

SHORT COMMUNICATION

Caregiver Empowerment in the Community: Health Gains and Multicultural Challenges in Rehabilitation Nursing

Empoderamiento del Cuidador Informal en la comunidad: Logros en Salud y desafíos multiculturales en Enfermería de Rehabilitación

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Cite as: Frasilho AR, Saraiva D, Margato D, Teixeira F, Frasilho V, Guerra N, et al. Caregiver Empowerment in the Community: Health Gains and Multicultural Challenges in Rehabilitation Nursing. South Health and Policy. 2025; 4:401. <https://doi.org/10.56294/shp2025401>

Submitted: 02-08-2024

Revised: 22-01-2025

Accepted: 20-05-2025

Published: 21-05-2025

Editor: Dr. Telmo Raúl Aveiro-Róbalo 

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ABSTRACT

The Caregiver Status was legally recognized in Portugal in 2019. Portuguese aging index and elderly dependency index increased in the last three decades, which has developed burden on caregivers. The empowerment of caregivers is an essential strategy to promote health gains, which is an indicator of rehabilitation nursing care. However, the multicultural nature of Portuguese society represents a significant challenge in this process. This theoretical-reflective article aims to analyze the empowerment process of the Caregiver in a community context, their health gains and the multicultural challenges for Rehabilitation Nursing. Caregiver empowerment is carried out by a reference Nurse, preferentially at home. The intervention of the Rehabilitation Nurse Specialist is essential to provide the Caregiver with the knowledge and skills needed to ensure performance of the activities of daily living, tools for the management of chronic disease, the prevention of complications and coping strategies. The empowerment process results in health gains for the Caregiver (for example, reduction of emotional overload and improvement in quality of life) and for the Person Cared For (for example, improvement in functional capacity and less exacerbation of chronic disease). Empowerment is efficient when it is structured, continuous and culturally sensitive, combined with appropriate monitoring by a Rehabilitation Nurse Specialist, with specific competencies on cultural diversity and training methods. It's suggested that health policies and multicultural community programs be created that facilitate the empowerment of Informal Caregivers and contribute to the sustainability of health systems.

Keywords: Caregivers; Community Health Services; Cultural Diversity; Empowerment; Health Gains; Rehabilitation Nursing.

RESUMEN

El Estatuto del Cuidador fue reconocido legalmente en Portugal en 2019. El índice de envejecimiento y de

dependencia de lo anciano en Portugal han aumentado en las últimas tres décadas, creando una sobrecarga para los cuidadores. El empoderamiento de los cuidadores es una estrategia imprescindible para promover logros en salud, siendo un indicador de la atención de Enfermería de Rehabilitación. Sin embargo, el multiculturalismo de la sociedad portuguesa representa un desafío importante en este proceso. Este artículo tiene como objetivo analizar el proceso de empoderamiento de Cuidador en su comunidad, demostrando las ventajas para la salud e los desafíos de la multiculturalidad para la Enfermería de Rehabilitación. El empoderamiento del cuidador lo realiza una enfermera de referencia, preferiblemente en el domicilio. La intervención de lo Enfermero Especialista en Rehabilitación es fundamental para dotar al Cuidador de conocimientos y herramientas para el cuidado, el manejo de enfermedades crónicas, la prevención de complicaciones y estrategias de afrontamiento. El proceso de empoderamiento genera logros en salud del Cuidador (reducción de la carga emocional y mejora de la calidad de vida) y de la persona cuidada (mejora de la funcionalidad y la exacerbación de enfermedades crónicas). El empoderamiento del Cuidador debe ser estructurado, continuo y culturalmente sensible, con la ayuda de lo Enfermero Especialista en Rehabilitación, con formación específica sobre diversidad cultural y métodos de educación. Se sugiere crear políticas de salud y programas comunitarios multiculturales que faciliten el empoderamiento de los Cuidadores Informales y contribuyan a la sostenibilidad de los sistemas de salud.

Palabras clave: Cuidadores; Servicios de Salud Comunitaria; Diversidad Cultural; Empoderamiento; Logros en Salud; Enfermería en Rehabilitación.

