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The Understanding of Informed Consent as a Practical Bioethical Problem. A Case Study of Hospital Pedagogy on Cancer Patients in Cuenca (Ecuador)

SUMMARY

The relationship between the informed consent sheet and education is crucial. Our objective is to highlight how patients' educational backgrounds impact the ethical rights within medical processes. Some patients face significant challenges in comprehending the significance and contents of the informed consent sheet. It's likely that they may not fully grasp the potential symptoms resulting from their treatment or even be aware of their inherent rights. This issue isn't merely psychological but rather a matter of education, requiring a comprehensive approach to educational development. Consequently, it becomes a social issue wherein both education and health play vital roles. This research delves into assessing the patients' literacy indicators, thereby evaluating their educational backgrounds. We address this within the framework of an ethical problem in hospital pedagogy, integrating educational and philosophical concepts. Employing qualitative analysis, we aim to understand patients' reading skills by conducting interviews, particularly focusing on circumstances of vulnerability due to illiteracy. These circumstances are categorized based on identified reading capabilities. By intertwining two knowledge domains, we aim to highlight human vulnerabilities that may not always be considered within the technical processes of healthcare workers and are rarely emphasized by educators or philosophers.

Keywords: informed consent sheet, education, hospital pedagogy, reading skills, trained conditions.

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INTRODUCTION

Bioethics and hospital pedagogy share multiple connections, with hospital pedagogy being a practical application while bioethics focuses on research. Traditionally, educators believed that implementing education within a hospital setting was challenging. However, over time, hospital pedagogy emerged as an innovative approach to extending education beyond conventional school spaces. It challenges existing pedagogical models by seeking avenues to educate through meaningful experiences, particularly in challenging environments and complex human scenarios.

The roots of hospital pedagogy lie in various educational practices supported by laws, institutional documents, and international agreements. According to Isabel Calvo (2017), hospital pedagogy often pertains to providing education to children facing prolonged hospital stays.

The support provided to such populations within hospitals fosters equality of opportunities, ensuring every child's right to education (Hospital Organization of Pedagogues in Europe, 2000, p. 36). In the United Kingdom, the National Association for the Welfare of Children in Hospitals (NAWCH) published a letter outlining Hospitalized Children's Rights in 1984. Subsequently, in 1986, the European Council released the European Children's Rights Letter, later endorsed by HOPE (Hospital Organization of Pedagogues in Europe) in 2000. Moreover, in 2013, the Latin-American Parliament (2013, p. 39) echoed similar sentiments. However, the scope of hospital pedagogy should not solely focus on children's rights; it's equally crucial for the educational conditions of hospitalized adults. This distinction is significant as adults in hospitals often lack adequate training and comprehension to exercise full autonomy—an indispensable element in bioethics both in theory and practice. Unlike children, who are typically represented by their parents or legal guardians, adults are responsible for their decisions, whether alone or in the company of others. The challenge arises when adults, due to their educational backgrounds, struggle to comprehend the content of the informed consent sheet. Therefore, in this research, it's imperative to recognize the correlation between autonomy, adults' levels of literacy and understanding, and the consequential impact on the informed consent process.

THEORETICAL FRAMEWORK

Research addressing the challenges related to reading and comprehending informed consent sheets exists, yet this area remains relatively underexplored within the realm of bioethics. While researchers haven't overlooked these issues, articles or data specifically focusing on this problem are scant in the field. Part of this scarcity may

be attributed to the perpetual priority given to health emergencies, which tends to overshadow educational concerns within hospital settings where diseases are treated. However, studies that do consider the informed consent sheet as an integral part of clinical or surgical processes underscore its significance. The assumption underlying these processes is that patients or their relatives possess the necessary skills to comprehend what they are signing, but this isn't always the case. The issues presented here intertwine ethical practices and pedagogy, both crucial within hospital contexts. Moreover, patients' educational challenges significantly impact bioethical processes and their underlying principles, suggesting a potential intersection for interdisciplinary collaboration.

Background

In developing countries, the illiterate population rate is higher than in developed Western countries. Hence this study begins by collecting cases in countries where similar traits occur, and places worldwide where the informed consent sheet cannot be understood by most. Several researchers state that it uses complex written language, making it difficult for illiterate or low-education people to understand and hence to keep their autonomy and rights. Informed consent is the document that guarantees the patient has received adequate information about their condition, treatments, and other options. When patients barely read, informed consent is no guarantee of the fulfillment or the autonomy principle in a doctor-patient relationship. This article explores several cases and circumstances in which the patient's educative conditions affect the guidelines of the informed consent sheet.

Seven years ago, Alaei et al. (2013) conducted a study highlighting the challenges faced by illiterate individuals above 40 years old diagnosed with esophageal cancer in Golestan Province, Northeastern Iran, regarding their understanding of informed consent sheets. This research underscores the difficulties encountered by illiterate adults in hospitals, where their autonomy is compromised due to their inability to comprehend crucial documents like the informed consent sheet. Consequently, they struggle to grasp the nature of their disease and the potential treatments required. The authors (Alaei et al., 2013) recommend simplifying informed consent documents, particularly in culturally diverse regions. Their study emphasizes the need for differentiated attention in environments with varying cultural backgrounds and dialects. Furthermore, the authors suggest that the awareness methodology employed in their study could serve as a foundational model, not only in Iran but also globally.

