

Invisible pain, denied rights: the struggle of those living with chronic pain and seeking accessibility

Dolor invisible, derechos negados: la lucha de quienes viven con dolor crónico y buscan accesibilidad

Dor invisível, direitos negados: a luta de quem vive com dor crônica e busca acessibilidade

Aline Voltarelli¹

ORCID: 0000-0002-3491-616X

Daniela de Stefani Marquez²

ORCID: 0000-0002-1463-2012

Claudia Rosana Trevisani Corrêa³

ORCID: 0000-0002-3158-8666

Wagner Rafael da Silva⁴

ORCID: 0000-0002-0952-4877

Annelisa Gregório Andreazzi⁵

ORCID: 0009-0002-2915-9528

João Márcio Andreu⁶

ORCID: 0009-0006-8357-3972

Milena Carla Queiróz⁷

ORCID: 0000-0003-0209-6379

Thayna Lima de Oliveira⁸

ORCID: 0000-0002-0411-8546

Gabrielle Cristinne Alves Gomes de Oliveira⁹

ORCID: 0000-0001-9114-4664

Antonio Altino dos Santos Junior²

ORCID: 0009-0006-5695-1835

¹Universidad de Ciencias Empresariales y Sociales. Buenos Aires, Argentina.

²Universidade do Rio Verde. Goiás, Brazil.

³Universidade São Caetano do Sul. São Paulo, Brazil.

⁴Universidade Brasil. São Paulo, Brazil.

⁵Centro Paula Souza. São Paulo, Brazil.

⁶Núcleo de Especializações Ana Carolina Puga. São Paulo, Brazil.

⁷Centro Universitário de Rio Preto. São Paulo, Brazil.

⁸Universidade Veiga de Almeida. Rio de Janeiro, Brazil.

⁹Universidade do Estado do Rio de Janeiro. Rio de Janeiro, Brazil.

How to cite this article:

Voltarelli A, Marquez DS, Corrêa CRT, Silva WR, Andreazzi AG, Andreu JM, Queiróz MC, Oliveira TL, Oliveira GCAG, Santos Junior AA. Invisible pain, denied rights: the struggle of those living with chronic pain and seeking accessibility. *Glob Acad Nurs.* 2025;6(Spe.1):e487. <https://dx.doi.org/10.5935/2675-5602.20200487>

***Corresponding author:**

alivolter@yahoo.com.br

Submission: 08-30-2025

Approval: 09-19-2025

Abstract

The study aimed to reflect on invisible pain and denied rights, addressing the often-neglected issues of people living with chronic pain and emphasizing the relevance of the right to health and accessibility in the context of comprehensive patient care. The research method is based on critical reflection and was supported by scientific publications collected from PubMed, Google Scholar, and SciELO, covering the period 2016 to 2025. Chronic pain, often invisible, exposes the vulnerability of those seeking care, highlighting the need for humanized care and policies that guarantee accessibility and dignity. Addressing chronic pain requires not only effective clinical interventions but also the application of biolaw, focusing on the legal and ethical protection of the patient's subjective experience, ensuring adequate accessibility policies for people with disabilities, and promoting comprehensive care capable of ensuring rights, dignity, and justice for those living with ongoing suffering.

Descriptors: Chronic Pain; Equal Rights; People with Disabilities; Equitable Health Policies; Equity.

Resumén

El estudio tuvo como objetivo reflexionar sobre el dolor invisible y los derechos negados, abordando las problemáticas a menudo descuidadas de las personas que viven con dolor crónico y enfatizando la relevancia del derecho a la salud y la accesibilidad en el contexto de la atención integral al paciente. El método de investigación se basa en la reflexión crítica y se apoyó en publicaciones científicas recopiladas en PubMed, Google Scholar y SciELO, que abarcan el período de 2016 a 2025. El dolor crónico, a menudo invisible, expone la vulnerabilidad de quienes buscan atención, destacando la necesidad de una atención humanizada y políticas que garanticen la accesibilidad y la dignidad. Abordar el dolor crónico requiere no solo intervenciones clínicas efectivas, sino también la aplicación del derecho biológico, centrándose en la protección legal y ética de la experiencia subjetiva del paciente, garantizando políticas de accesibilidad adecuadas para las personas con discapacidad y promoviendo una atención integral capaz de garantizar los derechos, la dignidad y la justicia para quienes viven con sufrimiento continuo.

Descriptores: Dolor Crónico; Igualdad de Derechos; Personas con Discapacidad; Políticas Sanitarias Equitativas; Equidad.

