent coding session, the principal investigator participated weekly for a month to finalise the interpretation of the codes and develop subthemes and themes. Special attention was given to identifying deviant cases that might challenge emerging patterns, thereby enhancing the robustness and validity of the findings. Throughout the process, the research team engaged in reflexive discussions during weekly meetings

Table 1 Demographic and practice characteristics of the 16 Lebanese physicians included in the study classified by specialty

PhRef	Age range	Years qualified	Rural/semi-rural/urban practice	Age of patients	Teaching practice	Specialty	Conditions treated
1	30–50	0–10	Urban	Newborns until 21 years old	No	General Paediatrics	Headaches, migraine, epilepsy and developmental disorders
9	30–50	11–20	Urban	Newborns until 18 years old	Yes	General Paediatrics	Epilepsy, developemental delay, neuromuscular disorders and others
11	30–50	11–20	Urban	Newborns until 18 years old	No	General Paediatrics	Psychomotor delay, epilepsy, neurological inflammation, neurological diseases and others
12	30–50	0–10	Urban	Newborns until 18 years old	Yes	General Paediatrics	Headaches, migraine, epilepsy and developmental disorders
14	50–70	11–20	Urban	Newborns until 18 years old	Yes	General Paediatrics	Psychomotor delay, myopathy, neuropathy, cerebral palsy and others
3	30–50	0–10	Semi-rural	Newborns until 20 years old	No	General Paediatrics	General paediatric services (routine checkups, respiratory tract infections…)
6	50–70	31–40	Urban	Newborns until 16 years old	Yes	General Paediatrics	General paediatric services (routine checkups, respiratory tract infections…)
7	30–50	0–10	Semi-rural	Newborns until 18 years old	Yes	General Paediatrics	General paediatric services (routine checkups, respiratory tract infections…)
13	50–70	31–40	Urban	Newborns until 18 years old	Yes	General Paediatrics	General paediatric services and neonatal care
4	30–50	0–10	Rural	Newborns until old age	No	Neurologist	Headaches, migraine and other neurological disorders
5	30–50	21–30	Semi-rural	15 years old and above	Yes	Neurologist	Headaches, migraine and other neurological disorders
8	50–70	31–40	Urban	14 years old and above	No	Neurologist	Headaches, migraine, muscle aches, epilepsy and others
10	50–60	21–30	Semi-rural	15 years old and above	Yes	Neurologist	Migraine and other neurological disorders and others
15	40–50	0–10	Rural	Newborns until old age	Yes	Neuropsychologist	behaviour problems, cognitive problems, social issues and others
2	60–70	21–30	Urban	Newborns until 16 years old	Yes	General Paediatrics	General paediatric and GI services
16	40–50	0–10	Urban	All ages	Yes	Psychiatrist	Mental health and physical problems with related medical treatments

to address any assumptions and refine the interpretations of the codes.[19] This comprehensive approach, supported by the systematic use of NVivo V.12 software, led to the identification of higher-order themes that encapsulated the core ethical issues in the treatment of children and adolescents with NDDs.

Patient and public involvement

Neither patients nor the general public were involved in the design or management of the study.

RESULTS

The study included 16 HCPs, consisting of 11 males and 5 females (table 1). Analysis of their responses revealed several key themes relating to the ethical complexities of managing patients with NDDs.

Decision-making in patients with NDDs

The study highlights the intricate ethical dilemmas involved in decision-making for patients with NDDs. Many HCPs advocate for assessing decision-making capacity based on individual cognitive abilities, rather than assuming all patients with NDDs are incapable of participating in their care. They argue that adolescents and patients with varying degrees of cognitive impairment should be engaged in care decisions according to their level of understanding and cognitive function. As one HCP states, 'Patients with NDDs, especially those in their adolescent phase, should be assessed based on the degree of severity' (table 2, IIIa), emphasising the necessity to tailor decisions to the patient's cognitive abilities (table 2, IIIb). This view challenges the blanket assumption that communication difficulties preclude meaningful involvement, promoting a more individualised and morally sensitive approach to patient care.