Corrigan (2003) argues that the existing informed consent model fosters unequal relationships, where the comprehension of the document is shaped by both doctors' and patients' expectations and values. This assessment by Corrigan (2003) stems from

observing the behavior of patients and doctors involved in drug and clinical trials, encompassing both sick patients and healthy volunteers. One heart attack survivor, interviewed as part of Corrigan's study, expressed great difficulty in deciding whether to consent to a clinical trial, stating that he would not have minded if the process had proceeded without his consent (Corrigan, 2003, p. 782). Frequently, individuals lack the necessary training to comprehend and sign an informed consent sheet, as it often contains technical jargon from the medical field, far removed from everyday language. Recognizing the patient's educational background as a fundamental aspect of the clinical process and involving the family in these decisions are crucial steps toward addressing these challenges.

Ochieng et al. (2014) conducted a study on surgical practices within university teaching hospitals in Uganda, highlighting a critical issue related to the timing of informed consent. The researchers observed that signatures are often obtained "before a patient's diagnosis is established, without a treatment plan in place" (Ochieng et al., 2014, p. 3). This circumstance underscores how problems surrounding informed consent significantly impact surgical procedures. Mere acquisition of a signature is deemed inadequate by the authors. Proposing a potential solution, Ochieng et al. (2014, p. 4) advocate for adapting informed consent documents to a comprehension-friendly template and providing doctors with training on ethical considerations. Despite the focus on areas outside Latin America in their research, the authors acknowledge the relevance of their findings to broader contexts.

Similar issues concerning informed consent have been documented in Latin America. Varástegui (2006, p. 1) conducted research in a prominent cancer center in Mexico, where the efficacy of informed consent was questioned for patients with limited education due to the "complexity of the information provided." The author (Varástegui, 2006, p. 3) evaluated Informed Consent (IC) procedures through three perspectives: the experiences of patients enrolled in clinical research trials, the perceptions of the participating doctors, and an analysis of randomly selected informed consent documents. The study is particularly insightful as it delves into the experiences of individuals from a lower socioeconomic stratum with limited education participating in clinical trials. Varástegui highlighted that "none of the patients perceived the consent's purpose as safeguarding their rights"; instead, they regarded the informed consent sheet as part of a questionnaire. Additionally, most patients found the doctor's explanations easier to comprehend than the content within the informed consent document (Varástegui, 2006, p. 5).

Colombian researchers Larreamendy, Córdoba, and Navarro (2011) conducted a study focusing on the comprehensibility of informed consent. Their research underscores the imperative to enhance the accessibility of informed consent documents for public

understanding. They advocate for the use of alternative content and multimedia approaches, including audio-visual aids, imagery, and colloquial phrases, to improve comprehension (Larreameindy, Córdoba, and Navarro, 2011, pp. 21-22).

The inquiry presented in this paper focuses on assessing the reading abilities and comprehension levels of cancer patients with limited education in Ecuador. The aim is to understand the challenges faced by patients and their families when confronted with informed consent sheets. While the study concentrates on adults, its significance spans educational, bioethical, and hospital pedagogy disciplines within the Ecuadorian context. Despite the term “pedagogy” traditionally relating to teaching children, this study draws data from adult individuals. As highlighted by Garcia (2017, p. 172), particularly in developing countries’ hospitals, the absence of public educational services within private health institutions, and vice versa, underscores a critical issue. Education should be perceived as a fundamental human right rather than a privilege, as this perception could otherwise create new barriers.

The diagnosis of reading conditions among hospitalized patients asserted in this research seeks to acknowledge the patients’ conditions, context, and possibilities of accomplishing autonomy rights with informed decision-making.

Theoretical meeting points between hospital pedagogy and bioethics

The systematic relationship between bioethics and hospital pedagogy remains largely unestablished. Notably, ethics committees often lack the regular presence of pedagogues and teachers. While there are scenarios where these professional figures should be included, their incorporation doesn’t occur as a routine practice. It’s crucial to consider instances where pedagogy plays a pivotal role in bioethics practice and vice versa—where bioethics influences pedagogical activities within clinical settings. Recognizing these intersections can enhance both fields’ effectiveness within healthcare environments.

This research primarily focuses on evaluating the reading comprehension and abilities of hospitalized patients. Concern about the educational conditions of these individuals was recognized through interviews with nurses and doctors. While these healthcare professionals acknowledged the importance of the informed consent sheet, they expressed a lack of knowledge regarding how to improve accessibility for individuals facing challenges in reading and comprehension. Consequently, they often seek assistance from pedagogues and teachers to address these situations. Recognizing this context, the researchers emphasized the necessity of assessing patients’ levels of reading comprehension to understand their circumstances better and explore potential solutions. This assessment involved analyzing patients’ abilities

to comprehend average-level texts, including short newspaper articles containing local facts.