Resumo

O estudo teve como objetivo refletir sobre a dor invisível e os direitos negados, abordando as questões frequentemente negligenciadas das pessoas que convivem com dor crônica e enfatizando a relevância do direito à saúde e da acessibilidade no contexto da atenção integral ao paciente. O método da pesquisa fundamenta-se em uma reflexão crítica e buscou respaldo em publicações científicas, coletadas das bases PubMed, *Google Scholar* e SciELO com recorte temporal de 2016 a 2025. A dor crônica, muitas vezes invisível, expõe a vulnerabilidade de quem busca cuidado, evidenciando a necessidade de humanização no atendimento e de políticas que garantam acessibilidade e dignidade. O enfrentamento da dor crônica exige não apenas intervenções clínicas eficazes, mas também a aplicação do biodireito, com foco na proteção legal e ética da experiência subjetiva do paciente, garantindo políticas de acessibilidade adequadas para pessoas com deficiência e promovendo um cuidado integral capaz de assegurar direitos, dignidade e justiça a quem vive com sofrimento contínuo.

Descritores: Dor Crônica; Igualdade de Direitos; Pessoas com Deficiência; Políticas Equânimes de Saúde; Equidade.



Introduction

The term "invisible pain" refers to the hidden and subjective nature of chronic pain, as it presents no clearly perceptible manifestations to others. It constitutes a particular experience, generally characterized by the lack of apparent physical signs, which can result in difficulties in understanding in the social and professional spheres, compromising the recognition and legitimization of the suffering experienced by the individual. Emotional pain tends to remain invisible in general care services due to several factors, notably the prevalence of a traditional clinical approach, which prioritizes objective signs and immediate pharmacological responses, to the detriment of subjective listening and the acceptance of emotional experiences. Invisible pain can result in misinterpretations or underestimation of suffering by society^{1,2}.

Strengthening the visibility of people with disabilities depends on profound structural and cultural changes that go beyond simple regulatory implementation. They require the concerted engagement of civil society, public authorities, and the private sector in strategies that promote the effective and sustained social inclusion of these individuals. Policymakers and administrators face the challenge of ensuring the availability and accessibility of healthcare for all, especially those living with invisible pain, considering the increased demand for professionals, the scarcity of healthcare, and unequal distribution. Generating and utilizing information is essential to guide decisions and political dialogue, promoting expanded access and coverage of services, strengthening the Unified Health System (SUS) toward universal healthcare, and ensuring the rights of people with disabilities, as provided for in Law No. 13,146/2015, to reduce denied rights and promote equitable healthcare policies²⁻⁴.

This study aimed to reflect on the invisible pain, denied rights, and stigma faced by people with disabilities, highlighting issues that are often overlooked.

Methodology

This study is a reflective literature review aimed at promoting a critical analysis of the topics covered, identifying key researchers, and distinguishing scientific evidence from opinion. This contributes to the reflection and updating of healthcare professionals and the improvement of clinical practice. The descriptors used were "Chronic Pain," "Equal Rights," "People with Disabilities," and "Equity Health Policies," spanning the period from 2016 to 2025. The databases used for the search were: PubMed, Google Scholar, and SciELO. The search, selection, and analysis period for the studies corresponds to August and September 2025.

Results and Discussion

Historically, people with disabilities have been rendered invisible in public policies, creating inaccessible societies and exacerbating their vulnerability. It is estimated that approximately 1 billion people worldwide have disabilities, the majority of whom live in developing countries and among the poorest. In Brazil, 24% of the

population has some form of disability. Despite the Brazilian Law for the Inclusion of Persons with Disabilities (Law No. 13,146/2015), access to rights and services still requires documentary proof of disability, which often limits their effectiveness. People with disabilities face barriers that result in poor health, lower educational attainment, reduced economic participation, greater poverty, and dependence. They have three times more difficulty accessing medical care and face limitations in rehabilitation due to financial, transportation, infrastructure, and professional training constraints. Access to water, sanitation, and public spaces is insufficient, and their vulnerability increases in natural disasters and humanitarian emergencies due to under-identification⁶.

People with chronic pain often experience "invisible pain," accompanied by neglect and limited access to adequate care, which constitutes a violation of their rights. In Brazil, even with legal frameworks and SUS guidelines, physical, communicational, and sociocultural barriers persist, hindering patient-centered care. The Neuman Model offers a framework for critical analysis and intervention planning, enabling nursing teams and multidisciplinary professionals to identify stressors, prevent complications, and promote individualized care. Applying this model demonstrates that integrating theory and practice promotes safer, more inclusive, and more efficient care, reinforcing the importance of professional training, effective communication, and institutional policies that support a preventive and inclusive approach for people with chronic pain⁶⁻⁸.

