

# Development of a Massive Open Online Course to Caregivers during the COVID-19 pandemic

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## Research Article

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# Abstract

## Background

The COVID-19 disease caused several challenges to health systems, namely an increase in morbidity and mortality. The elderly are more vulnerable to this disease and more susceptible to develop serious complications. The WHO, recommends healthy directives to the elderly and their caregivers in the pandemic context. The Massive Open Online Courses (MOOC) emerge as a solution to support the empowerment of family caregivers of vulnerable people, especially in times of social isolation.

## Objectives

the study sought to develop and validate a MOOC, integrating personal and housing hygiene measures to be adopted in self-care related activities, surveillance and monitoring by caregivers of the most vulnerable home-dwelling dependent people, in order to provide safe care and prevent coronavirus infection.

## Methods

A methodological study was developed with two phases. Phase 1 aimed to validate the contents to be integrated into the MOOC and its development. Phase 2, a pilot study was carried out with a convenience sample of 33 caregivers to verify the adequacy of the course to its target audience, involved a group of caregivers. Caregivers filled one questionnaire to assess the gathered knowledge, the Family Caregiving Factors Inventory (FCFI), one sociodemographic questionnaire and the questionnaire to evaluate the acceptance of the MOOC.

## Results

Participants presented an average knowledge score before attending the MOOC of 14.94 (SD = 2.72) and after viewing the course of 16.52. The questionnaire to evaluate the acceptance of the MOOC, following the TAM model, shows that the caregivers were satisfied with the course, considering it useful, with clear and understandable information. Through the FCFI the vast majority of caregivers showed adequate knowledge to respond to the care challenges and good personal and social resources to accompany their family members.

## Conclusions

This MOOC constitutes an important tool to raise awareness and provide better training to informal caregivers.

## Introduction

The current pandemic situation, caused by a Coronavirus infection SARS-CoV-2, has placed an enormous challenge to health systems, and increased morbidity and mortality in the general population, caused by the COVID-19 disease. The World Health Organization (WHO) reports more than 2.5 million new cases and 29 466 deaths caused by the disease between October and November of 2021 in the European region (1).

Data from 2020 suggests that more than 95% of deaths occurred in people aged over 60, with more than 50% being aged 80 and over (2).

Although all age groups are at risk of contracting COVID-19, the elderly have an increased risk of developing serious conditions if they contract the disease (2). The elderly become even more vulnerable because of their frailty situation, resulting from the ageing process (3). For example, they are more prone to weak immune system that can translate into the development of more serious complications and with less favourable outcomes when they contract the disease (4).

However, vulnerability does not occur only from losses arising from physical and mental decline, due to the ageing process. Similarly, people with multi-morbidities, living in unfavourable social and economic contexts, with difficulties accessing health care, with disabilities or in a dependent state, may also present greater vulnerability (4).

In order to counter this trend, the WHO (1) advises the implementation of personal and daily measures to halt the spread of the virus, among other directives. It also emphasizes careful approaches to the elderly, their families and caregivers in the pandemic context. Due to the particular frailty condition, the elderly need to have, for example, a healthy diet, medication to maintain their health and well-being, and access to social resources. To this end, the focus should be on the dissemination of accurate and clear information, to ensure that patients and their caregivers understand how to stay physically and mentally healthy during the pandemic, and what to do if they become ill (2).

In Portugal, data released in the *Relatório da Primavera* [Spring Report] (5), pointed to 110,355 home-dwelling adults dependent on self-care, of which 48,454 were totally dependent. Also, it is estimated that there are 1.4 million informal caregivers in Portugal (6). It is widely known that caregivers lack more information on how to care for the most vulnerable people in a home context. Most of these people depend on care from family members who are often poorly prepared and lack support from health professionals. However, there is a gap in what can be done to empower these caregivers to face the new challenges faced by the pandemic.

There are various pedagogical alternatives to habilitate nurses to provide better support. In this sense, the introduction of digital solutions is considered crucial since it contributes to increasing access to information and represents a substantial part of the nursing care transformation plan. Nowadays, information and communication technologies (ICT) are used in all educational environments and are essential in the daily interventions of nurses. The recent technological advancements have greatly influenced educational strategies in nursing. With the pandemic, the need to revise the teaching-learning methods arose, and formal education was replaced and/or supplemented by distance education, where virtual classes and other online tools have become essential (7, 8).