INTRODUCTION

In Portugal, the legal figure of Informal Caregiver (IC) emerged in 2019 through the Informal Caregiver Statute, which regulates the rights and duties of the IC and the Caregiver.⁽¹⁾ The role of IC can be exercised by the spouse or relatives up to the 4th degree of the Caregiver.^(1,2)

There are two types of CI: Main and non-Main.^(1,2) The Main IC accompanies and cares for the person continuously, shares a home and has no income. The non-Main IC accompanies and cares for the person sporadically and may have a professional income or income from the care they provide.⁽¹⁾ The IC is responsible for assisting with Activities of Daily Living (ADLs), providing emotional support and helping to manage the therapeutic regime of the Caregiver who is dependent on others.^(2,3)

In January 2025, there were 1,6405 IC in Portugal.⁽⁴⁾ The average age of the caregivers was 62 and the percentage of elderly caregivers was over 56%.⁽⁴⁾ In addition, in several studies, the majority of caregivers are elderly and/or have dementia.^(3,5-13)

The Portuguese Order of Nurses has defined the objectives of rehabilitation nursing as promoting self-care and maximizing the functionality of the person being cared for. To this end, it is essential to empower the IC, with a view to continuity of care and the reintegration of the person into the family and community, guaranteeing their dignity and quality of life.⁽¹⁴⁾

Empowerment is the acquisition of knowledge and skills to gain greater control and power over decision-making and actions that influence your health and that of the person you care for.^(11,15) It is a multidimensional process, involving the Person Cared For, the IC and the social, cultural and religious environment.⁽¹¹⁾ The Portuguese Directorate-General for Health considers IC empowerment to be an essential strategy for improving people's health.⁽¹⁶⁾

Rehabilitation Nursing care is evaluated through indicators associated with health gains at a personal, family and social level.⁽¹⁴⁾ Portugal is also currently a multicultural society,⁽¹⁷⁾ so the aim of this article is to analyze the process of empowering the IC in a community context, their health gains and the multicultural challenges for Rehabilitation Nursing care.

METHOD

A theoretical-reflective approach was used. A literature review was carried out during the month of March 2025 using the MeSH descriptors (Caregivers), (Empowerment), (Rehabilitation Nursing), and (Community Health Services) and the DeCS descriptor (Health Gains) in the Google Scholar and PubMed databases and on the EBSCOhost electronic platform. We considered articles published in scientific journals since 2020, with relevant information on the IC training process in a community context and/or the health gains obtained through the training process. Legislation, books and reference documents on the subject were also used to complement the review and support the reflective analysis. The main ideas were analyzed from a multicultural perspective in Rehabilitation Nursing in order to respond to the aforementioned objective.

DEVELOPMENT

Training the Informal Caregiver in a Community Context

In 2023, Portugal had the 2nd worst Ageing Index and the worst Dependency Index for the Elderly in the European Union, which has grown significantly over the last three decades.⁽¹⁸⁾ This data poses challenges for the IC, since ageing involves physiological changes that can increase the degree of dependency of the Person Cared For and, consequently, overload and cause symptoms of anxiety and depression for the IC.^(3,5,6,7,8,9,10,11,12,13,19) The IC is usually also elderly, so they may find it difficult to provide full care.^(7,16,20)

To help overcome the challenges, the IC Statute defined the right to training, information on good health practices and clarification on social support,⁽¹⁾ making IC empowerment relevant. Capacity building is a systematic, holistic and continuous process.^(3,9,11) This process is carried out by the Reference Nurse,^(3,9) in consultations, home visits, telephone contact and training sessions.^(7,9) However, IC training does not yet have an official structure that can be replicated.^(9,10,11,21)

The IC should be involved in planning their training,^(3,9) identifying the training needs, objectives and motivations of each IC.^(3,5,22,23) Generally, the IC needs knowledge and competence in techniques for carrying out the Caregiver's ADLs, managing the chronic illness, adapting the environment, preventing complications^(3,11,20,24,25) and coping strategies for themselves.^(10,11) The process is more efficient at home, as the variables that influence care are present,⁽⁵⁾ making it easier to understand and adapt to the cultural ideals of the Caregiver and the IC.⁽²⁶⁾

The empowerment of the IC brings with it ethical dilemmas, particularly regarding the delegation of nursing care to the IC, since the IC has no academic or professional training to provide care and provides care without supervision.⁽³⁾ In addition, most ICs blindly trust in their abilities and consider that they carry out the tasks correctly.⁽²⁵⁾

