

# Moral structuring of children during the process of obtaining informed consent

Anderson Díaz-Pérez (✉ [ander2711@gmail.com](mailto:ander2711@gmail.com))

Universidad Simon Bolivar <https://orcid.org/0000-0003-2448-0953>

Elkin Navarro Quiroz

Universidad Simon Bolivar

DILIA APARICIO MARENCO

Corporacion Universitaria Rafael Nuñez

---

## Research article

**Keywords:** Autonomy, paternalism, doctor–patient relationship, consent, informed consent in minors, capacity, children, understanding, moral, practices, paediatrician, clinical, investigator, biomedical

**Posted Date:** January 14th, 2020

**DOI:** <https://doi.org/10.21203/rs.2.20813/v1>

**License:** © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

---

**Version of Record:** A version of this preprint was published on November 25th, 2020. See the published version at <https://doi.org/10.1186/s12910-020-00540-z>.

# Abstract

**Background.** Informed consent is an important factor in a child's moral structure from which different types of doctor–patient relationships arise. Children's autonomy is currently under discussion in terms of their decent treatment, beyond which it is perceived by clinicians and/or researchers.

**Methods.** This is a transversal, qualitative study via a subjectivist approach and a interpretivist approach. The study was performed by conducting semi-structured interviews of 21 people by clinicians and researchers. Data analysis was performed with the SPSS 21® and Atlas Ti 7.0® programmes.

**Results.** Influential practices in the doctor–patient relationship were approach and paternalistic. In the deliberative model, the child is expected to have a moral awareness of their care. The paternalistic model determined that submission was a way of structuring the child, since he or she is considered to be a subject of extreme care.

**Conclusions.** The differentiated objectification [educational] process recognises the internal and external elements of the child. Informed consent proved to be the appropriate means for strengthening moral and structuring the child.

## Background.

Research in this area has shown that it has not been easy to clearly and precisely determine when human beings begin to be autonomous subjects and legally responsible for their actions. In this sense, authors such as Nuño Gutiérrez, et al. state that consent is a process by which children are given basic information about an investigation, provided they demonstrate '... the ability to express preferences and understand the nature and purpose of the research techniques'[1].

In this order of ideas, Freeman states that children's rights are very important, and therefore, they must be treated equally and even as autonomous beings [2], with the child's 'best interests' in mind, which may be gained through the means of consent [3]. Thus, developing a child's autonomy is as important as that of any other person, regardless of what stage of development they are in. Conversely, Sayoux and Frometa mention that research related to children's autonomy is limited to a historical and philosophical description of the need to consider the parents in decision-making, beginning with informed consent, wherein the child is a secondary subject who is not considered capable of decision-making [4]. The family plays an important role in the interaction of complex networks in the parent–child relationship, which is reflected in the child's dependence and vulnerability and their decision-making capability [5].

However, studies such as the one proposed by Manson and Tucker F refer to the need to implement a transitional paternalism where it is not the child's competence that is evoked but their flexibility, which leads to the normative power to morally structure the child to take responsibility for their decisions to an admissible extent. More specifically, clinicians and researchers should prefer the fair methods which give

greater respect for the child's decisions rather than the symmetrical alternative of whether to consent [6, 7].

Clinicians and investigators (C&I) should be aware that childhood is a stage in which the child develops a basic dependence on others; [8] therefore, transitional paternalism appeals to an individual's obligations to help others self-govern [6, 7]. Likewise, López Serrano states that clinicians and researchers should recognise minors as moral subjects only in their particular and unique evaluative aspects and extremely slightly from a normative and universal outset. In other words, they recognise them as subjects with a universal right but not beyond the developmental moment they have reached [8].