Informed consent, while rooted in the values of bioethics and international agreements on clinical care, often overlooks practical aspects and customary habits. Consequently, it becomes a matter of practical ethics involving moral foundations. According to Constanza Ovalle (2015, p. 79), contemporary ethical value in clinical research tends to prioritize the pursuit of knowledge over the well-being of trial volunteers, although ensuring protection from potential harm remains paramount. Ovalle (2015, p. 85) observes a shift in the role of healthcare ethics committees, noting a reduction in their proactive engagement to promote and oversee ethical practices. Instead, they've become confined to bureaucratic procedures, treating informed consent as a legal requirement rather than recognizing it as a practical component responding to the moral underpinnings of autonomy.

Autonomy highlights an inescapable moral value for medical practice and professions. Fernando Lolas (1998, p. 52, own translation) states that viewing autonomy as individualism is a mistake. Rather the concept of autonomy is related to:

„The regard for people's autonomy as moral agents able to make informed decisions is essential in bioethics language. Only the permission bestowed by somebody can legitimize an action in which they are involved. The value of people is unconditional, and they should be regarded as goals, not means, with the freedom to live and decide free of interferences.“

Some aspects have not always been considered in informed consent procedures. Among the elements that should be acknowledged are the patient's social environment, psychological state, familial context, vulnerability due to race, and educational level.

In human history, autonomy and decision-making have not always been adequately considered during abusive practices against certain population groups. Since World War II, it has been essential for both men and women to participate willingly as research subjects (Ramšak, 2020, p. 14), and for this, access to information is fundamental. For example, in the Ecuadorian context, vulnerable populations often exhibit lower educational levels, impacting their understanding of informed consent sheets. Unfortunately, this aspect has not always been given due attention by physicians, researchers, psychologists, and healthcare staff. While hospital pedagogy addresses children's educational needs through resilient elements, didactic activities, and tailored teaching methods, as well as the empowerment of hospital teachers to suit their situation (Jimenez, Montes & Alcocer, 2019, p. 9), it is equally important to promote the autonomy of literate adults in hospital settings.

Since the SARS-CoV-2, also known as Covid-19, pandemic disrupted our social life, it has underscored a widespread lack of understanding regarding diseases. Health concerns have not always captivated universal interest, but the Covid-19 crisis is reshaping social perceptions about these issues. There is a growing need for pedagogical approaches that promote autonomy and foster knowledge about human rights beyond hospital settings. From a bioethical perspective, as hospitals face overwhelming patient numbers, concerns about having to prioritize certain individuals over others have become a significant challenge for both healthcare institutions and citizens.

Latin America lacks a healthcare system capable of meeting the demands amidst the Covid-19 pandemic crisis. According to Duilio Fuentes and Yolanda Angulo (2020, p. 11), three primary reasons support this assertion: firstly, the deficiency in infrastructures, medical tools, equipment, and human resources. Secondly, challenges in management hinder effective research initiatives. Thirdly, a lack of emphasis on health education contributes significantly to this issue. The authors emphasize the critical role of educational and social conditions in fostering health awareness.

Similarly, patient care in Latin America is characterized by inequality within an unethical system. From a clinical standpoint, healthcare workers dealing with Covid-19 diagnoses face numerous ethical dilemmas that instill uncertainty and fear in both patients and their families during the care process. These dilemmas include issues such as social stigma and psychological harm experienced by patients, inadequacies in the informed consent process, and the ethical considerations regarding risks and benefits in treatment procedures (Duilio Fuentes and Yolanda Angulo, 2020, pp. 11-12, translated).

Additional comments by the authors (Fuentes & Angulo, 2020, p. 12) address bioethical concerns in Latin America, such as the use of chlorine as a preventive measure and the disregard for social distancing practices. The concept of disease pedagogy emerges, aiming to educate individuals about understanding risks and adhering to sanitary guidelines for coexisting with the disease. Recent years have underscored social issues within the healthcare system. People seek information and demand governmental measures to ensure protection. However, from an individual standpoint, the disease remains unfamiliar, lacking clear and comprehensive information.

METHODOLOGY

The epistemological approach employed in this research is qualitative. Hernández-Sampieri and Mendoza (2018, p. 390, personally translated) define the qualitative

approach as ‘the understanding of phenomena through exploration from the viewpoint of participants in their natural environment, considering context, and delving into their perspectives, interpretations, and meanings.’ This epistemology focuses on individuals’ experiences within a specific context, emphasizing a deeper understanding of the issues at hand.

The researchers employed a range of instruments, including interviews, assertive reading tests, and surveys that align with a qualitative exploratory approach, aiming to derive meaning from data without merely reducing it to numerical or statistical views. While patterns and differences in data might be utilized to reinforce analysis, the emphasis remains on a qualitative understanding (Hernández-Sampieri and Mendoza, 2018, p. 10, translated). Thus, the diagnostic proposals encompass various instruments that complement the chosen epistemological perspective.