There are no validated assessment tools to directly monitor IC empowerment.⁽²⁷⁾ However, empowerment is effective when the IC demonstrates self-efficacy,^(6,7,27,28,29) control over their life,^(7,29) learns to take care of themselves, shares the experience of caring and knows the social support system.⁽²⁸⁾

The IC must participate in the discussion of policies on IC,⁽¹⁾ namely by participating in the Portuguese National Association of Informal Caregivers, whose mission is to defend the interests of IC, through democratic activity to define and implement public policies that guarantee the application of the IC Statute and the maintenance of dialogue, collaboration and work for a just and supportive society.⁽³⁰⁾

This is relevant in a multicultural community with diverse languages, where each person tries to safeguard their cultural identity through constant dialog and sharing.⁽¹⁷⁾ Multiculturalism can lead to language barriers and it can be difficult for nurses to understand cultural differences, negatively affecting the training process.⁽²¹⁾

Health Gains for the Informal Caregiver and the Person Cared For

Health gains can be assessed using life satisfaction assessment instruments, such as the Satisfaction with Life Scale, and, in the case of the IC of a person with dementia, the Gain in Alzheimer's Care Instrument.⁽¹²⁾

Several studies have shown that training the IC facilitates a reduction in the symptoms of anxiety and depression associated with caregiving.^(6,7,8,12,13,23,29) It also reduces the burden and promotes their physical and social well-being,^(5,7,13) reduces musculoskeletal injuries,⁽¹⁹⁾ increases the IC's motivation,^(5,6,12) promotes the establishment of constructive relationships^(6,7,13,23,24,28) and improves the IC's quality of life.^(8,11) In addition, it improves the functional capacity of the Caregiver,^(5,7,11) increases their lifespan, reduces episodes of exacerbation of the chronic disease⁽⁵⁾ and improves their quality of life.^(5,11)

Implications for Rehabilitation Nursing practice

IC training is most effective when it is carried out by a specialist nurse.^(9,10,21) The Rehabilitation Nurse Specialist (RNS) has specific competencies to intervene in IC training, so they must teach, instruct and train the IC on alternative techniques and technologies for carrying out the Caregiver's ADLs and optimizing their functionality,⁽¹⁴⁾ architectural barriers, transforming the physical environment to ensure safety, monitoring the Caregiver's condition⁽⁵⁾ and coping strategies to optimize the IC's adaptation.^(5,8,12) The process should preferably take place in a community and/or home context,⁽¹⁶⁾ which is why there needs to be an increase in the number of RNSs in primary health care.

The ethical dilemma of delegating care can be overcome by having the RNS monitor the IC's performance.⁽³⁾ Autopsy is a useful strategy for discussing aspects of care that need to be improved with the IC.^(8,25) To do this, the RNS needs to communicate effectively, and should therefore deepen their knowledge of communication techniques.⁽⁹⁾

It is essential to provide the RNS with training in cultural diversity in order to acquire multicultural awareness and techniques for overcoming language barriers, recognizing and valuing cultural differences,⁽²¹⁾ for example, in the academic training of nursing or in complementary training. Thus, the RNS will have strategies for adapting to their intervention in a multicultural community, promoting inclusive practices, with the IC adhering to the

training plan.

Rehabilitation Nursing policymakers and academics should create training curricula for ICs and provide specific training for RNSs to be able to implement effective programs and plans aimed at IC empowerment. (9,10,11,21,23) Evaluation tools should also be developed to monitor IC empowerment and more studies should be carried out to identify health gains.

CONCLUSIONS

The reflective analysis showed that the RNS's intervention is central to IC empowerment. The training plan should be specific to each IC, preferably implemented at home and with consideration for the cultural ideals of the IC and the Caregiver in order to improve the quality of the training process and the provision of care to the Caregiver.

Empowering the IC leads to health gains for the IC and the person being cared for. For the IC, it increases their sense of mental well-being and, for the Caregiver, it improves their functionality and quality of life.

The RNS faces several ethical and cultural challenges with regard to IC empowerment, which can be overcome through RNS training and continuous IC monitoring through the Reference Nurse method.

It is suggested to design multicultural community health policies and programs that facilitate IC empowerment, in order to contribute to the sustainability of health systems, with the implementation of IC empowerment programs in a multicultural community context.