Elements of dominance emerge as influential practices from the way clinicians and researchers (C&R) perceive children's autonomy or their moral development; these are manifested in the doctor-patient relationship during the process of obtaining informed consent. Thus, Sánchez Vázquez proposed a classification system that can illustrate the type of doctor-patient power relationships that emerges from an applied ethics perspective. This could explain the dynamics of informed consent, including paternal-moral, normative-legal and differential type relationships [9]. Influential relationships respond to different logics when addressing the ethical problem surrounding the figure of the child, for example, the paternal-moral relationship conceives the child only as a 'social being', which is the object of care. The normative-legal relationship introduces the universal dimension brought about by the human rights phenomenon, in which the child is already treated as a dignified being with full rights. Finally, the differential relationship considers the child's particular and unique perspective, highlighting the constant alternation of each child between autonomy and subjective vulnerability [9].

In summary, the different types of doctor-patient relationships help us reflect on a child's autonomy and design moral structuring guidelines (educative) for each type of patient. It should be mentioned that the current guidelines do not clearly describe when to request a child's consent for research, especially when they show a capacity for understanding [10]. Some studies describe what this minimum requirement should be from health personnel when children are taken into their care and required to provide their consent without coercion, considering their needs, calling them by their name, among other things, which define the axiological, teleological and deontological elements [11, 12], thus contributing to the child's moral strengthening. Thus, autonomy interpreted as the child's moral maturity could depend on how they assume their self-care practices and even recognise the importance of accepting their participation in an investigation [13]. These elements could lead to the C&R treating the child as a moral subject worthy of respect, with agency or self-government capacity [6, 7, 14], which is demonstrated by their self-care practices [12]. Conversely, according to an analysis of practices adjusted to international standards for research in children, it also helps to examine the possible dilemmas and tensions raised, regarding a child's autonomous capacity, which are constantly evolving from a particular social and historical context [1, 4, 8, 12]. In many countries, these rules mention the responsibility of assessing a child or adolescent's (minor's) autonomy in decision-making, wherein each case is unique and particular, in this way of achieving consent regulation.

Informed consent converges influential practices of a deliberative or submissive type. Thus, as Powell and Buchanan expressed it: 'It is a complex construct where particular values and beliefs influence the way of conducting research' and thus perceiving the 'other' [15]. Undoubtedly, it is imperative to understand that beyond the principles of beneficence, justice and respect as normative elements, the sociocultural aspects of children and their families must be considered; otherwise, it may lead to an extreme paternalistic relationship [3, 6, 13].

It is clear that children, being a vulnerable population, require representation by their legal guardians, regardless of the C&R's perception of the child's moral development [8], which is not under discussion nor is it considered a problem or ethical dilemma. The problem lies in acknowledging the 'other', that is, the child as a moral subject, which confirms the guardian's decision owing to the understanding and moral structuring that they have received from clinicians or researchers through an educative process to which the family substantially contributes [6, 16]. Consequently, informed consent does not end when the child leaves the practice or agrees to participate in an investigation; conversely, it is strengthened when the child practices self-care, establishing their best interest in improving or contributing to scientific knowledge above the needs characteristic of their age [10, 12, 17].

There are not many studies that identify the practices of researchers and clinicians regarding children's participation in research and their consent for treatment [11, 12, 17]. Most studies are limited to providing a description of the individual abilities of children and adolescents (minors), without mentioning anything about the meaning of autonomy and influential practices that emerge from C&R to recognise the child's autonomy during the process of obtaining informed consent [6, 16]. However, they prove that the ethical challenges regarding biomedical research in children and adolescents (minors) are not simple when considering the moral capacity to make decisions, which could promote a relationship of extreme paternalism [18].

Authors Opel believe that children's participation in biomedical research is justified because they contribute to improving treatments and diagnostic methods and serve to establish guidelines for the control and management of paediatric diseases because this is research cannot be conducted in adults [19]. In this sense, informed consent could be obtained more for administrative reasons than owing to moral duty [12]. López mentions that C&I should consider the evaluation of the child's moral development based on the articles of the United Nations Children's Fund (UNICEF), which address the participation of children in research [8, 20, 21]. Article 12 states that 'Children who can establish their own opinions should have the right to express them and have them taken into account'. Article 13 states that 'Children are free to not participate and should not be pressured'. Therefore, 'participation is a right, not an obligation' [8]. Ultimately, the child's decision is a subjective fact for C&R, and therefore, it should be interpreted according to the framework of bioethic principles, in which the principle of beneficence prevails over the principle of autonomy without prior evaluation. This statement indicates that the conception of beneficence could be considered to be paternalistic [22, 23].