The Massive Open Online Courses (MOOC) emerge as a solution to support the empowerment of family caregivers of vulnerable people, especially in times of social isolation. These courses are presented as a new pedagogical approach that help overcome learning barriers. The MOOC incorporates a social model, a distributed network approach, with significant autonomy of the user, aimed at adults interested in lifelong learning, from a perspective of continuous training (9). The paradigm shift and growth of MOOCs are a reality due to the increase of online learning and development in e-learning. As the conceptualizations of MOOCs begin to transform, variations will be adapted to unique contexts, focusing on the needs of the target audience and human connections (9).

Intending to contribute to the empowerment of the caregiver, the present study aimed to develop and validate a MOOC, integrating personal and housing hygiene measures to be adopted for self-care related activities, surveillance and monitoring by caregivers of the most vulnerable home-dwelling impaired person, in order to provide safe care and prevent coronavirus infection.

## Methods

A methodological study was developed with two phases. Phase 1 aimed to develop and validate the contents to be integrated into the MOOC. Subsequently, in phase 2, a pilot study was carried out with a convenience sample, to verify the adequacy of the course to its target audience.

### Phase 1

A set of topics considered relevant for the caregiver were selected: COVID-19 prevention measures, feeding and hydration, positioning and transfer, hygiene care, prevention of pressure injuries, prevention of falls and medication management. The content production process began with the design of a plan considering the pandemic situation and was grounded on scientific evidence. The course was divided into nine modules: I - Presentation of the course; II - COVID-19 prevention measures; III - Feeding and hydration; IV – Positioning V - Transfer; V – Hygiene care; VI - Dressing/Undressing; VII - Prevention of pressure injuries; VIII – Falls prevention; and IX - Medication.

It should be noted that part of the proposed contents had already been worked on previously and were integrated into a digital platform (<http://pope.esenf.pt/intentcare>), intended for informal caregivers, so they were now restructured and integrated into this course (feeding and hydration, positioning; transfer; hygiene care and medication), with the contents related to COVID-19 prevention measures, prevention of pressure injuries and falls prevention developed specifically for this MOOC.

These new contents were developed according to the recommendations of the methodology Plain Language, following the four steps: adaptation to the target population, language and style, organization, layout and design (10), using the Delphi study and nominal group techniques.

Regarding COVID-19 prevention measures, a panel of experts was invited to conduct the Delphi study. This study type, which involves a group of experts allows to formulate judgements, to evaluate and classify a set of ideas on specific issues (11). The selection of the experts followed the recommendations of Boateng and collaborators (12). The expert group included a public health doctor, six public health nurse specialists and two specialists in the area of infection prevention and control), a microbiologist and an infectious disease specialist. A total of 17 questions were formulated (Table 1) and respective answers, based on the Strategic Preparedness and Response National Plan to the Disease by New Coronavirus, by the Portuguese General-Directorate of Health, and grounded on available scientific evidence. A grid was elaborated with the detailed guidelines of the measures to be integrated into the course, and a simple language was used, without technical terms to facilitate its understanding. The document was sent to the experts, who were asked to express the relevance and clarity of each information unit by assigning each a score on the importance and applicability (from 5 being very important/clear to 1 being nothing or little important/confusing). The experts were informed that the parameters with a score of less than 4 would be eliminated or reformulated according to suggestions and comments received. A period of 3 weeks was given to submit the complete document.

Table 1  
Guiding questions sent to experts

Questions
1. What is COVID-19?
2. What are the symptoms of COVID-19?
3. Is it only people with symptoms who transmit the disease?
4. What is the incubation period of the disease (being the time it takes from one being infected to developing symptoms)?
5. Is there a treatment for COVID-19?
6. How is COVID-19 transmitted?
7. What is community transmission?
8. What are the prevention measures?
9. Why and when should one wash their hands?
10. What are the measures of social distancing?
11. What are the measures of respiratory etiquette?
12. What measures to take when being on public transportation?
13. What personal protection measures to take when providing care?
14. What measures to take when leaving home?
15. What measures to take with housing hygiene?
16. What surveillance and monitoring measures should one have with the family member?
17. How to express affection and care without compromising the safety of the person receiving care?

