

Development of an online course for caregivers of older stroke patients

Elaboração de um curso online para cuidadores familiares de pessoas idosas após acidente vascular cerebral

Desarrollo de un curso online para cuidadores familiares de personas mayores tras un acv

Débora Francisco do Canto^a 

Francine Melo da Costa^a 

Lediane Raquel Woiciechoski^b 

Ana Luísa Petersen Cogo^a 

Lisiane Manganelli Girardi Paskulin^a 

How to cite this article:

Canto DF, Costa FM, Woiciechoski LR, Cogo ALP, Paskulin LMG. Development of an online course for caregivers of older stroke patients. Rev Gaúcha Enferm. 2023;44:e20230040. doi: <https://doi.org/10.1590/1983-1447.2023.20230040.en>

ABSTRACT

Objective: To describe the development process of a massive, open, and online course for family caregivers of older people who had a medically diagnosed stroke.

Method: Experience report on the development of a massive, open, and online course. The preparation of the course took place from July 2021 to October 2022 and consisted of the stages: definition and analysis of the contents of the course; construction and approval of the storyboard; digital construction and approval of the early version; making the project available on a digital platform; preliminary evaluation and approval of the final version.

Results: The course aims to provide tools for the family care of older people who have suffered a stroke, improving their ability to provide care. It was built in twelve modules, using demonstrative videos, hypertext, pictures, and narrations.

Conclusion: The course development process required a team with expertise in different areas and had a positive preliminary assessment.

Descriptors: Educational technology. Education, nursing. Stroke.

RESUMO

Objetivo: Descrever o processo de desenvolvimento de um curso massivo, aberto e online para cuidadores familiares de pessoas idosas com diagnóstico médico de AVC.

Método: Relato de experiência do desenvolvimento de um curso massivo, aberto e online. A elaboração do curso ocorreu de julho de 2021 a outubro de 2022 e foi composta das etapas das de definição e análise do conteúdo do curso; construção e aprovação do storyboard; construção digital e aprovação da versão parcial; disponibilização em plataforma digital; avaliação preliminar e aprovação da versão final.

Resultados: O curso visa instrumentalizar os cuidados familiares de pessoas idosas que sofreram acidente vascular cerebral, melhorando a sua capacidade de cuidar. Foi construído em doze módulos, com a utilização de vídeos demonstrativos, hipertexto, figuras e narrações.

Conclusão: O processo de desenvolvimento do curso requereu uma equipe com expertise em diferentes áreas e apresentou uma avaliação preliminar positiva.

Descritores: Tecnologia educacional. Educação em enfermagem. Acidente vascular cerebral.

RESUMEN

Objetivo: Describir el proceso de desarrollo de un curso masivo, abierto y en línea para cuidadores familiares de personas mayores con diagnóstico de accidente cerebrovascular.

Método: Relato de experiencia de un curso masivo, abierto y en línea. Se preparó al curso de julio de 2021 a octubre de 2022. Sus etapas fueron: definición y análisis del contenido; construcción y aprobación del storyboard; construcción digital y aprobación de la versión parcial; disponibilidad en plataforma digital; evaluación preliminar y aprobación de la versión final.

Resultados: El curso tiene como objetivo dar herramientas para cuidadores familiares de personas mayores que han sufrido accidentes cerebrovasculares. Fue construido en doce módulos, con el uso de videos demostrativos, hipertexto, fotografías y narraciones.

Conclusión: El proceso de desarrollo del curso requería un equipo con experiencia en diferentes áreas y la evaluación preliminar fue positiva.

Descriptor: Tecnología educacional. Educación en enfermería. Accidente cerebrovascular.

^a Universidade Federal do Rio Grande do Sul (UFRGS). Escola de Enfermagem. Programa de Pós-Graduação em Enfermagem. Porto Alegre, Rio Grande do Sul, Brasil.

^b Universidade Federal do Rio Grande do Sul (UFRGS). Escola de Engenharia e Faculdade de Arquitetura. Programa de Pós-Graduação em Design. Porto Alegre, Rio Grande do Sul, Brasil.