It’s also crucial to emphasize that the scope of this research is exploratory. As Swaraj (2019, p. 667) notes, ‘exploratory research is necessary to gain initial insights into problems, enabling their formulation for more precise investigation.’ Therefore, this exploration aims to establish a foundation regarding the relationship between informed consent and patients’ educational levels. The former represents an applied ethics theme, whose origins are rooted in the latter—a fundamentally educational problem.

Research processes

The process began by assessing the hospital infrastructure. During a previous project called ‘Reading for Everybody,’ researchers encountered hospitalized patients who exhibited clear difficulties in comprehension due to their educational levels. This realization prompted researchers to verify their reading abilities and comprehension levels. To conduct this evaluation, a local news article was selected, considering that most patients lacked an understanding of the oncological process, and many had not completed their schooling. A questionnaire constructed as a ‘reading comprehension assessment,’ as described by Grande and Abascal (2005), was used as a technique to gather information from the population. The data collected from the interviews with the population was then analyzed using a qualitative approach.

The interview questions were structured and suited to the hospital’s phases:

1. Oral consent explaining to the participants the objective of the inquiry and expressing confidentiality.
2. Management of the data according to every context.
3. Read-through and questions suited to understanding reading levels.

Patients were assessed within their respective contexts, taking into account their mood and psychological conditions. It's important to note that the general profile of patients falls within the intermediate percentiles of the Ecuadorian population. The hospital where these patients received care belongs to SOLCA, an organization dedicated to combating cancer. While this organization supports the impoverished population, a significant portion of the patients comes from middle-class society. Despite this, it's noteworthy that reading levels are not necessarily high, given Ecuador's prevalence of lower reading levels compared to the rest of the Latin American region. This situation reflects systematic educational deficits rooted in schooling. While this study did not analyze patients' social percentiles, it's essential to recognize that in the Ecuadorian context, lower reading levels don't always correlate with individuals having fewer economic resources.

For the next stages of the investigation, polls were used; where Grande and Abascal (2005) established that information should be homogeneous and based on the poll's structure. Pilot studies were also developed to detect different features from a unique standard.

Due to complications arising from chemotherapy in the patients, the researchers opted not to administer the mental organizing items. The research was tailored to the individual contexts and conditions of the selected participants, taking into account their oncological, psychological, physical, and cognitive states.

The interview conducted followed a semi-structured format, incorporating open-ended questions (Pelález et al., 2013, p. 13). The interview guidelines were designed to foster a dialogue with the patients, encouraging an open exchange of thoughts among participants. To validate the instruments, indicators from the questions were utilized in assessing content validity, following suggestions by Flick (2007) as outlined by Escobar and Cuervo (2008).

Categories

- Informed consent.
- Bioethical autonomy.
- Reading understanding levels.
- Contextualization of population obtained during analysis of information to create tools picked for separation and ensemble.

Itinerary

Table 1. Technicals and tools.

| Techniques | Tools | Reliability | Validity |
|-----------------|---|--|--|
| Interview | - Protocol questions. - Recording. | - Piling. - Review through experts. | - Validity from experts. - Structural validity. |
| Poll/Evaluation | - Validation of strategies. - Structural validity. | - Piling. - Review through experts. | - Validity of experts. - Structural validity. |

The instrument utilized in this study was constructed based on the aforementioned categories. According to Sarmiento (2007, p. 334, translated), categories ‘depict situations using meaningful units (derived from interviews, observations, and questionnaires) and charts displaying frequencies and percentages (derived from questionnaires and reports)’—serving as a roadmap in research development. This approach means that both polls and interviews are assessed within predetermined categories to collectively contextualize pertinent information.

Table 2. Theoretical framework, analysis of categories and indicators.

| Theoretical Framework | Analysis of Categories | Indicators |
|---|---|---|
| Informed Consent (Cañete, Guilhem and Brito 2012). | Law document that allows decision-making: - Access. - Understanding. | - The patient read or not Informed Consent. - The patient received an explanation. - The patient was able to understand the content: • Explanation. • Decision. • Authorization. |
| Bioethical autonomy (Beauchamp and Childress 2001). | Elements for to take decisions: - Knowledge. - Treatment. - Effects. | - Knowledge about disease. - Knowledge about medicines. - Patient’s knowledge about effects of treatment and medicines. - Options. |

| | | |
|--|--|--|
| Reading understanding levels (Parodi, 2011) (Benítez, 2014). | Reading understanding levels is recognized: - Critic. - Inferential. - Literary. | - Able to do a discourse from the reading. - Able to deduce ideas. - Identifies features in the text. |
| Contextualization (ASCO, 2018). | - Socio-economic characterization. - Level of choosing of population. - Cognitive problems of the oncology population. - Oncology conditions. | - Place of residence. - Family conditions. - Schooling level. - Graduation year. - Daily readings. - Books and reading frequency. - Psychological effects of the disease. - Cognitive impairment of the disease. - Knowledge of disease. |