A study analyzed the barriers that influence access to health services for people with disabilities, categorizing them into physical, transportation, economic-social, technological, communication and information, organizational and political, healthcare, attitudinal, cultural, and symbolic barriers. The results can support health managers and professionals in adopting more inclusive practices and seeking solutions to improve access and quality of care for people with disabilities⁹.

In 2012, the Ministry of Health enacted Ordinance No. 793, which created the Care Network for Persons with Disabilities (RCPD) as part of the National Plan "Living Without Limits." At the municipal level, the RCPD operates primarily through Primary Health Care (PHC), promoting early identification, reception, health education, social inclusion, clinical protocols, home care, and adaptation of the school environment. Specialized Care (SC) is offered by Specialized Rehabilitation Centers (CERs) and Orthopedic Workshops, which regulate shared care with the PHC, ensuring continuous flows, qualified care, and professional training. Hospital care expands access to regulated rehabilitation beds. The RCPD is part of the Health Care Network (RAS) model, which seeks to overcome service fragmentation through the cooperative integration of services coordinated by the PHC¹⁰.

The lack of standardized strategies compromises clinical assessment, therapeutic adherence, mental health, and patient safety. Given their central role in care, nursing must lead inclusive communication practices, validate



understanding with the patient and their caregivers, and document specific needs in a structured manner in the medical record, ensuring that the entire team recognizes and respects them. Ableism, whether explicit or subtle, sustains practices that infantilize, invisibilize, or blame people with disabilities. Continuing education programs must shift the focus from adapting the individual to adapting the system, incorporating competence and cultural humility as permanent attributes of professionals. Quality assessment of care for people with disabilities must identify deficiencies and enable accountability, indicating practical measures for correction. This may require the creation of new governance structures or the strengthening of existing ones, ensuring that inclusive care strategies are applied at all levels. The World Health Organization advocates that it is crucial to recognize that accountability is not unidirectional. Processes should support both top-down performance management and bottom-up communication between quality improvement teams, subnational bodies, and national authorities, ensuring that the specific needs of people with disabilities are consistently considered and addressed¹¹.

It is crucial to consider that inclusive work environments allow nurses with disabilities to actively participate in care and leadership, expanding their repertoire and contributing to overcoming stigmas. Healthcare programs still have curricular gaps related to disability, accessibility, mental health, and universal care design, and recent mapping in medicine and reports in the field of nursing indicate heterogeneous advances and poorly operationalized regulations. The cross-curricular incorporation of content such as disability bioethics, assistive technologies, accessible communication, complex case management, and mental health promotion, along with active methodologies involving real users and simulation with accessibility features, constitutes a pragmatic path. In the workplace, institutions that adopt structured inclusion policies, including reasonable accommodations, ergonomic

assessment, inclusive human resources flows, and continuing education, demonstrate benefits for individuals, teams, and organizational outcomes^{11,12}.

Studies show that nursing acts as a bridge between institutional guidelines and clinical practice, using indicators to highlight the clinical, social, and mental health value of interventions. Ethical care for people with disabilities should be guided by the principles of autonomy, justice, non-discrimination, and mental health promotion, guiding institutional practices and policies equitably. Pain is often rendered invisible, resulting in barriers to the exercise of basic rights, social inclusion, and access to health services. The study emphasizes the importance of public policies, clinical practices, and communication strategies that consider the subjective experience of pain, promoting accessibility, humanization, and equity in care. Furthermore, it highlights the need to train healthcare professionals to recognize and validate chronic pain, ensuring appropriate interventions and respect for patient autonomy¹³.

Conclusion

Health promotion in the context of chronic pain should contribute significantly to improving the quality of life and social inclusion of those affected. Despite advances, much of the national research still focuses on disciplinary approaches, highlighting gaps in terms of an intersectoral perspective and the protection of human rights. Physical, communicational, and attitudinal barriers persist, as well as limitations related to infrastructure, human resources, and professional training. Health work management still does not fully incorporate the principles of inclusion and universal accessibility. In this context, nursing plays a strategic role in promoting equity, requiring robust institutional policies, ongoing training, systematic monitoring of results, and broad social participation to ensure inclusive and quality care.