REFERENCES

1. Assembleia da República. Lei n.º 100/2019. Diário da República no 171/2019 – 1ª série Portugal; 2019 p. 3-16.
2. Departamento de Prestações e Contribuições. Guia Prático - Estatuto do Cuidador Informal Principal e Cuidador Informal não Principal. 2025.
3. Martins MM. Cuidador Informal - Refletir sobre a sua Identidade. In: Melo L, Gabinete de Comunicação I e RP do CH e U de C, editors. Literacia em Saúde, um Desafio Emergente - O Poder e a Dimensão do Cuidador Informal no Sistema de Saúde. 1ª edição. Coimbra: Centro Hospitalar e Universitário de Coimbra; 2021.
4. Segurança Social. Estatuto Cuidador Informal - Evolução do número de Cuidados Informais com Estatuto Deferido por Mês em Portugal Continental. [cited 2025 Mar 11]. https://www.seg-social.pt/estatisticas-detalle/-/asset_publisher/GzVlhCL9jqf9/content/estatuto-do-cuidador-informal
5. Martins R, Santos C. Capacitação do Cuidador Informal: O Papel dos Enfermeiros no Processo de Gestão da Doença. *Gestão e Desenvolvimento*. 2020;28(28):117-37. <https://revistas.ucp.pt/index.php/gestaoedesenvolvimento/article/view/9468>
6. Kamalpour M, Aghdam AR, Watson J, Tariq A, Buys L, Eden R, et al. Online health communities, contributions to caregivers and resilience of older adults. *Health Soc Care Community*. 2021;29(2):328-43. <https://pubmed.ncbi.nlm.nih.gov/33278312/>
7. Raemdonck E, Lambotte D, De Witte N, Gorus E. Giving voice to informal caregivers of community-dwelling older adults: A systematic review of empowerment interventions. *Health Soc Care Community*. 2022;30(6):e3354-68. <https://pubmed.ncbi.nlm.nih.gov/35899425/>
8. World Health Organization. Evidence Profile: Caregiver Support. 2017. 1-35 p.
9. Ferraz L, Gonçalves M, Ferreira A, Vidinha T, Marques A. Estratégias promotoras da capacitação do cuidador informal: estudo qualitativo. *Revista de Investigação & Inovação em Saúde*. 2025;8(1):1-23. <https://riis.essnortecvp.pt/index.php/RIIS/article/view/417>
10. Afonso CIC, Madeira ACS, Magalhães SPLVT de. Post-informal caregiver's perspectives and experiences of the support network: a systematic literature review and meta-synthesis. *Revista da Escola de Enfermagem da USP*. 2024;58. <https://pubmed.ncbi.nlm.nih.gov/39514690/>
11. Reis G, Bule MJ. Capacitação e Atividade de Vida. In: Marques-Vieira C, Sousa L, editors. *Cuidados de Enfermagem de Reabilitação à Pessoa ao Longo da Vida*. Lisboa: Lusodidacta; 2016. p. 57-65.