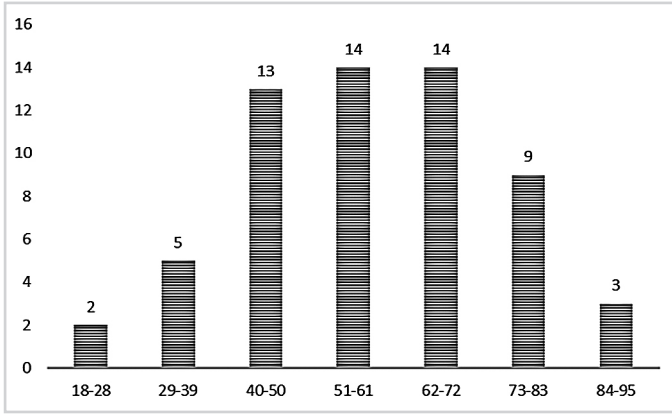
RESULTS

These samples align with the categories delineated in Tables 1 and 2, presenting outcomes derived from interviews with 66 individuals. The daily patient footfall at the hospital's ambulatory ranges between 30 to 50 people. For our study, we selected an average sample of patients daily over two months during the morning hours on weekdays. Below is a chart illustrating the education levels of the patients

Table 3. Education levels of the patients.

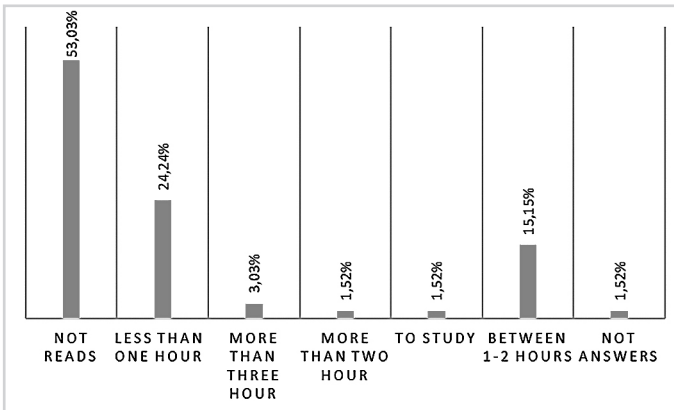
| | | |
|------------------------------------|----|---------|
| Undergraduate Degree not concluded | 2 | 3,03% |
| Undergraduate Degree concluded | 6 | 9,09% |
| Advanced technical not concluded | 3 | 4,55% |
| Advanced technical concluded | 3 | 4,55% |
| Postgraduate concluded | 1 | 1,52% |
| Bachelor's degree not concluded | 16 | 24,24% |
| Bachelor's degree concluded | 22 | 33,33% |
| Basic Education not concluded | 2 | 3,03% |
| Basic Education concluded | 11 | 16,67% |
| | 66 | 100,00% |

The individuals interviewed mostly fell between the ages of forty and seventy. The lowest count was among those under forty, while the highest frequency was seen in the over seventy to ninety-five age bracket. (Six participants declined to disclose their age).



Graph 1. Ages of patients.

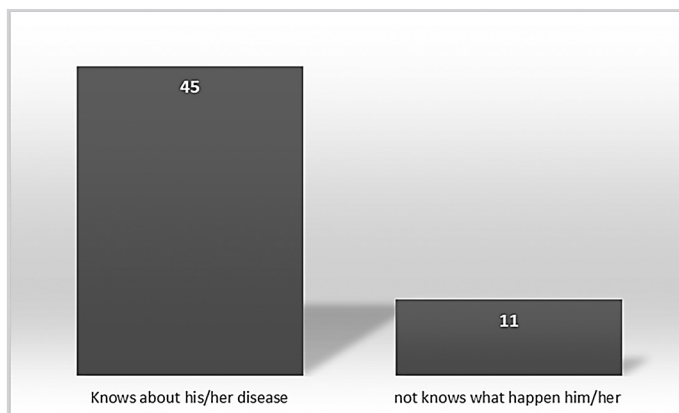
In response to the question ‘Do you know how to read?’, 90.91% (60 individuals) answered affirmatively, 6.06% (4) denied, and 3.03% (2) did not respond. Similarly, when asked about writing, all those who confirmed reading also claimed to write. However, four participants declined to answer, and two individuals who couldn’t read also mentioned they couldn’t write. Regarding the frequency of reading among each active person (including pensioners), the results are as follows:



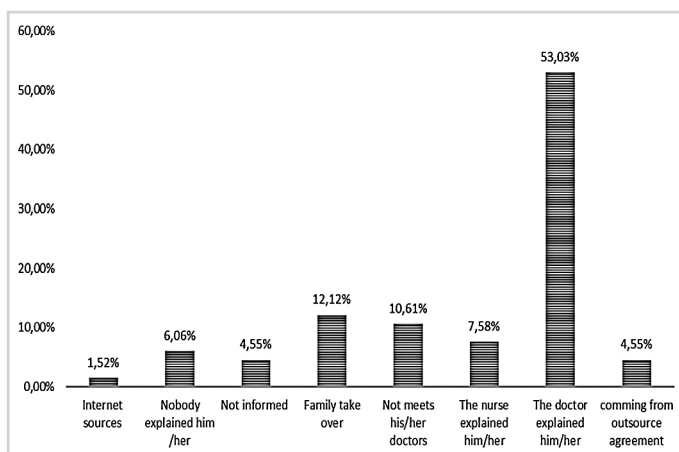
Graph 2. Reading frequency hours by day.