The child's moral development should not be considered to be a limitation but a variation in the exercise of obtaining consent, taking into account the child's reasoning and common sense expressed in a language adapted to their cognitive development [12]. The child's will to volunteer must be free but with the joint support of their guardian, clinician or researcher, family and environment (heteronomy) [6, 9, 16, 24]. According to Kottow (2007), 'the ethical concept of informed consent depends on the abolition of all unjustified medical paternalism'[25]. Therefore, the aim of this study was to describe the influential practices that exist between C&R and children with chronic diseases during the process of obtaining informed consent expressed in the doctor-patient relationship

## Methods

A qualitative study was proposed to examine human behaviour and the motives that govern it based on the social reality of a practice emerging from what they mean, as in a 'historical ontology of ourselves'[26] or a 'criticism of what we say, think and do'[27]. From the epistemological perspective, subjectivism was considered to be a position to recognise, understand and interpret the meaning of meanings and practices [27]. The information was analysed with an interpretivist approach within a transverse timeframe, placing the clinician and researcher at the centre of the phenomenon as the ones who construct, interpret and modify reality [28, 29]. Population: C&I who have direct contact with children diagnosed with some type of degenerative chronic disease.

### Inclusion criteria

Specialists and subspecialists working in the city of Barranquilla who wish to participate in the investigation and who have or have not published independent studies on clinical treatments for children and adolescents with autoimmune diseases. The type of sampling was by convenience and saturation. Thirty interviews were conducted, 21 of which met clear criteria when answering questions. Directors of research groups endorsed by Colciencias in the city of Barranquilla, Colombia. Principal investigators of research projects with projects endorsed by a national or international entity related to children with autoimmune disease. Co-investigators of research projects with projects endorsed by a national or international entity. Rheumatologists, paediatricians, pulmonologists, among others, who conduct their clinical practice on populations of children with some type of diagnosis of degenerative chronic disease.

For the qualitative analysis of information as a first measure, researchers and clinicians described the meaning of autonomy and influential practices regarding a child's autonomy according to their moral maturity. A semi-structured non-directive interview was conducted for this purpose, which was processed through the analysis of information content to conceptualise the categories [30]. For these analysis dynamics, the Dragon Notes® and Atlas Ti 7.0® programmes were used, for which the following analysis technique was proposed:

- Count: The way of finding, in a preliminary way, what is known and the emergent of the phenomenon regarding the meanings of autonomy and their relationships with influential practices.

- Identification of patterns and themes: the most frequently repeated words were tracked to find categorical relationships and to establish influential relationships with the child.
- Examination of the plausibility of the findings: its purpose was to contribute to the conclusions of the initial impressions, which made it possible to determine the guidelines in the analysis stages and contrast the construction of conclusions.

## Results

In this study, 61.9% of C&R were between the ages of 21 and 30 years, 23.8% were between 31 and 40 years of age and 9.5% were between 60 and 69 years of age. Clinicians had an average experience of 8–9 years of clinical practice. A clinician who is also a researcher had 45 years of experience in both clinical practice and research in the biomedical field.

Power relations: Category Analysis

The categories based on the influential relationships between C&R when considering the child as an autonomous subject are the following.

There were two types of influential relationships found mentioned in the interviewees' discourse: the deliberative model, in which the clinician or researcher acts as a mentor, contributing to the construction of the child's autonomy and moral development. In the paternalistic model, the C&R act more as guardians and may even involve subjugation practices; i.e. not taking into consideration the child's opinion and invoking the principle of beneficence as an ethical way to justify their practice based on regulations (principle of justice).

Category: Deliberative model

In the deliberative model, the clinician and researcher act as teachers and contribute to the child's moral development under perceived elements, such as autonomy, and his or her understanding of the disease.

