



Short communication

Humanized diagnostics: The patient at the center - communication that heals

Diagnóstico humanizado: El paciente en el centro - la comunicación que cura

Diagnóstico humanizado: O paciente no centro - comunicação que cura

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Submitted on: 02/23/2024

Revision on: 04/24/24

Approved on: 04/25/24

Abstract

Throughout this text, the importance of creating humanized diagnostic protocols is discussed. These should allow healthcare professionals to provide clear and truthful information about pathologies and/or disabilities in a humane and delicate manner, facilitating their understanding by the patient and their family. Humanized diagnosis is not just part of a “politeness” protocol in the doctor-patient relationship, but an integral and relevant part of the procedure for treating a disease or disability. This approach requires an interdisciplinary perspective, as there are elements that are linked to the strictly medical-scientific, legal-legislative-jurisprudential, and political aspects of this topic.

Keywords: Disability; Diagnosis; Health protocols; Patient rights; Informed consent.

Resumen

Este texto plantea la importancia de confeccionar protocolos de diagnóstico humanizado que permitan a los profesionales de la salud brindar información sobre patologías y/o discapacidades de manera clara y veraz, humana y delicadamente, facilitando su recepción por parte del paciente y su familia. El diagnóstico humanizado no forma parte únicamente de un protocolo de “urbanidad” en el vínculo médico – paciente: es parte integrante y relevante del procedimiento o tratamiento. Este abordaje exige una mirada interdisciplinar. En esta temática hay elementos que se vinculan a lo médico – científico; lo jurídico – legislativo – jurisprudencial y lo político.

Palabras clave: Discapacidad; Diagnóstico; Protocolos de salud; Derechos del paciente; Consentimiento informado.

Resumo

Ao longo deste texto, discute-se a importância da elaboração de protocolos diagnósticos humanizados que permitam aos profissionais de saúde fornecerem informações sobre patologias e/ou incapacidades de forma clara e verdadeira, ao mesmo tempo em que humanizada e delicada, facilitando seu acolhimento pelo paciente e sua família. O diagnóstico humanizado não é apenas parte de um protocolo de “civildade” na relação médico-paciente, mas parte integrante e relevante do procedimento para realizar o tratamento de uma doença ou deficiência. Essa abordagem requer uma abordagem interdisciplinar. Nessa disciplina há elementos que se vinculam ao médico-científico; as esferas jurídica, legislativa e política.

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Palavras-chave: Incapacidade; Diagnóstico; Protocolos de saúde; Direitos do paciente; Consentimento informado.

The biographies that have been written about Jérôme Lejeune, and the writings he has left us as a legacy, are surprising for the human, close and affable way in which he treated his patients and their families. The man who discovered the genetic cause of Down syndrome; the scientist who astonished his audiences and received awards from the most prestigious academies of science, spoke face to face with his patients, and offered advice to their families, bringing them a peace that had eluded them until then⁽¹⁾.

When some concepts such as inclusion and diversity were practically unknown, and disability was not accepted, but only tolerated or hidden, there are countless stories of mothers who came to her office full of pain and even shame for having given birth to someone who was out of what was understood as normality, and left comforted and full of love for their child⁽²⁾.

The great merit, the enormous contribution that Lejeune has left us, has not only been his talent as a researcher and scientist, but also the joy, generosity and humility with which he related to his collaborators and his patients.

When the communication of a diagnosis related to an illness or disability is received in a clear, positive and hopeful manner - from a professional who understands how the person will feel - one will be able to process the situation quickly and appropriately. On the contrary, if this communication conveys insecurity, anguish or reproaches, valuable time for the treatment may be lost while the “mourning” is being elaborated.

Even today it is common to find professionals who are not prepared to convey the existence and reality of situations that will directly affect the life of a person and his or her family.

The 20th century - and even more so the present one - was characterized by the development of biological sciences and technology in all processes of human endeavor. We are amazed by the speed and depth with which studies, treatments and diagnoses are carried out. No one doubts that medical technology has made an enormous leap in quality in the last century, that life expectancy has grown enormously and that the quality with which these years are carried forward is better today than it was a hundred years ago^(3,4).

On the other hand, explains Le Méné⁽⁵⁾, recent times have been marked by a gradual loss of awareness of the importance of conceiving the patient as a unit of body, mind and spirit, and not as an accumulation of organs and functions. This situation implies a burden and difficulty for families that makes it more difficult for them to receive news of medical diagnoses involving them.

Argentina, Brazil and other countries in the region can proudly say that they have very high-level professionals, with sophisticated academic and practical training, and that their health systems have the necessary tools to provide services in an adequate manner. This contributes to the knowledge that patients' difficulties will be well attended from the technical point of view, but we cannot ignore the fact that both a disability and an illness cause wear and tear and worry in all the members of a family.