Conversely, a minority of HCPs hold that patients with severe NDDs lack sufficient decision-making capacity, thus justifying surrogate decision-making by parents or guardians. These practitioners maintain that significant cognitive impairments necessitate a focus on family-centred decision-making, particularly when the patient's ability to engage is minimal. As one HCP explains, 'Patients with NDDs do not have the ability to participate in decision-making, and the decision should be made by their surrogates, typically their parents'' (table 2, IIIc). This perspective also implies that communication should be limited to the family, with the view that 'children and adolescents, particularly those with NDDs, are not directly or indirectly involved' (table 2, IIId). Such an approach raises ethical concerns about potentially marginalising patients, who may still possess valuable insights into their own care.

Furthermore, assessing patient autonomy remains a crucial ethical consideration. For example in a case presentation, of a patient aged 10–20 with ASD, HCPs stressed the importance of determining her capacity to communicate and understand information: 'The patient's capacity to communicate and express her opinions is essential' (table 2, VIa). Neglecting this capacity can lead to inefficiencies and missed opportunities for involving the patient in her care decisions (table 2, VIb). While some physicians advocate for incorporating patient opinions into decision-making when feasible, others believe that parental opinions should take precedence, reflecting the ethical tension between respecting patient autonomy and addressing practical limitations (table 2, VIc). This ongoing debate underscores the complexity of ethical decision-making in NDD care, highlighting the need for a balanced approach that respects both patient capacities and practical constraints, ultimately guiding HCPs towards more morally nuanced clinical practices.

Ethical and practical approaches to patient care in Lebanon

In Lebanon, the ethical complexities surrounding the care of patients with NDDs reveal a significant divergence in practice and perspective among HCPs. This inconsistency underscores the intricate moral considerations that guide clinical decisions and the varying interpretations of ethical principles in patient care.

A key ethical issue is the approach to patient care based on the severity and specific needs of individuals with NDDs. Paediatric neurologists, such as PhRef 9, argue that 'Children with NDDs should be approached with a specialized type of care' (table 2, IIa), advocating for tailored care that addresses the unique challenges presented by different levels of cognitive impairment. This stance highlights a commitment to ethical principles that prioritise individualised care and recognise the diversity of patient needs. In contrast, general paediatricians and other non-specialists, such as PhRef 3, suggest that patients with NDDs should be managed similarly to other patients (table 2, IIb). This more generalised approach raises questions about the adequacy of care for patients with complex needs and the application of ethical principles in ensuring that all patients receive appropriate and effective treatment.

The debate extends to the provision of health information tailored to patients with NDDs. There is a strong argument for ensuring that all patients receive relevant health information, regardless of cognitive ability. Paediatric neurologist PhRef 11 emphasises, 'It is beneficial to have a prior assessment of the patient's comprehension and understanding of information' (table 2, VIc), supporting a tailored approach to communication that respects patient autonomy and capacity. However, some physicians, including PhRef 10, contend that providing such information may be ineffective if patients cannot comprehend or communicate, viewing it as a 'waste of time and energy' (table 2, IVb). Despite these concerns, other paediatric neurologists (PhRef 1 and 12) integrate tailored information into their clinical practice as a standard part of care (table 2, IVc), underscoring the ongoing commitment to individualised patient engagement.

Ethical considerations in the specialized approach and patient autonomy

In Lebanon, the ethical complexities surrounding the care of patients with NDDs are shaped by specialised approaches to consultation and the nuanced handling of patient autonomy. These practices reflect the moral considerations that guide healthcare HCPs in their clinical interactions.

Physicians generally adopt a specialised approach when consulting with patients with NDDs. This process begins before the patient enters the room. Observations of the patient's actions, behaviour and mannerisms provide initial insights into their condition (PhRef 9, table 2, Va). To ensure comprehensive care, physicians like those in urban settings (PhRef 12) schedule well-spaced appointments to avoid rushed interactions (table 2, Vb). They also meticulously review the patient's medical and family history, including prior psychomotor assessments, prenatal conditions, and details about the NDD's severity and progression (PhRef 1, table 2, Vc). During examinations, physicians explain their actions to the patient, adopting a gentle approach and using touch as a comforting tool (PhRef 4, table 2, Vd and Ve). They then discuss suitable treatments and referrals with the patient and their surrogates to ensure a collaborative approach (PhRef 5).