■ INTRODUCTION

The significant increase in life expectancy requires us to reach an ambitious goal, that is, to maintain functional independence until the end of life. Some pathological conditions interfere in this process, among which are strokes — one of the main causes of disability in the older population⁽¹⁾. Older persons who survived a stroke usually need help with self-care after hospital discharges, and strategies have been developed considering several possible health scenarios, to guarantee quality in the transition of care⁽²⁻⁶⁾.

A cross-sectional study, carried out in the south of Brazil, described the actions of informal caregivers of older persons who suffered strokes and the difficulties they faced. Their main health care activities included providing materials and/or support for them to eat, dress, and take medication. The activities caregivers found as the most challenging were transferring and positioning the older person⁽⁷⁾.

Literature described educational interventions for the family caregivers of older people who suffered strokes. Regarding interventions with digital technology, smartphones are playing a key role, especially in the field of health education and promotion⁽⁸⁻¹⁰⁾. Caregivers often face many obstacles to participate of in-person, manual, and individualized interventions, such as the lack of adequate transportation, of financial means to attend sessions, of someone with whom to leave the person receiving care, and limited time, due to the demands of care. Virtual interventions can facilitate access, offering a promising alternative^(9,10).

Mass, online, open courses (MOOCs) are educational activities in virtual environments, developed in academia since 2008. MOOCs, among other things, enable access to a wide range of topics produced by teaching and research institutions, leading to large learning communities. Their disruptive and democratic nature helps MOOCs reach diverse audiences in different countries^(11,12).

Interventions with digital technology aimed at informal caregivers have been described since 2010 with satisfactory results, namely: improvements in the mental health of caregivers; greater capacity to solve problems associated with care; and prevention of issues caused by overload⁽⁶⁾. Considering this trend, this proposal was carried out in a line of research that studies the topic of older stroke patient care, in the field of nursing and aging.

Virtual interventions for caregivers are recent and deserve to be better tested, especially in the national context. Furthermore, these interventions explore alternatives to the transition of care, in addition to optimizing resources and strengthening the central role of the nurse as educators in actions of care transition. The goal of this study is to describe

the developing process of a MOOC for family caregivers of older persons who had a medically diagnosed stroke.

■ METHOD

This is an experience report to build and develop a MOOC for family caretakers of older people with strokes, written by nurses aided by a programmer. An experience report is here understood as the description of a practice that is relevant for the academic environment, as it allows comprehending possibilities of interventions in the field while aiding academic and professional education⁽¹³⁾.

The elaboration of the MOOC is a stage of the PhD thesis of two nurses who currently work in the care and education of older people and their families. The study that will be carried out using the MOOC as an educational intervention is a pragmatic essay. Its sample will include family caregivers of older people who had strokes and were admitted into a tertiary hospital in southern Brazil. During the development of these digital resources, we had the support of the Center of Pedagogical Support to Distance Education (NAPEAD), and of an external programmer was invited to the project.

The course was developed from July 2021 to October 2022, and the programmer built the MOOC using the software Articulate Storyline 360. The research project that originated the construction of the MOOC was approved by the Research Ethics Committee of the General Hospital of Porto Alegre under CAAE opinion: 59589922.0.0000.5327 and registered on clinicaltrials.gov under identification NCT05553340.

■ RESULTS

The development process of the MOOC had the following stages: definition and analysis of the contents of the course; construction and approval of the storyboard; digital construction and approval of the early version; making the project available on a digital platform; and preliminary evaluation and approval of the final version⁽¹⁴⁾.

Definition and analysis of the contents of the course:

the theme and content of the course were determined considering previous studies developed in the research line, that is, those whose topic was the education of family caregivers of elders who had strokes^(2,15,16). It is entirely based on the Educational Manual for Family Caregivers of Older Persons after a Stroke⁽¹⁶⁾. The MOOC aims to give family caregivers the tools they need to assist older people in daily life activities after discharge. It is divided in 12 modules that can be accessed as many times as necessary by caregivers, in any order. The modules, which last from 2 to 17 minutes, are: What is a stroke?; Caring for the caregiver; Food care;

Medication care; Hygiene care and waste; Oral hygiene and mouth care; Skin care; Positioning care; Care when putting or taking off clothes; Environment care; Tracheostomy care; and What to do if you suspect another stroke? Each module gives orientations on how to provide care. For example, the module “Tracheostomy Care” has videos showing how to manage the cannula, make the dressing, clean the internal cannula, and exchange the fastening cord.