12. García-Castro FJ, Hernández A, Blanca MJ. Life satisfaction and the mediating role of character strengths and gains in informal caregivers. *J Psychiatr Ment Health Nurs*. 2022;29(6):829-41. <https://pubmed.ncbi.nlm.nih.gov/33904250/>
13. Kolodziej IWK, Coe NB, Van Houtven CH. The Impact of Care Intensity and Work on the Mental Health of Family Caregivers: Losses and Gains. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*. 2022;77:S98-111. <https://pubmed.ncbi.nlm.nih.gov/35191980/>
14. Ordem dos Enfermeiros. Regulamento das Competências específicas do enfermeiro especialista em Enfermagem de Reabilitação. Portugal: Diário da República, 2a Série; 2019 p. 13565-8. https://www.ordemenfermeiros.pt/arquivo/legislacao/Documents/LegislacaoOE/Regulamento_125_2011_CompetenciasEspecifEnfreabilitacao.pdf
15. Chen X, Xiao X, Huang X, Wang R, Yang J, Yang L, et al. Empowerment and quality of life: the mediating role of self-efficacy and health literacy among spousal caregivers in China. *Health Promot Int*. 2023;38(5):1-12. <https://pubmed.ncbi.nlm.nih.gov/37874985/>
16. Direção-Geral da Saúde. Plano Nacional de Saúde 2030. Saúde Sustentável: de tod@s para todo@s. 2022. <https://pns.dgs.pt/wp-content/uploads/2025/01/Manual-PNS.pdf>
17. Martins MT. Portugal Multicultural: O Multiculturalismo Europeu e o seu Impacto na Sociedade Portuguesa. Universidade Aberta; 2020. <https://www.proquest.com/openview/b90e7cacb5c79df06310e778225c5555/1?pq-origsite=gscholar&cbl=2026366&diss=y>
18. PORDATA. Índice de envelhecimento e outros indicadores de envelhecimento. [cited 2025 Mar 29]. <https://www.pordata.pt/pt/estatisticas/populacao/populacao-residente/indice-de-envelhecimento-e-outros-indicadores-de>
19. Matos MJ, de Araújo C. PREVENÇÃO DE LESÕES MÚSCULO-ESQUELÉTICAS NOS CUIDADORES INFORMAIS DEPENDENTES NO DOMICÍLIO Intervenção do enfermeiro especialista em Enfermagem de Reabilitação. *Revista Portuguesa de Enfermagem de Reabilitacao*. 2021;4(1):56-63. <https://rper.aper.pt/index.php/rper/article/view/157/286>
20. Mendes JP, Mariz M, Loureiro M, Bento M da C, Cardoso C, Caridade J. Famílias que integram pessoas dependentes no Autocuidado e os recursos utilizados pelas Famílias e Enfermagem de Reabilitação. *Revista Portuguesa de Enfermagem de Reabilitação*. 2024;7(2). <https://rper.pt/article/view/35656/27141>
21. Mihu L, Marques RMD, Pontifice Sousa P. Strategies for nursing care of critically ill multicultural patients: A scoping review. *J Clin Nurs*. 2024;33(9):3468-76. <https://pubmed.ncbi.nlm.nih.gov/38590046/>
22. Santos A, Fonseca MJ, Gomes J, Soares S, Ribeiro C. A Intervenção do Enfermeiro de Reabilitação na Capacitação do Cuidador Informal do Idoso Dependente por AVC: um estudo quase-experimental. *Revista Portuguesa de Enfermagem de Reabilitação*. 2023;6(2):e339. <https://rper.aper.pt/index.php/rper/article/view/339/566>
23. Registered Nurses' Association of Ontario. Person- and Family-Centered Care. Clinical Best Practice Guidelines. Toronto; 2015. <https://rnao.ca/bpg/guidelines/person-and-family-centred-care>
24. Santos AS, Silva LC da, Muniz ME, Farah F, Souto DO, de Almeida RB, et al. Translation, Reliability and Development of a Calculator for the Brazilian Portuguese Version of the Family Empowerment Scale (FES) in Caregivers of Individuals With Cerebral Palsy. *Child Care Health Dev*. 2024;50(6):1-12. <https://pubmed.ncbi.nlm.nih.gov/39491476/>
25. Ferraz R. A autoscopia na investigação em educação: compreensão teórico-metodológica de uma observação reflexiva. *Revista Momento - diálogos em educação*. 2022;31(3):140-60. <https://periodicos.furg.br/momento/article/view/14279/9888>
26. Santos GA dos. Multiculturalismo e Direitos: uma abordagem conceitual. *Revista Gestão & Políticas Públicas*. 2020;10(1):11-31.

27. Sanches R, Rodrigues T, Cardoso L, Santos F, Radovanovic C. Instrumentos de avaliação das competências do cuidador informal: revisão integrativa. *Revista Científica de Enfermagem*. 2021;11(35):365-72. <https://www.recien.com.br/index.php/Recien/article/view/465/468>
28. Sakanashi S, Fujita K, Konno R. Components of Empowerment among Family Caregivers of Community-Dwelling People with Dementia in Japan: A Qualitative Research Study. *The Journal of Nursing Research*. 2021;29(3):1-8. <https://pubmed.ncbi.nlm.nih.gov/33840772/>
29. Liu X, Wang S, Wei L, Liu Y, Bian J, Wang S, et al. The impact of empowerment theory-based health education on Alzheimer's disease informal caregivers: a randomized controlled trial. *Front Public Health*. 2024;12(August):1-13. <https://pubmed.ncbi.nlm.nih.gov/39257940/>
30. Associação Nacional Cuidadores Informais. Associação Nacional Cuidadores Informais. Sobre Nós. [cited 2025 Apr 24]. <https://ancuidadoresinformais.pt/>

FINANCING

The authors did not receive financing for the development of this research.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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