In their role as mentors, the C&R accompany the child and his or her family actively and reflectively through a doctor–child–guardian-type relationship, which favours the child's state of mind. It also contributes to motivating the child to pursue treatment and to understand the consequences of not undergoing it. However, the C&R understand the importance of the beliefs of the child's family, the configurative elements of cognition typical of the child's age and their experience with illness. In other words, the C&R favoured constructing the child's moral judgements to create a healthy relationship with themselves and their environment, thus strengthening their will for higher care as well as their sense of utility, as shown in the following statements in the constant dialogue category:

Emerging category: Constant dialogue

C&R mention the need to promote dialogue with the child to establish empathic links using different methods, to achieve a child's understanding and increase their responsibility and autonomy.

Question: Describe how you would tell a child about new treatment and what determines the degree of information provided.

- Coded speech [E-21]-[1:41]: First, ease of communication to provide clear information and more so in adolescents because they have difficulty in accepting the disease. Therefore, we must begin to explain the disease to the child in a basic way because information reassures them and more so if it is repetitive and time is taken to provide the information.

Emerging category: Participation

According to the C&R, structuring the child to strengthen their autonomy and moral development implied gaining their participation as an active moral subject and holding them accountable for their self-care practices in terms of following the treatment instructions, i.e. being responsible for their actions.

Question: From your clinical or investigative practice, how do you think you contribute to the strengthening of moral development, which is understood to be the child's independence, freedom and responsibility to make moral judgements?

- Coded speech [E-7]-[1:209]: In clinical practice, it is the contact with the patient when addressing adverse situations by means of a good doctor–patient relationship that leads to better results and also to the patient's cognitive development after the event.

Emerging category: Knowledge

For C&R, the child's knowledge of their illness contributes to the type of doctor–patient relationship that may emerge, especially the deliberative one, which directly influences the child's will, as in the way in which they obtain and analyse the information consulted on the internet, and their mood and motivation, as stated in the following statements:

Question: Based on your experience, what would a child's ability to make an important decision regarding their health, specifically their self-care, depend on?

- Coded speech [E-6]-[1:133]: It depends on their degree of knowledge of their disease and the commitment it generates, recognising that given its chronicity, they should practice better self-care to counteract relapses.

Question: Do you consider that the experience of paediatric patients with respect to their autoimmune disease contributes to the development of their moral judgements? If your answer is yes, justify your answer.

- Coded speech [E-5]-[1:155]: Currently, the availability of information and technological advances make these types of patients more informed about their disease and allows them to develop moral judgements at a very young age.

Question: Doctor, from your point of view, can maturity that may be demonstrated by the child regarding self-care be extrapolated to other areas of their life and, if so, in what sense?

- Coded speech [E-18]-[1:184]: Yes, because of the positive stance they assign to their self-care projects them to other areas or aspects of their life.

Category: Paternalistic model

C&R state that they contributed to the child's development or moral maturity based on elements such as acceptance. When the C&R determine that the child does not have a good understanding of the information and their common sense is not developed, they consider that it is owing to a lack of cognitive capacity, which may be affected by the type of illness that afflicts them, the lack of maturity at their age and suffering when experiencing pain or fear. All these factors prevent the child from reaching an adequate degree of responsibility for their self-care and responsibility. Therefore, the clinician has to behave as a guardian owing to the child's high vulnerability, and even refer them to psychological support along with the parents. Thus, C&R are in a doctor-guardian-child-type relationship, as represented in the following statements:

Question: Doctor, how do you consider the child with autoimmune disease?

- Coded speech [E-6]-[1:257]: A subject who must receive special care and assistance because of their vital vulnerability.

Emerging category: Submission

This emerging category is related to the fact that they immediately ignore the child's autonomy when the child does not accept what is set out by the clinician or the researcher or presents arguments that go against the treatment proposed by the clinician.

Question: What elements do you think are important when considering whether a child can make a decision regarding the new treatment?