Constructing and approving the storyboard: A storyboard was created for the proposed module structure, including reference images for each slide, the texts for the final screen of the course, and an audio recording by a professional speaker. In this stage, we held meetings with the NAPEAD team and professionals who had previous experience elaborating MOOCs. The storyboard was reviewed during an online meeting with five researchers in the same line of research, who were experts on the topic. This stage lasted three months.

Digital construction and approval of the early version: Each module developed by the programmer received a preliminary approval from the professionals who built the storyboard, and possibilities of improving it were identified. As a group, we decided that, for the visual identity of the MOOC to be in accordance with the expectations and profile of future users, we would need to create a character to be used in the course, choose a color for the background, and insert animations and music. Other resources used were images, videos demonstrating care activities, figures, and hypertexts. The videos were recorded by the nurses in the laboratory of nursing education practices, using hospital material and mannequins. This stage lasted approximately six months.

Making the project available on a digital platform: The programmer hosted the course in the Moodle platform, which belongs to the Universidade Federal do Rio Grande do Sul, where the associated nursing post-graduation program is located.

Preliminary evaluation and approval of the final version: After the MOOC was included on a digital platform, we carried out a preliminary evaluation. The goal of this evaluation was to ascertain how easy it was to access and navigate, and to evaluate its functionality and how easy it is to understand. This stage included three family caregivers of older persons who had survived strokes and were hospitalized. The mean age of the caregivers was 53, while the mean age of the patients with stroke was 67. The three caregivers were invited to participate, providing consent and filling in an assessment instrument. Caregivers had free access to any module they wanted. The mean time spent in the course was 34 minutes. The three caregivers gave positive

feedback about the proposal, its visual presentation, and content, in addition to its ease of access and navigation. Regarding suggestions, two caregivers suggested that the volume of the audio in the course should be increased. This stage lasted for a week.

■ DISCUSSION

Patients and caregivers need education regarding many specific aspects of the stages of recovery after a stroke, due to their lack of practical capacity related to care⁽⁶⁾. Regarding the content of the course, which addressed topics regarding day-to-day practical care, an integrative review attempted to analyze, in the Brazilian context, how families provide assistance to elders with stroke, and what type of care these elders receive. The activities that stood out in that study were drug administration, monitoring of physiological functions, guidance on the use of medical devices, dressing, guidance on nutritional status, neurological status, in addition to actions to prevent pressure injuries, bronchoaspiration, and trauma⁽¹⁷⁾.

Literature has also shown the potential of MOOC style courses as tools that enable the transmission of knowledge, making available quality information in the field of health education for a large audience^(11,12).

Regarding the characteristics of the digital material developed, a study about Learning How to Learn (LHTL), one of the most popular MOOCs in the world, with almost 2.5 million students registered in their first four years, found that adult learning is more difficult when the person has no time, is under high levels of stress, and when their brains cannot be as fast⁽¹⁸⁾. Authors described the multimedia principles which have shown success, since, in multimedia learning, people build mental representation from written or spoken texts, but also from images, pictures, animations, or videos⁽¹⁸⁾. To elaborate the MOOC for family caregivers of elders after strokes, we took into account the aspects highlighted by that study, including the elaboration of the course in modules; clear, objective, and informal narrations; and the use of images and demonstrative videos.

A systematic review with a meta-analysis showed that there are no educational interventions using technologies targeted at informal caregivers of people who survived strokes, which is a glaring absence. This study showed that, although caregivers believe that using technologies can be beneficial for providing a more efficient and less stressful care, many of them have focused on interventions for caregivers of patients with Alzheimer’s or dementia⁽⁸⁾.