More than half of the respondents have jobs where reading isn’t essential for their role. Those who study or have jobs involving three to one hours of reading make up less than ten percent. Conversely, over twenty percent have jobs necessitating less than an hour of reading, indicating that nearly eighty percent read sparingly or not at all as part of their occupation.

Consequently, the majority's reading habits might not equip them to understand even the fundamental concepts in the informed consent sheet. Regarding their medical condition, patients were specifically queried about their awareness of the illness and their preferred sources of information that might aid in better understanding their situation.



Graph 3. Knowledge about the disease.



Graph 4. Sources of information.

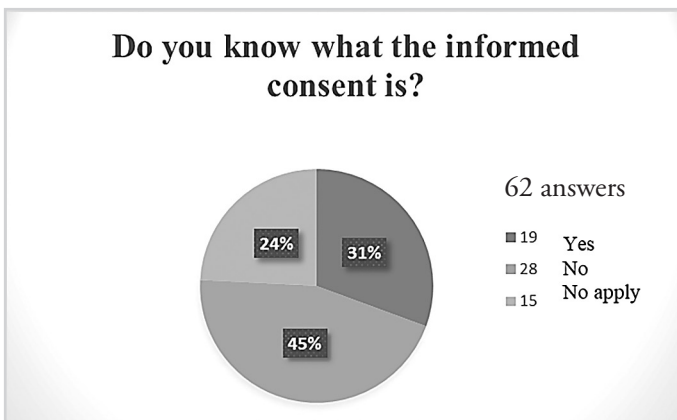
It's concerning that among the 66 individuals surveyed, 11 had no knowledge of their ailment. This lack of awareness severely impacts their autonomy, raising questions about how these patients can provide something akin to informed consent. Interestingly, among the 45 patients who claimed awareness of their condition, their sources of information varied. Notably, less than two-thirds, accounting for 53%, did not receive information directly from their doctor, despite the doctor being the primary source of information recommended for patients. Apart from official channels, information obtained from family, nurses, the Internet, or other sources shouldn't solely serve as the primary source

of information. While they might supplement understanding, these sources might not be adequate. In some instances, these alternative sources become the sole providers of information. As per protocol, it's the responsibility of the medical and psychological team to educate patients about their condition and its nature.

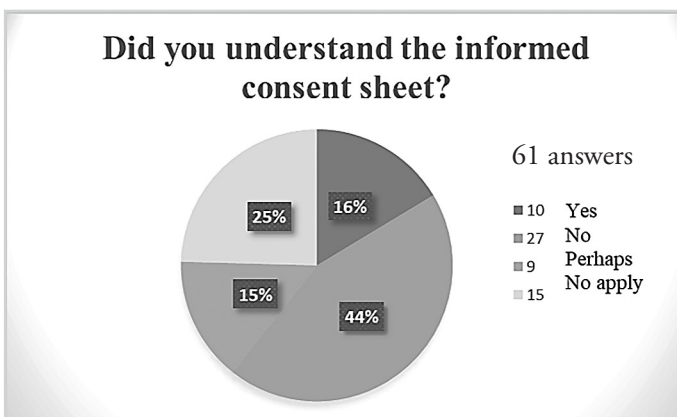
On the informed consent three questions were asked:

1. Do you know what informed consent is?
2. Did you understand the informed consent sheet?
3. Have you read the informed consent sheet?

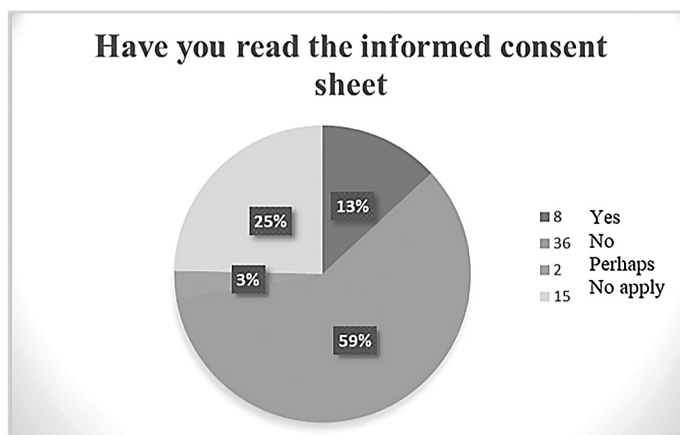
The answers that were drawn from each question appear in the next three graphs, presented as numbered:



Graph 5. Knowledge about informed consent.



Graph 6. Understanding of informed consent.



Graph 7. Reading of informed consent.

The graphs illustrate that the concept of informed consent is unfamiliar to the majority of patients. Only a small percentage demonstrate any understanding of informed consent, while others chose not to respond. Notably, a considerable number of patients have difficulty comprehending the informed consent document, with a significant percentage admitting to not having read it.