- Coded speech [E-1]-[1:91]: An autonomous child, that is, with recognition of their responsibility, because their disagreement denotes their lack of maturity.

Emerging category: Acceptance

C&R considered that a child should accept the treatment or research protocol designed for their care without further conflict as a way of proving their maturity, as represented in the following statements:

Question: What elements are important to consider when deciding whether or not a child can make a decision regarding the new treatment?

- Coded speech [E-18]-[1:92]: An autonomous child, that is, with recognition of their responsibility, because the child's disagreement denotes a lack of maturity.

Emerging category: Guardian

The C&R considered that a child's vulnerability is owing to elements of their age or pathological status and the characteristics of the medications. Therefore, it is the clinician's duty to be guided by elements of his or her judgement as an expert, beyond what the child or even the parents may consider. Therefore, clinicians, above all, consider themselves as guardians, bearing in mind the principles of bioethics [justice and non-maleficence] of childcare, as represented in the following statements:

Question: Based on your experience, what would the child's ability to make an important decision regarding their health, specifically their self-care, depend on?

- Coded speech [E-14]-[1:143]: The limitations or adverse effects that may occur due to medication administration.

Question: Do you consider that the experience of paediatric patients with some type of autoimmune disease contributes to the development of moral judgements? If your answer is yes, justify your answer.

- Coded speech [E-12]-[1:161]: Yes, they are patients with few options who require the implementation of new support means.

## Discussion.

What autonomy means, as stated by C&R with respect to the child, is what regulates the influential practices when obtaining informed consent to consider the child as an active moral subject. However, we must consider that the factors inherent in the child as well as external factors (family, clinical, research and sociocultural factors) should contribute to the formulation and implementation of strategies that strengthen the child's moral development; this element has been raised as a process of Differentiated Objectivization [Educative] (POED) [31, 32].

Foucault stated that the idea that the child's moral recognised by C&R must be based on a POED is confirmed, i.e., through the influential relationships that emerge while obtaining informed consent [33]. To provide the POED, the characteristics of each minor and degree of maturity that emerges from their self-care practices must be taken into account as well as their understanding of the risks and benefits of the treatments. The above requires practices of subject objectification that will depend on internal and external elements, i.e., 'the subject is found to be divided within or divided from others', wherein this process is 'objective' [33].

In short, the child's vulnerability should not justify a violation of their right to consent. Conversely, it is the moral duty of C&R to contribute to the development of their autonomy based on the informed consent process. According to Herder, human beings come into the world 'weak [...], needy [...], lacking the

teachings of nature [...], lacking skills and talents', as quoted in Kottow (2012) [34]. However, 'man is nothing more than a blade of grass, the most fragile thing in nature, but it is a blade of grass that thinks' [35].

According to the above, considering a child as mature depends a lot on the judgement and common sense developed as a result of their experience with the disease. Authors such as Nunner-Winkler and Sodian consider that a child's maturity is related to their experience with the disease when recognising risks and benefits in line with their negative or positive emotions, which structures the way of being and existing in the world that could be perceived by the clinician as autonomy which was proved in this study [36].

In summary, the legal framework that defines the child's autonomy and experiences defines their moral development.

Regarding the influential practices in the doctor-patient relationship, it was found that the principles of autonomy and beneficence emerged in the deliberative model, turning the relationship into a trinomial of active participation (clinician or researcher-child-guardian). The principle of beneficence was found to be at the time that the C&R provide elements from the communication process related to providing clear information, which contributes to the child's moral development so that he or she is aware of their decision and of the different risks and benefits to which they are exposed if they do not think positively about their treatment or their duty towards future generations when talking about biomedical research. This means that C&R increasingly require communication skills but also require knowledge and ethical attitudes to assess a child's competencies, as Drane (1999) states, who designed a methodology keeping in mind the proportionality criterion between the severity of the decision and the child's degree of moral competence [37].

Michaud mentions that there is a need to apply the principles of bioethics, but the rights of the child should also be considered, and they should be considered as subjects with their own personality and having rights themselves [38]. In this sense, should a child be considered mature or autonomous? C&R affirm that this acknowledgement depends a lot on their level of understanding of the disease and how they practice self-care in addition to the child's degree of dependence on their parents.