The MOOC presented in this study is an important innovation in the national context. Internationally, regarding support to stroke survivors and their caregivers, a Chinese

research protocol was published in 2019 to create the first multidisciplinary virtual clinic for stroke care, led by nurses⁽¹⁹⁾.

This is the first opportunity for nurses who provided assistance to older persons and their caregivers to build a MOOC, and, therefore, it is a limitation of this study. We believe that the main benefit it will bring to the field is improving the assistance to family caregivers of older patients who survived strokes.

■ CONCLUSION

The development process of a MOOC required a team with experts from different fields, coupled with the knowledge from researchers and nurses who worked in this specific area and the technological support from NAPEAD professionals to develop the digital material. The course received a positive preliminary evaluation from its target audience regarding its content and functionality and represents an important advance in nursing, since it creates digital educational technology.

We recommend developing more MOOC-type courses, and evaluating their accessibility and functionality with a larger audience.

■ REFERENCES

1. World Health Organization [Internet]. Global Health Estimates 2020: Disease burden by cause, age, sex, by country and by region, 2000–2019. Geneva: WHO; 2020 [cited 2023 Apr 12]. Available from: <https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/ghe-leading-causes-of-death>
2. Day CB, Bierhals CCBK, Mocellin D, Predebon ML, Santos NO, Dal Pizzol FL, et al. Nursing home care intervention post stroke (SHARE) 1 year effect on the burden of family caregivers for older adults in Brazil: a randomized controlled trial. *Health Soc Care Community*. 2021;29(1):56–65. doi: <https://doi.org/10.1111/hsc.13068>
3. Silva JK, Boery RNSO. Effectiveness of a support intervention for family caregivers and stroke survivors. *Rev Latino Am Enfermagem*. 2021;29:e3482. doi: <https://doi.org/10.1590/1518-8345.4991.3482>
4. GokUgur H, Erci B. The effect of home care for stroke patients and education of caregivers on the caregiver burden and quality of life. *Acta Clin Croat*. 2019;58(2):321–32. doi: <https://doi.org/10.20471/acc.2019.58.02.16>
5. Zhang L, Zhang T, Sun Y. A newly designed intensive caregiver education program reduces cognitive impairment, anxiety, and depression in patients with acute ischemic stroke. *Braz J Med Biol Res*. 2019;52(9):e8533. doi: <https://doi.org/10.1590/1414-431X20198533>
6. Araújo O, Lage I, Cabrita J, Teixeira L. Training informal caregivers to care for older people after stroke: a quasi-experimental study. *J Adv Nurs*. 2018;74(9):2196–206. doi: <https://doi.org/10.1111/jan.13714>
7. Predebon ML, Dal Pizzol FL, Santos NO, Bierhals CCBK, Rosset I, Paskulin LMG. The capacity of informal caregivers in the rehabilitation of older people after a stroke. *Invest Educ Enferm*. 2021;39(2):e03. doi: <https://doi.org/10.17533/udea.iej.v39n2e03>
8. Andrades-González I, Romero-Franco N, Molina-Mula J. e-Health as a tool to improve the quality of life of informal caregivers dealing with stroke patients: Systematic review with meta-analysis. *J Nurs Scholarsh*. 2021;53(6):790–802.
9. Deeken F, Rezo A Hinz M, Discher R, Rapp MA. Evaluation of technology-based interventions for informal caregivers of patients with dementia – a meta-analysis of randomized controlled trials. *Am J Geriatr Psychiatry*. 2019;27(4):426–45. doi: <https://doi.org/10.1016/j.jagp.2018.12.003>
10. Etxeberria I, Salaberria K, Gorostiaga A. Online support for family caregivers of people with dementia: a systematic review and meta-analysis of RCTs and quasi-experimental studies. *Aging Ment Health*. 2021;25(7):1165–80. doi: <https://doi.org/10.1080/13607863.2020.1758900>
11. Eccleston C, Doherty K, Bindoff A, Robinson A, Vickers J, McInerney F. Building dementia knowledge globally through the Understanding Dementia Massive Open Online Course (MOOC). *NPJ Sci Learn*. 2019;4:3. doi: <https://doi.org/10.1038/s41539-019-0042-4>
12. Clafin S, Klekociuk S, Campbell J, Taylor B. Reasons for non-completion of a massive open online course about multiple sclerosis: a mixed methods study. *Mult Scler Relat Disord*. 2022;67:104092. doi: <https://doi.org/10.1016/j.msard.2022.104092>
13. Mussi RFF, Flores FF, Almeida CB. Pressupostos para a elaboração de relato de experiência como conhecimento científico. *Práxis Educ*. 2021;17(48):60–77. doi: <https://doi.org/10.22481/praxisedu.v17i48.9010>
14. Parulla CD, Galdino DM, Dal Pai D, Azzolin KO, Cogo ALP. Nursing assessment: the elaboration and development of a massive open online course. *Rev Gaúcha Enferm*. 2020;41(spe):e20190199. doi: <https://doi.org/10.1590/1983-1447.2020.20190199>
15. Santos NOD, Predebon ML, Bierhals CCBK, Day CB, Machado DO, Paskulin LMG. Development and validation a nursing care protocol with educational interventions for family caregivers of elderly people after stroke. *Rev Bras Enferm*. 2020;73(Suppl 3):e20180894. doi: <https://doi.org/10.1590/0034-7167-2018-0894>
16. Fuhrmann AC, Bierhals CCBK, Santos NO, Machado DO, Cordova FP, Paskulin LMG. Construction and validation of an educational manual for family caregivers of older adults after a stroke. *Texto Contexto Enferm*. 2021;30:e20190208. doi: <https://doi.org/10.1590/1980-265X-TCE-2019-0208>
17. Pio LFS, Gondim JA, Araujo OGB, Andrade Junior FV, Magalhães IG. Assistência domiciliar e cuidados a pacientes idosos no Brasil após acidente vascular cerebral: revisão integrativa. *Res Soc Dev*. 2021;11(14):e368111436463. doi: <https://doi.org/10.33448/rsd-v11i14.36463>
18. Oakley BA, Sejnowski TJ. What we learned from creating one of the world's most popular MOOCs. *NPJ Sci Learn*. 2019;4:7. doi: <https://doi.org/10.1038/s41539-019-0046-0>
19. Chau JPC, Lo SHS, Lee VWY, Choi KC, Shum EWC, Hung ZSS, et al. Effectiveness and cost-effectiveness of a virtual multidisciplinary stroke care clinic for community-dwelling stroke survivors and caregivers: a randomised controlled trial protocol. *BMJ Open*. 2019;9(5):e026500. doi: <https://doi.org/10.1136/bmjopen-2018-026500>