Contact with a loved one's suffering is deeply affecting, but the way doctors communicate their news can make that reality more bearable, or much worse⁽⁶⁾.

A relevant fact is that very often specialists communicate their conclusions without having discussed them with the rest of the professionals involved in a treatment. This implies that it will be the parents who will have to "moderate" the indications of one or the other because they conflict... More than partial communications, in the case of disability or complex diseases it is of vital importance that the medical teams work as such and not as isolated professionals.

Another circumstance linked to communication, the neglect of which causes distress - sometimes premature or unnecessary - is the use of complex technical words, unknown to people outside the scientific discipline, even before the confirmation of a disease. Just as in the world of law we are insistently encouraged to write rulings and opinions -and to give advice in general- in a clearer way - in order to be understood by those who can be tried- health professionals should move in the same direction. This idea in no way implies losing sight of the fact that each area of knowledge has its own specific technical terminology that allows us to avoid expressing ambiguities or vagueness that must be avoided at all times.

Dr. Untoiglich⁽⁷⁾ has developed a concept that summarizes what we are trying to convey: "In childhood, diagnoses should be written in pencil". Experience indicates, on the contrary, that many professionals provide diagnoses written with "indelible ink", which they later have to "cross out" because they discover that their initial prognosis was neither inexorable nor accurate.

Although indirectly linked to this topic, another difficult circumstance is mentioned. Families are confronted daily with inefficient and meaningless bureaucratic procedures that they have to go through in order to achieve what is rightfully and justly theirs. There are authorizations and registrations that have to be made in order to move forward with studies, consultations, etc. that should be eliminated or simplified so that they do not mean superlative expenses for patients and their families.

Of course, there are professionals who are oblivious to this type of claims, and do not need anyone to "teach" them how to communicate their diagnoses, because they speak from the heart and imbued with a deep common sense; however, as the importance of this approach cannot depend on special temperaments or the existence of an "instinct" that leads a professional to act in this way, it is necessary to focus on the development of these competencies where professionals receive their training, and on the development of protocols that provide tools for this purpose.

In Argentina, on May 10, 2023, Law n. 27,716⁽⁸⁾ on Humanized Diagnosis for cases of Trisomy 21 detection was enacted, which provides for the development of protocols for the support of people who receive this diagnosis for their unborn or newborn child.

This law aims to ensure that information is provided through adequate interpersonal communication, in an objective manner and with updated information⁽⁹⁾.

As we have seen, an approach to the disability situation from this perspective will be a powerful contributor to the effectiveness of the steps that will then begin to be taken.

This information, which must be objective and up-to-date, must be provided within a framework that respects the family's due intimacy, since, as we have seen and as is obvious, there is also a period that we could call "mourning", which must be respected and understood.

This information, according to article 5 b), must be provided with the necessary time for the family to process it correctly, so that they can make any pertinent consultations and evacuate any doubts that may arise.

The same article, in the following paragraph, states that the information provided must be respectful of the dignity of persons with disabilities and in accessible formats with a human rights

perspective; in other words, the regulation is not limited to establishing the obligation to provide complete information, but rather provides guidelines and directives to ensure that this communication is correct and effective.

Finally, and mentioning a point of crucial relevance, Article 6° establishes that at the time of communication, recommendations for clinical follow-up, resources, information on support and support groups and associations, rights that assist the person with disabilities and his/her family, information sites, etc., should be given.

In compliance with Article 4° of the Convention on the Rights of Persons with Disabilities⁽¹⁰⁾, Argentine law also provides for the training of health personnel in the social model of disability and the early care of children born with this genetic condition, in order to favor their full inclusion. This training is key to obtaining better results, faster decisions, and facilitating the start of treatments that may be necessary to achieve the best development of the person with a disability. Ultimately, the aspiration of each family is to achieve the full development of the health and personality of the patient with a disability, within a framework of increasing autonomy.

The Humanized Diagnosis Law⁽⁸⁾ establishes, then, the need to develop protocols and generate and systematize information on Down syndrome cases, seeking to improve the statistical quality of these situations, and thus promote better decisions in health policies, and more assertive lines of work for better care and treatment of patients.

We cannot fail to mention that, despite being a law dictated specifically for the Down syndrome diagnosis stage, paragraph f) of article four establishes the inclusion in the law of other conditions associated with disability that may deserve the same considerations, broadening its scope of application.

The spirit that permeates the provisions of this law seeks the full labor and social insertion of people with Down syndrome and other disabilities, making their rights visible, ensuring their full development and avoiding any sign of discrimination that may exist.

From the entire regulatory text it is clear the importance of making these communications in an assertive manner, respecting the dignity of the person with disabilities and seeking the defense and protection of the rights they have as a person, and those specifically granted and recognized by special laws⁽⁹⁾.

Finally, the regulation establishes that the provinces may adhere to the drafting of their respective protocols, requiring a subsequent regulation, which is currently at an incipient stage.