According to Labouvie-Vief, there is a relationship between consent and parental authorisation, wherein each has a different purpose;[39] for example, the guardian's supervision is intended to protect the child from taking unreasonable risks and to strengthen their autonomy when making fair and responsible decisions for their health. Conversely, consent is a communicative process with which one must try and strengthen the sense of usefulness and ensure that the child adheres to treatment for life. Even 9-year-old children have demonstrated the ability to make reasonable choices as long as these choices are explained to them using appropriate language [40, 41].

## Conclusions

In POED, different nuances could be expected regarding the practices based on the different models of the doctor–patient relationship. According to the deliberative model, C&R hope that the child is aware of their illness and acquire moral awareness of their care to the extent that their experiences have a positive impact on their health. This element of moral development will depend on the child’s age and on the degree of independence they may have from their family and the level of understanding of the information provided, that is, their common sense. The opposite is the paternalistic model, in which submission is a way of structuring the child because they are considered to be a passive subject of extreme care, worthy of protection and care. Therefore, C&R consider that structuring a child and perceiving them as an autonomous subject is only possible when they adhere to treatment and responsible self-care, regardless of their parents’ support, bearing in mind that it also depends on the type of disease.

## Abbreviations

POED

Differentiated Objectivization Process [Educative]

CeR

C&R

Child

Child and adolescents

## Declarations

- **Ethics approval and consent to participate**

The research was approved by the El Bosque University Doctoral Program Ethics Committee, who determined that the research conforms to Resolution 8430/93 of the Colombian Ministry of Health, classifying the study as risk-free. The subjects of research were taken from both clinicians and researchers, the respective written informed consent as provided by resolution 0008430/93 of the Colombian COMPES document, which is related to the declaration of Helsinki to maintain the confidentiality of the information of the researchers as determined by the ethics and research committee.

The declarations of Manzini (2000) and the Belmont Report (1979) set the guidelines mentioned below:

- Inform participants [C&R] about the process for obtaining information and how interviews or other instruments will be coded to safeguard participants’ identities
- The right to participate or not and the right to withdraw from the study at any time
- Confidentiality and anonymity of the interviewees, both C&R and for the child and legal guardians, if required
- To report on the study objectives and ensure that the data will not be used for purposes other than those in this investigation both verbally and in writing [informed consent]

- Consider the CV of the project investigator who will conduct the interview and how important it will be to create a climate of trust during the interview
- Request authorisation to record conversations and transcribe information
- Provide study participants with a report on the final study results so that they can verify the elements stated therein before the project is supported or published
- **Consent for publication**

Not applicable

- **Availability of data and materials**

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

- **Competing interests.**

The authors declare that they have no competing interests

- **Funding**

Not applicable

- **Authors' contributions**

AD: Principal investigator. Project Design and methodological adjustments and information analysis

EN: Information Analysis and theoretical contrast

DA: Theoretical and methodological adjustments

All authors read and approved the final manuscript

- **Acknowledgements**

We would like to thank the Bioethics Doctoral Program at El Bosque University. We also thank Simón Bolívar University for allowing the pilot test to be applied in its paediatric specialisation programme to validate the final tool.

- **Authors' information (optional)**

The authors work as researchers in various universities in Colombia, specifically in the Caribbean Region. They have training at the level of doctorates and master's degrees in bioethics and basic biomedical sciences in which it is required to tend for the communication process in the moral structuring of the patient or the subject investigating at the time of taking informed consent / assent.