■ **Author contributions:**

Project administration: Débora Francisco do Canto, Francine Melo da Costa, Lisiane Manganelli Girardi Paskulin.

Concept: Débora Francisco do Canto, Francine Melo da Costa, Lisiane Manganelli Girardi Paskulin.

Writing – original draft: Débora Francisco do Canto, Francine Melo da Costa, Lediane Raquel Woiciechoski, Ana Luísa Petersen Cogo, Lisiane Manganelli Girardi Paskulin.

Writing – revision and editing: Débora Francisco do Canto, Francine Melo da Costa, Lediane Raquel Woiciechoski, Ana Luísa Petersen Cogo, Lisiane Manganelli Girardi Paskulin.

Investigation: Débora Francisco do Canto, Francine Melo da Costa, Lisiane Manganelli Girardi Paskulin.

Methodology: Débora Francisco do Canto, Francine Melo da Costa, Ana Luísa Petersen Cogo, Lisiane Manganelli Girardi Paskulin.

Software: Lediane Raquel Woiciechoski.

Supervision: Lisiane Manganelli Girardi Paskulin.

The authors declare that there is no conflict of interest.

■ **Corresponding author:**

Débora Francisco do Canto
E-mail: dcanto@hcpa.edu.br

Received: 02.16.2023
Approved: 05.17.2023

Associate editor:

Carlise Rigon Dalla Nora

Editor-in-chief:

João Lucas Campos de Oliveira