The issue of patient autonomy further complicates the ethical landscape. For instance, when assessing a 14-year-old patient with ASD, some physicians emphasise the importance of evaluating the patient's capacity

Table 2 Representative quotations illustrating ethical and practical challenges in the care of patients with neurodevelopmental disorder, in Lebanese physicians

Theme	Reference	Quotations
I. Struggles with medical ethics principles and their interrelation	(a)	Physician 2: "Autonomy is when we tell the patient everything regarding the treatments and its successes and side effects, what other options for treatment are present and what suits the patient"
	(b)	Physician 11: "Justice is that each patient should have his rights, despite the region, religion and socioeconomic status"
II. Conflicting views on ethical care in Lebanon	(a)	Physician 16: "These patients have special situations; they are different and not retarded. We shouldn't treat them the same way, even the location and type of cabinet shouldn't be the same"
	(b)	Physician 17: "The doctor's job here is talking them into accepting it and how to live with it without making the child feel as he/she are different, not normal"
III. Exploring the spectrum of decision-making	(a)	Physician 13: "It depends on the degree of severity. Some patients have ADHD but are very good and cognizant"
	(b)	Physician 10: "but there are cases that differ from each other, the degree of developmental disorder differs, they are different from a patient to another and I personally think that the excellence of a doctor is showed by his capability to know the degree of developmental delay this child has"
	(c)	Physician 2: "Their parents are the ones to take the decision. Such patients don't have the ability to participate in taking a decision"
	(d)	Physician 11: "Usually we communicate and talk to the parents and not the children. Therefore, children usually don't know what is happening. Children are not even in direct relation with everything"
	(e)	Physician 11: "It's not possible to ask a child of 11-year-old to ask his opinion. The final decision is always to the parents"
IV. Tailoring health information to patients	(a)	Physician 13: "The patient should understand that he/she should take the medication in order to live normally and carry out with all activities and not get seizures, but the doctor wouldn't straight up say "this medication is for brain electricity" because the patient wouldn't understand"
	(b)	Physician 10: "If the patient doesn't have the capacity to communicate and comprehend, I would consider these efforts to be a loss of energy from my part"
	(c)	Physician 12: "The doctor should explain to the patient. As a neuropediatric, I see the patient for around 30 to 45 min per session, so definitely I will have to explain to the patient as would any other neuropediatrician"
V. Specialised approach to consultation in Lebanon	(a)	Physician 1: "First of all, it is important to set an appointment beforehand, especially for the patients with ASD. The doctor starts work at 10, but for patients with ASD, he will set their appointment at nine because such patients won't be comfortable with waiting outside"
	(b)	Physician 1: "In general, once the patient enters the clinic, his/her actions should be watched (how they speak and move, if there are repetitive behaviors, eye contact…)"
	(c)	Physician 11: "Always you have to go back to the story from the beginning. The pregnancy, birth conditions, psychomotor tests every month. Them we can go for the family history, if there's any consanguinity…"
	(d)	Physician 16: "I would call out the steps (what tests I'm going to do or what treatment is going to be used) to the parents in front of the patients so the patient would know what is going to be done to her"
	(e)	Physician 6: "However, I would approach the child in a gentler way by doing less aggressive exams in order not to disturb him/her"
VI. Exploring the extent of patient autonomy offered	(a)	Physician 12: "If the child is able to communicate, then of course she would take the patient's opinion"
	(b)	Physician 10: "If he is able to communicate of course but if he's not able to communicate, I wouldn't waste my time and talk to him"
	(c)	Physician 8: "We should be using the pre-assessments, that are unfortunately absent in Lebanon, to guide our practice"

Continued

Table 2 Continued

Theme	Reference	Quotations
VII. Promoting effective active listening and communication	(a)	Physician 13: “We communicate with these patients in many times, because sometimes their answers is more reliable than their parents”
	(b)	Physician 5: “Maybe it would be through a tap on the back or a smile, as much as a doctor can to properly engage with the patient during the patient’s visiting time”
	(c)	Physician 9: “I would tell the patient, about their conditions and treatments and give them the needed insight in a simple way, without getting into details”
VIII. Patient–provider communication and relationship challenges	(a)	Physician 10: “I don’t know how much the time; the mental capacity and the financial abilities do doctors have right now that allow him to do the proper work like they used to before”