DISCUSSION

Although various research studies have explored information and topics related to informed consent and its correlation with patients' reading levels, these findings did not entirely meet the scope of this investigation, which focuses on the Latin American region and specifically Ecuador. However, the concern surrounding this issue is evident, with existing research inquiries into the relationship between informed consent and patients' educational backgrounds.

Alaei et al.'s (2013) article presents data regarding the acceptance of experiential verbal informed consent among rural populations, especially among illiterate individuals. These findings challenge the sole reliance on written documents for consent, highlighting the efficacy of verbal agreements within certain communities. Additionally, research has delved into healthcare workers' perceptions of the informed consent process.

In Ochieng et al.'s (2014) study, which focused on intern doctors, specialists, postgraduates, and general practitioners, respondents highlighted the uncertainty surrounding professional responsibility during patient interactions. The study indicated that doctors and nurses often operate without a clear delineation of professional responsibilities. Specifically, in surgical procedures, the surgeon assumes primary and ultimate responsibility for the patient's care (Ochieng et al., 2014, p. 4).

Verástegui's (2006, p. 10) recommendation to utilize video formats for informed consent aims to aid patient understanding by presenting rights in a simple audiovisual manner, using respectful language suited for the general populace. While the idea of employing video-based informed consent is innovative, it caters to an average audience and may not effectively accommodate diverse groups with varying skills and educational levels. Videos, albeit helpful, may serve as supplements to a standardized format, as patients' competencies are intricately tied to complex socio-educational backgrounds.

The ongoing discussion around informed consent encompasses two main viewpoints: one rooted in autonomy and the other in trust (Tucak & Pelčić, 2022, p. 291). This research, which commences here, acknowledges the significance of both autonomy and trust-based approaches. It recognizes that educational levels among potential patients pose challenges affecting both autonomy and trust within the applied context.

Autonomy thrives in an educational system that nurtures critical thinking and ethical deliberation based on values. Challenges within the Ecuadorian educational system not only affect technical skills and rights advocacy but also impede the critical evaluation of values. Consequently, the integration of education and bioethics, particularly within healthcare and education systems, becomes imperative. Additionally, from a trust-based perspective, elevating educational standards within the bioethical informed consent process becomes essential. Increased education levels should instill confidence, rooting trust not in ignorance but in knowledge.

CONCLUSION

Hospital pedagogy, closely entwined with bioethics, presents significant potential for development. This work proposes investigating the reading levels of adults, aligning with social research objectives. Furthermore, beyond social research, hospital pedagogy holds promise in aiding adults to comprehend informed consent sheets and other aspects pertinent to bioethical processes.

It seems that within the Ecuadorian context, the concept of informed consent lacks significance among most patients, often not garnering the attention it deserves. In the relationships between patients, family members, and doctors, informed consent isn't consistently regarded as an ethical cornerstone. While the primary aim of medical treatment is to restore health or alleviate suffering, patients might not fully appreciate the importance of the processes leading to these outcomes. Similarly, doctors and institutions might only briefly consider the moral dimensions of informed consent, paying minimal attention to the ethical rights and responsibilities outlined in the consent sheet.

The teaching of bioethics is currently limited to specialized departments and committees, yet it should extend beyond these confines. Access to basic bioethical principles should be available to individuals outside academia and healthcare settings. Patients facing medical procedures or treatments should possess an understanding of their rights and the ethical values that guide healthcare professionals and institutions. This knowledge empowers individuals to advocate for their rights and expect respectful treatment from healthcare providers throughout their medical journey.

From this point of view, hospital pedagogy implies the teaching of bioethics since we see an implicit need in the fact that many people do not understand the informed consent sheet. If we look at the situation that we have investigated in developing countries, such as Ecuador, most of the people surveyed have low levels of reading abilities and there are even cases of illiteracy. Hospital pedagogy is especially meaningful in developing countries to help vulnerable people, to the extent that this discipline reinforces bioethical values that can be applied to defend the dignity of the person. We must not forget that reading problems in adults affect their ability to understand the informed consent sheet and these problems are educational, with consequences for the defense of bioethical values. Thus, bioethics can be included in hospital pedagogy as the second entails the first concept. In any case, the goals of promoting human dignity are related to educational rights (also for adults) as well as to the foundations of bioethics.