References

1. Silva WLS. A dor invisível: desafios no reconhecimento da saúde mental em ambulatórios de clínica geral [Internet]. 2023 2025 [citado 5º de setembro de 2025];7(8):e7032. Disponível em: <https://periodicos.newssciencepubl.com/arace/article/view/7032>. Acesso em: 5 set. de 2025.
2. Morgan J. Space matters: co-creating youth-friendly services. *Lancet Child Adolesc Health*. 2024;8(4):253–254. doi:10.1016/S2352-4642(24)00049-X.
3. Oliveira APC de, Mion ABZ, Di Donato G, Galante ML, Batista HFB, Craveiro I, Mishima S, Laus AM, Teixeira ASG, Ventura CAA. Desafios, políticas e estratégias determinantes para garantir a Disponibilidade e Acessibilidade da Enfermagem no Brasil: um protocolo de scoping review. *Glob Acad Nurs* [Internet]. 30º de novembro de 2023 [citado 5º de setembro de 2025];4(2):e363. Disponível em: <https://www.globalacademicnursing.com/index.php/globacadnurs/article/view/468>
4. Diniz dos Santos D, Moreira dos Santos F. A influência da falta de visibilidade das pessoas com deficiência na garantia de seus direitos civis [Internet]. *Real*; 2025 [citado 2025 Set 5]. Disponível em: <https://revistas.icesp.br/index.php/Real/article/view/6139>.
5. Silva de Araújo AP, Bogossian T, de Gouvea Dantas Motta AC, Chaves R. Os direitos trabalhistas e previdenciários dos profissionais da saúde em tempo de pandemia. *Glob Clin Res* [Internet]. 20º de julho de 2022 [citado 5º de setembro de 2025];2(2):e40. Disponível em: <https://globalclinicalresearchj.com/index.php/globclinres/article/view/50>.
6. Pereira EL, Alecrim CGM, Silva DFL, Salles-Lima A, Santos GCG, Resende MC. Invisibilidade sistemática: pessoas com deficiência e Covid-19 no Brasil. *Interface (Botucatu)*. 2021;25(Suppl 1):e200677. doi:10.1590/interface.200677
7. Sousa RP de, Oliveira AV de, Silva JSLG, Rocha G de A, Oliveira DF de, Ramos RM de O, Balbino CM. Conectando pontos: assistência multidisciplinar à saúde do indivíduo sob a ótica de Betty Neuman. *Glob Acad Nurs* [Internet]. 25º de setembro de 2024 [citado 5º de setembro de 2025];5(3):e443. Disponível em: <https://www.globalacademicnursing.com/index.php/globacadnurs/article/view/546>



8. Macedo MS, Saldanha JHS, Tavares LRC, Ribeiro KSQS, Silva SLA, Ferrari FP, Nogueira RR, Almeida MMC. Modelos de organização da atenção básica e práticas de cuidado à pessoa com deficiência no Brasil. *Ciência & Saúde Coletiva* [Internet]. 2025 [citado 2025 set 5];30(2):e16312023. Disponível em: <https://doi.org/10.1590/1413-81232025302.16312023>.
9. Geraldo JPB, Andrade SMO. Pessoas com deficiência e as barreiras aos serviços de saúde: uma metassíntese. *Res Soc Dev*. 2022;11(6):e29082. doi:10.33448/rsd-v11i6.29082.
10. Onocko-Campos RT, Campos GWS, Ferrer AL, Corrêa CRS, Madureira PR, Gama CAP, Dantas DV, Nascimento R. Avaliação de estratégias inovadoras na organização da Atenção Primária à Saúde: Evaluación de estrategias innovadoras en la organización de la Atención Primaria de la Salud en Campinas, Sureste de Brasil. *Rev Saude Publica* [Internet]. 2012 Fev;46(1): [citado 2025 set 5]. Disponível em: <https://doi.org/10.1590/S0034-89102011005000083>.
11. Organização Mundial da Saúde. Manual para a política e estratégia nacionais de qualidade. Genebra: Organização Mundial da Saúde; 2018 [citado 2025 set 5]. Disponível em: <https://iris.who.int/bitstream/handle/10665/272357/9789240005709-por.pdf>.
12. Voltarelli A. Saúde mental e pandemia. *Glob Clin Res* [Internet]. 2º de fevereiro de 2024 [citado 5º de setembro de 2025];4(1):e57. Disponível em: <https://globalclinicalresearchj.com/index.php/globclinres/article/view/61>.
13. Lisboa LV. O alívio da dor como forma de legitimação dos direitos humanos: uma análise crítica. *Rev Dor*. 2016;17(1):45-50.