*Quotations are sometimes slightly modified in order to enhance readability

to communicate and express opinions (PhRef 11, table 2, VIa). Ignoring this aspect can lead to inefficiencies in care (PhRef 10, table 2, VIb). To optimise the evaluation, a prior assessment of the patient’s comprehension is recommended (PhRef 7, table 2, VIc). While some physicians advocate for incorporating patient opinions into the decision-making process, others, such as those in semi-rural areas (PhRef 10), argue that parental opinions should take precedence due to the patient’s limited cognitive abilities.

Ethical dimensions of communication and relationship building

In Lebanon, the ethical complexities surrounding the care of patients with NDDs are highlighted by the challenges in communication and relationship building between HCPs and patients. The discrepancies in practice and the resulting ethical dilemmas shed light on how moral considerations guide clinical interactions.

Promoting effective active listening and communication is crucial, regardless of the severity of a patient’s condition. For instance, paediatric neurologist PhRef 9 emphasised the importance of engaging directly with patients, noting that ‘children and adolescents, in some cases, are more reliable in providing answers and preferences than their parents’ (table 2, VIIa). This perspective underscores the ethical need to value and incorporate patient input, even when cognitive limitations are present. Nonverbal communication techniques, such as a smile or a reassuring touch, are also considered vital for engaging patients with limited cognitive abilities, as highlighted by PhRef 1 and PhRef 12, who view these techniques as essential components of patient care (table 2, VIIb). Moreover, simplifying information to include patients in the clinical process, even in advanced cases, aligns with the views of PhRef 11, who believes in integrating patient opinions whenever possible (table 2, VIIc). However, the development of a strong patient-provider relationship can be hindered by parental attitudes. As noted by PhRef 4, some parents perceive their child as inherently incapable, which can limit direct patient engagement and hinder the therapeutic relationship.

On the other hand, the overall enhancement of patient-provider communication and relationships remains a significant challenge in Lebanon. Factors such as time constraints, limited mental capacity, and financial limitations have been consistently reported as barriers to providing comprehensive care. According to PhRef 7, these constraints often result in a focus on addressing the disease itself rather than the patient’s holistic well-being (table 2, VIIIa). This situation reflects a broader ethical concern about the adequacy of care and highlights the need for systemic improvements to support meaningful and effective patient interactions.

DISCUSSION

The care of patients with NDDs is often inadequate, particularly in developing countries, with HCPs sometimes demonstrating attitudes that contradict ethical principles.[20] It is unsurprising that only paediatric neurologists (PNs) in our study were capable of managing patients with NDDs while strictly adhering to ethical principles in their practice, given their extensive specialised training and expertise in child neurology care. PNs undergo rigorous residency training followed by additional fellowship programmes that focus specifically on the diagnosis and treatment of neurological disorders in children. This specialised training equips them with both the knowledge and ethical grounding needed to handle the complex needs of patients with NDD. There is a growing demand for PNs due to the rise in first visits; however, projections show that the number of PNs is unlikely to meet future demand.[21 22] According to workforce projections, the number of PNs is not expected to increase in the future to meet the demand for this specialty.[23] In some developing countries, there is already a shortage of PNs, a lack of resources, and cultural barriers contributing to unmet needs among patients with NDDs, despite having some of the highest rates of autism in the world.[24] Our findings show that all physicians, regardless of their specialty, must acquire the skills necessary to ethically manage patients with NDDs, emphasising a need for more comprehensive training across all healthcare disciplines.[25 26]

Our findings also highlight that some HCPs disregard ethical principles, particularly older-generation doctors who adopt paternalistic behaviour. These findings align with previous studies indicating that older doctors are prone to sidestepping ethical principles, favouring a more paternalistic approach to patient care.[27] This tendency is exacerbated by the economic and healthcare crises in countries like Lebanon, where resource constraints and systemic challenges further compromise the ethical treatment of patients with NDD.[28 29] Such environments create conditions where non-specialised doctors may neglect the rights of patients with NDDs, particularly in terms of participation in decision-making and being fully informed about their medical conditions.[11] This neglect represents a significant violation of the ethical principle of autonomy, as recognised by major professional societies.[30] Studies show that engaging children in healthcare decisions and asking about their preferences are becoming a crucial value. It is important to respect patients' autonomy during their clinical care, and their opinions should not be disregarded based solely on their ability to communicate.[31]