REFERENCES

- Alaei, M., Pourshams, P., Altafi, N., Gogiani, G. & Jafari, E. (2013). Obtaining Informed Consent in an Illiterate Population. *Middle East J Dig Dis*, 5, 37-40.
- Calvo, M. I. (2017). La pedagogía hospitalaria: clave en la atención al niño enfermo y hospitalizado y su derecho a la educación. *Aula*, 23, 33-47.
- Corrigan, O. (2003). Empty ethics: the problem with informed consent. *Sociology of health & illness*, 25(3), 768-792.
- Escobar, J. & Cuervo, A. (2008). Validez de contenido y juicio de expertos: una aproximación a su utilización. *Avances en Medición*, 6(1), 27-36.
- Flick, U. (2007). *Introducción a la investigación cualitativa*. Madrid: Ediciones Morata.
- Fuentes, D. & Angulo, Y. (2020). Desafíos bioéticos en el contexto de la pandemia por el covid-19 en Latinoamérica. *Revista Latinoamericana de Bioética*, 20(1), 11-13.
- García Álvarez, A. (2017). The role of pedagogy into hospital education in South Africa: an institutional and curricular study. *Tendencias pedagógicas*, 29, 169-188.
- Grande, I. & Abascal, E. (2005). *Análisis de Encuestas*. Madrid: Esic Editorial.
- Hernández-Sampieri, R. & Mendoza, C. (2018). *Metodología de la investigación: Las rutas cuantitativa, cualitativa y mixta*. México: Editorial Mc Graw Hill Education.
- Jimenez, N. N. V., Montes, J. E. O., Alcocer, E. C. P. (2019). La pedagogía hospitalaria: un espacio de amor y reconocimiento para el paciente pediátrico oncológico. *Texto & Contexto Enfermagem*, 28. <http://dx.doi.org/10.1590/1980-265X-TCE-2018-0112>

- Larreameydy-Joers, J., Córdoba Candia, M. & Navarro Roldán, C. (2011). Contenido y comprensibilidad de consentimientos informados: estudio comparativo entre ciencias biomédicas y ciencias sociales. *Revista colombiana de bioética*, 6(1), 9-23. <https://doi.org/10.18270/rcb.v6i1.1265>
- Lolas, F. (1998). *Bioética*. Santiago de Chile: Editorial Universitaria, S.A.
- Ochieng, J., Ibingira, C., Buwembo, W., Munabi, I., Kiryowa, H., Kitara, D., Bukuluki, P. Nzarubara, G. & and Mwaka, E. (2014). Informed consent practices for surgical care at univesity teaching hospital: a case in a low resource setting. *BMC Medical Ethics*, 15(40).
- Ovalle Gómez, C. (2015). Educación en bioética como apuesta crítica a escenarios transhumanistas. *Revista Colombiana de Bioética*, 10(2), 74-87. <https://doi.org/10.18270/rcb.v10i2.1758>
- Peláez, A., Rodríguez, J., Ramírez, S., Pérez, L., Vázquez, A. & González, L. (2013). *La Entrevista*, http://www.uam.es/personal_pdi/stmaria/jmurillo/InvestigacionEE/Presentaciones/Curso_10/E
- Ramšak, M. (2020). Medical racism. *Jabr – European Journal of Bioethics*, 11(1), 9-36. <https://doi.org/10.21860/j.11.1.1>
- Swaraj, A. (2019). Exploratory Research: Purpose And Process. *Parishellean*, XV(2), 665-670.
- Tucak, I. & Pelčić, G. (2022). Informed Consent and Public Health: The Case of Childhood Vaccination. *Jabr – European Journal of Bioethics*, 13(2), 287-308. <https://doi.org/10.21860/j.13.2.3>
- Verástegui, E. L. (2006). Consenting of the vulnerable: the informed consent procedure in advanced cancer patients in Mexico. *BMC Medical Ethics*, 7(13).

Poimanje informiranog pristanka kao praktičnog bioetičkog problema: studija slučaja bolničke pedagogije na onkološkim pacijentima u Cuenci (Ekvador)

SAŽETAK

Povezanost između informiranog pristanka i obrazovanja ključna je. Naš je cilj naglasiti kako obrazovna pozadina pacijenta utječe na etička prava u medicinskim procedurama. Neki pacijenti imaju velike poteškoće s razumijevanjem značaja i sadržaja obrasca informiranog pristanka. Izgledno je da neće u potpunosti shvatiti potencijalne simptome do kojih može doći zbog njihova liječenja ili da neće biti svjesni svojih prirodnih prava. Ovo nije samo psihološki problem, već pitanje obrazovanja koje zahtijeva sveobuhvatan pristup obrazovnom razvoju koje na kraju postaje društveno pitanje u kojem i obrazovanje i zdravlje imaju ključne uloge. Ovo istraživanje proučava indikatore pismenosti pacijenata, čime se procjenjuje njihova obrazovna pozadina. Ovime se bavimo unutar okvira etičkog problema u bolničkoj pedagogiji, spajajući obrazovne i filozofske ideje. Koristeći se kvalitativnom analizom, cilj nam je razumjeti vještine čitanja pacijenata provođenjem intervjua, pritom naglašavajući okolnosti ranjivosti kao posljedice pismenosti. Ove su posljedice kategorizirane prema zapaženim sposobnostima čitanja. Isprepletanjem ovih dvaju polja znanja želimo naglasiti ljudske ranjivosti koje se možda ne uzimaju uvijek u obzir unutar tehničkih procedura zdravstvenih djelatnika i koje edukatori ili filozofi rijetko naglašavaju.

Ključne riječi: obrazac informiranog pristanka, obrazovanje, bolnička pedagogija, vještine čitanja, uvjeti osposobljavanja.