Several Argentine provinces are in the process of analyzing the rules of adhesion, after which progress must be made in the regulation, drafting of protocols and their implementation.

The province of Salta, through Law n. 8,387 of July, 27, 2023⁽¹¹⁾ and the province of Córdoba, through Law n. 10,946 of December, 6, 2023⁽¹²⁾ have implemented it in their respective jurisdictions and there are already commissions with the task of drawing up the protocols to be implemented.

These commissions have already made concrete advances that give us hope that in the coming months the law on humanized diagnosis will begin to be a concrete and applicable reality in some of the country's jurisdictions.

These protocols constitute one of the most important challenges facing health professionals today.

It is a corroborated fact that the way in which the existence of a disability, a disease or the need for treatment is communicated can determine the greater or lesser success of the steps taken.

Communicating a diagnosis according to these guidelines is not merely a rule of "civility" between the professional and the patient, but is an integral part of the treatment that will need to be implemented.

Recognizing the importance of special communications for these cases and establishing mandatory training for professionals and the need to draw up these protocols are valuable and positive signs that Argentine society and its legislators are capable of recognizing the wealth that people with disabilities contribute to society as a whole. To this end, we will have to work to break down the barriers that still exist for the full development of the person. Clearly, then, it is possible to take steps in the right direction to achieve a reality that goes beyond inclusion: true and complete coexistence.

Acknowledgments

I thank the Universidad Siglo 21 and the Fundación Jérôme Lejeune Argentina.

Conflict of interest

The author declares that there is no conflict of interest.

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References

1. Dugast A. Jérôme Lejeune: La libertad del sabio. Buenos Aires: Bonum; 2021.
2. Lejeune C. La dicha de vivir. Madrid: Rialp; 2012.
3. Lodeiro AR. Esperanza de vida al nacer. Contribuciones y desafíos de la microbiología. Revista argentina de microbiología. 2020 [cited April 24, 2024]; 52(2): 85-87 DOI: <https://doi.org/10.1016/j.ram.2020.03.001>
4. Manzano FA. Tendencias mundiales y regionales de la esperanza de vida en edades extremas: Periodo 1950 – 2015. Revista Cardinalis. 2020 [cited April 24, 2024]; 8(14): 213-241. Available at: <https://revistas.unc.edu.ar/index.php/cardiac/article/view/29873>
5. Le Méné JM. Nascituri te salutant: La crise de conscience bioéthique. París: Salvator; 2009.
6. Gutiérrez Fernández R. La humanización de (en) la atención primaria. Revista Clínica de medicina de familia. Feb. 2017 [cited April 24, 2024] 10(1): 29-38. Available from: http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S1699-695X2017000100005&lng=es&nrm=iso
7. Untoiglich G. En la infancia los diagnósticos se escriben con lápiz. Buenos Aires: Noveduc; 2019.
8. Argentina. Presidencia de la República. Ley de Diagnóstico Humanizado, n° 27.716. Asegura la contención y acompañamiento de las personas que reciben un diagnóstico de Trisomía 21/síndrome de Down para su hijo en gestación o recién nacido, mediante una adecuada comunicación interpersonal e información objetiva y actualizada de la condición informada. Argentina, 10/05/2023. Boletín Oficial de la República Argentina. Available at: <https://www.boletinoficial.gob.ar/detalleAviso/primera/286053/20230510>
9. Lafferriere JN. Análisis de la Ley 27.716 de Diagnóstico humanizado. Buenos Aires: Editorial La Ley; 2023.
10. United Nations. Convención Sobre los Derechos de la Persona con Discapacidad. [Internet]. Available at: https://www.un.org/esa/socdev/enable/documents/tccco_nvs.pdf
11. Salta. Senado y la Cámara de Diputados de la Provincia de Salta. Ley provincial n° 8.387. Adhiere a la Provincia de Salta a la ley nacional n° 27.716 de diagnóstico humanizado. Salta, 27/07/23. Boletín n° 21542, on August 30, 2023. Available at: <https://boletinoficialsalta.gob.ar/instrumento.php?cXdlcnR5dGFibGE9THw4Mzg3cXdlnR5>
12. Cordoba. Gobierno de la Provincia de Cordoba. Ley provincial n° 10.946. Adhere a lo dispuesto en Ley Nacional n° 27716 de Diagnóstico Humanizado. Cordoba, 06/12/23. Boletín Oficial de la Provincia de Cordoba, 1ª seccion. on August 30, 2023. Available at:

https://boletinoficial.cba.gov.ar/wp-content/4p96humuzp/2024/01/1_Secc_260124.pdf

How to cite

Caballero-Sonzini LM. Humanized Diagnostics: The patient at the center - the communication that heals. *Cadernos Ibero-Americanos de Direito Sanitário*. 2024 apr./jun.;13(2):92-97

<https://doi.org/10.17566/ciads.v13i2.1232>

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