Many HCPs advocate for a nuanced approach that considers individual cognitive abilities rather than assuming a blanket incapacity among all patients with NDDs. This perspective aligns with existing literature that emphasises the importance of engaging patients in their care decisions according to their level of understanding.[32] For instance, studies have shown that adolescents with varying degrees of cognitive impairment can contribute meaningfully to discussions about their treatment when their capacities are appropriately assessed and supported. This individualised approach contrasts sharply with the views of some practitioners who argue that severe cognitive impairments justify surrogate decision-making by parents or guardians. This divergence reflects a broader ethical tension in the field, as highlighted in the literature, where the balance between respecting patient autonomy and ensuring safety in decision-making is a recurrent theme.[33] Another significant theme advocated for is the approach to communication and the provision of health information tailored to patients with NDDs. The study highlights a strong argument for ensuring that all patients receive relevant health information, regardless of their cognitive abilities. Paediatric neurologists advocate for assessing patients' comprehension and understanding, which aligns with existing research that emphasises the benefits of supported decision-making models.[34]

Moreover, our study underscores the importance of respecting patient autonomy, a principle that is frequently overlooked, particularly in cases where patients' communication abilities are limited. Current professional standards emphasise that decision-making capacity is not solely determined by age or cognitive ability, and even patients with partial cognitive abilities should have some influence over their healthcare.[30] Therefore, integrating the concept of assent is crucial, serving as a fundamental step towards exercising more complete autonomy and fostering an environment where patients are active participants in their care.[10 35]

Our findings also highlight the critical need for building trust between patients and physicians, a process that can be facilitated by minimising wait times and ensuring referrals to specialised healthcare providers. Additionally, our research indicates that there is insufficient emphasis on allowing children and adolescents with NDDs to express their opinions and views—a fundamental requirement under the Convention on the Rights of Persons with Disabilities (CRPD). The CRPD asserts that children with disabilities have the right to express themselves freely on all matters affecting them, and that children as young as 8 years old should be allowed to independently voice their health-related expectations and feelings. This aspect of patient care is crucial for ensuring that healthcare practices align with international human rights standards and truly respect the dignity and autonomy of young patients.[36 37]

Our study provides a critical evaluation of the current stance of physicians regarding the care of patients with NDDs, particularly in relation to adherence to ethical principles. It highlights significant areas of incoherence among physicians and underscores the need for policies, guidelines and quality measures to improve healthcare for patients with NDD. However, it is important to acknowledge the limitations of our study, including the small number of PNs interviewed and the challenges in fully capturing the effectiveness of medical consultations and adherence to ethical principles. Furthermore, the translation process between English and Arabic may have resulted in some loss of meaning, which could have influenced the interpretation of the data. Despite these limitations, our study contributes valuable insights into the ethical complexities of NDD care and offers practical implications for enhancing the quality of healthcare for this vulnerable population.

CONCLUSION

Despite the widespread misconception that individuals with NDDs, specifically adolescents, are unable to participate in medical decision-making, possess autonomy, or have full disclosure rights, our research has brought to light the pressing need for enhanced awareness and understanding of ethical considerations in their care. Although HCPs with specialised knowledge are equipped to care for individuals with NDDs, a large proportion of practitioners in Lebanon lack a comprehensive understanding of the ethical considerations essential for providing optimal care. This underscores the significance of promoting awareness and education in this field, as medical proficiency alone is inadequate to ensure ethical and compassionate care. This study represents a novel examination of the state of ethics in clinical practice in Lebanon and serves as a clarion call for HCPs, policymakers and the general public to give priority to the ethical considerations in the care of individuals with

NDDs, not only in developing countries, but also in developed countries.

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Patient consent for publication Not applicable.

Ethics approval Our study was approved by The Lebanese University Faculty of Medical Sciences Ethical Committee (approval no. CUER 49-2021). Participants gave informed consent to participate in the study before taking part.

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Data availability statement Data are available upon reasonable request.

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