# References

- 1 Nuño Gutiérrez BL, Becerra Hernández JJ, San Martín AH, et al. Consideraciones éticas para la investigación médica con adolescentes. *Rev Médica Inst Mex Seguro Social* 1996; 34(3) (1996 Mayo-Jun P):189–93.
  - 2 Freeman MD. Taking children's rights more seriously. *Int J Law Policy Fsam* 1992;6(1):52–71. doi: [10.1093/lawfam/6.1.52](https://doi.org/10.1093/lawfam/6.1.52)
  - 3 Harrison C, Laxer RM. A bioethics education program in pediatric rheumatology. *J Rheumatol* 2000;27(7):1780–2.
- Sayoux AMG, Frometa TG. Aspectos Bioéticos en la Práctica de la Reumatología pediátrica su autonomía relación médico paciente. *Rev Cuba Reumatol* 2003;1(1):36–40.
- 5 Harrison C, Kenny NP, Sidarous M, et al. Bioethics for clinicians: 9. Involving children in medical decisions. *CMAJ Can Med Assoc J J Assoc Medicale Can* 1997;156(6):825–8.
  - 6 Manson NC. Transitional paternalism: How shared normative powers give rise to the asymmetry of a dolescent consent and refusal. *Bioethics* 2015;29(2):66–73. doi: [10.1111/bioe.12086](https://doi.org/10.1111/bioe.12086)
  - 7 Tucker F. Developing autonomy and transitional paternalism. *Bioethics* 2016;30(9):759–66. doi: [10.1111/bioe.12280](https://doi.org/10.1111/bioe.12280)
  - 8 López MLS. Aspectos éticos de la investigación en salud en niños. *Rev Colomb Bioét* 2014;9(1):183–96.
  - 9 Sánchez Vázquez MJ. *Ética e infancia: el niño como sujeto moral*. 2007.
  - 10 Sibley A, Pollard AJ, Fitzpatrick R, et al. Developing a new justification for assent. *BMC Med Ethics* [Internet]. 12 de enero de 2016 [citado 22 de agosto de 2019];17. Disponible en: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4709867/>
  - 11 Díaz-Pérez A, Yáñez-Torregroza Z, Gómez JL, et al. Communication process for the strengthening of the care of the minor in a pediatric unit. *Glob J Health Sci* [Internet]. 7 de septiembre de 2018 [citado 22 de agosto de 2019];10(10):p84. Disponible en: <http://www.ccsenet.org/journal/index.php/gjhs/article/view/0/36780> doi: [10.5539/gjhs.v10n10p84](https://doi.org/10.5539/gjhs.v10n10p84)
  - 12 Perez AD, Ochoa ADV, Oñate ZR. The informed consent/assent from the doctrine of the mature minor. *Glob J Health Sci* [Internet]. 24 de julio de 2018 [citado 22 de agosto de 2019];10(8):p124. Disponible en: <http://www.ccsenet.org/journal/index.php/gjhs/article/view/75947>
  - 13 Turkoski BB. When a child's treatment decisions conflict with the parents'. *Home Healthc Nurse* 2005;23(2):123–6. doi: [10.1097/00004045-200502000-00023](https://doi.org/10.1097/00004045-200502000-00023)

- 14 Nussbaum MC. Crear capacidades: propuesta para el desarrollo humano 2012.
- 15 David T, Tonkin J, Powell S, et al. Ethical aspects of power in research with children. 2005.
- 16 Ho A. Relational autonomy or undue pressure? Family's role in medical decision-making. *Scand J Caring Sci* 2008;22(1):128–35. doi: [10.1111/j.1471-6712.2007.00561.x](https://doi.org/10.1111/j.1471-6712.2007.00561.x)
- 17 Pérez AD. Significados de autonomía durante la toma del asentimiento informado al menor con enfermedad autoinmune percibidos por los clínicos e investigadores. *Rev Colomb Bioét* 2018;13(2):8–25.
- 18 Rodriguez-Osorio CA, Dominguez-Cherit G. Medical decision making: paternalism versus patient-centered (autonomous) care. *Curr Opin Crit Care* 2008;14(6):708–13. doi: [10.1097/MCC.0b013e328315a611](https://doi.org/10.1097/MCC.0b013e328315a611).
- 19 Opel DJ, Wilfond BS, Brownstein D, et al. Characterisation of organisational issues in paediatric clinical ethics consultation: a qualitative study. *J Med Ethics* 2009;35(8):477–82. doi: [10.1136/jme.2008.027896](https://doi.org/10.1136/jme.2008.027896)
- 20 UNICEF P des N. Fondo de las Naciones Unidas para la Infancia (UNICEF). PLAN [Online]. 2011;
- 21 Unicef. Estado mundial de la infancia. Unicef 1984.
- 22 Beauchamp TL, Childress JF. Principles of biomedical ethics. USA: Oxford University Press 2001.
- 23 Demenchonok E. 10. The universal concept of human rights as a regulative principle: Freedom versus paternalism. *Am J Econ Sociol* 2009;68(1):273–301. doi: [10.1111/j.1536-7150.2008.00624.x](https://doi.org/10.1111/j.1536-7150.2008.00624.x)
- 24 Macias Gelabert AM. El consentimiento informado en Pediatría. *Rev Cuba Pediatría* 2006;78(1):0–0.
- 25 Kottow M. Participación informada en clínica e investigación biomédica: las múltiples facetas de la decisión y el consentimiento informados. *Red Latinoamericana y del Caribe de Bioética UNESCO* 2007.
- 26 Monatschrift B, ist Aufklärung W. Michel Foucault. What is Enlightenment? New York, NY: Pantheon 1984.
- 27 Packer M. La ciencia de la investigación cualitativa. *Ediciones Uniandes-Universidad de los Andes* 2013.
- 28 Bautista C. Proceso de la investigación cualitativa: Epistemología, metodología y aplicaciones. *Manual Moderno* 2011.
- 29 Pérez AD, Díaz GO, Robles NR. Uso de paquetes informáticos para el análisis de datos en ciencias biomédicas y sociales. *Cienc E Innov En Salud* 2015.
- 30 Bardin L. Análisis de contenido (Vol. 89). Ediciones Akal. 1991;

- 31 Hersh RH, Reimer J, Paolitto DP. El crecimiento moral: de Piaget a Kohlberg. Vol. 34. Narcea Ediciones 1984.
- 32 Almagiá EB. El desarrollo moral: una introducción a la teoría de Kohlberg. *Rev Latinoam Psicol* 1987;19(1):7–18.
- 33 Foucault M. El sujeto y el poder. *Rev Mex Sociol* 1988;50(3):3–20. doi: [10.2307/3540551](https://doi.org/10.2307/3540551)
- 34 Kottow M. Vulnerabilidad entre derechos humanos y bioética. Relaciones tormentosas, conflictos insolutos. *Derecho PUCP* 2012;(69):25–44.
- 35 Pascal B. Pensamientos, ed. y trad. J Llansó Madr Alianza. 1986.
- 36 Nunner-Winkler G, Sodian B. Children's understanding of moral emotions. *Child Dev* 1988;59(5):1323–38. doi: [10.1111/j.1467-8624.1988.tb01501.x](https://doi.org/10.1111/j.1467-8624.1988.tb01501.x)
- 37 Drane JF. Las múltiples caras de la competencia. En: Bioética para clínicos. Editorial Triacastela 1999: 163–76.
- 38 Michaud PA. Assessing adolescent capacity for decision making in clinical care: the practical application of bioethics and human rights principles. In: International handbook on adolescent health and development. Cham: Springer 2017:359–72.
- 39 Labouvie-Vief G, Grün D, Studer J. Dynamic integration of emotion and cognition: Equilibrium regulation in development and aging. *Handb Life-Span Dev* 2010.
- 40 Burke TM, Abramovitch R, Zlotkin S. Children's understanding of the risks and benefits associated with research. *J Med Ethics* 2005;31(12):715–20. doi: [10.1136/jme.2003.003228](https://doi.org/10.1136/jme.2003.003228)
- 41 Hurley JC, Underwood MK. Children's understanding of their research rights before and after debriefing: Informed assent, confidentiality, and stopping participation. *Child Dev* 2002;73(1):132–43. doi: [10.1111/1467-8624.00396](https://doi.org/10.1111/1467-8624.00396)