The use of appropriate terminology was carefully addressed by the experts' panel and modifications of syntax and lexicon were potentially suggested to facilitate understanding.

In the inherent questions in the COVID-19 introduction theme, the experts considered the importance of adding arterial hypertension to the set of diseases that put the person at risk of suffering major complications of the disease.

Theoretical justifications about the incubation period and transmission of the disease were simplified. Some specifications were also considered and simpler terms were used to facilitate understanding.

The personal protection measures to be adopted when providing care, when leaving home and housing hygiene registered a lower degree of agreement and the selected recommendations were less restrictive than initially proposed. For example, it was initially suggested to change shoes when entering the house and to put on a mask before leaving the house and remove it only when entering the house. In the surveillance and follow-up measures to be carried out with the family member, the telephone contact of the National Health Service (SNS) dedicated line was introduced.

The contents related to the prevention of pressure injuries and falls were developed by the research team and validated by a focus group. This group consisted of five nurses belonging to a research center in health technologies and health services, recruited to the nominal group technique. This technique allowed, quickly, generating consensus on the

relevant information to be transmitted. This work methodology followed the recommendations of McMillan and collaborators (13).

Subsequently, each module was recorded on video in a studio and content were later edited with animations to further disseminate the message. Other pedagogical resources facilitating learning were also developed for each module, namely written synthesis of the contents to be made available on a static web page, a questionnaire so that participants could validate their knowledge after viewing the videos and a support manual in portable document format.

The MOOC was set up on an open-access platform, managed by the Scientific Computing Unit of the Portuguese Foundation for Science and Technology. This platform that promotes digital development, inclusion and digital literacy, education and qualification of the working population, allows the creation of courses in MOOC format, open and accessible to all, being part of the transversal actions of the Portugal INCoDe.2030 initiative.

## **Phase 2**

The course was tested through a pilot study, consisting of caregivers of people dependent on self-care activities, residing in a northern city of Portugal. Participants were recruited through convenience sampling from one caregiver association. Caregivers had to agree to participate in the study, be 18 years old or older, to have internet access at home and digital skills to deal with information technologies or, in their absence, have the support of a family member or significant other.

The caregivers attended the MOOC and were interviewed by a nurse from the aforementioned association. The nurse collected information about the caregiver's profile and his/her perception of the adequacy and relevance of the course, by applying four questionnaires, three of which were developed specifically for the present study. Also, face-to-face meetings, telephone calls and videoconferences were used by the nurse to clarify any doubts about the registration process and access to the platform.

## **Material**

The sociodemographic questionnaire allowed characterizing the participants regarding age, marital status, education, cohabitation, work condition, years of care, kinship and support in care.

The knowledge questionnaire was applied by a test with 20 questions to evaluate the contents of the course. The questions were focused on the signs, symptoms, and measures of transmission of SARS-CoV-2 infection, and general measures of prevention, personal protection and surveillance. They also focused on the frequency of position change, benefits of transfer, hygiene care, prevention of pressure injuries and falls, measures promoting hydration and healthy eating, attitudes towards food refusal, safe use of medicines and care regarding personal protective equipment. Each question had 4 possible answers and each correct question was scored with 1 point. The questionnaire was applied before, and two weeks after the caregiver completed the MOOC.

The questionnaire to evaluate the acceptance of the MOOC was developed according to the Technology Acceptance Model (TAM) (14). It includes 14 questions about the duration, the adequacy of the contents, the language, the sound images, the captions, their contribution to the learning of content appropriate to the condition of caregiver and interest in using. The responses were presented in a 5-point Likert ordinal scale of agreement, ranging from 1 (totally disagree) to 5 (totally agree). A section was also provided for participants to make comments and suggestions.

The FCFI (15) comprises 4 dimensions that evaluate the caregiver resources, knowledge of care, caregiver expectations and difficulties in caring tasks according to the health professional's perspective. The knowledge relates to the degree

of understanding that the caregiver has regarding the factors that can influence the patient's health condition, the environmental factors that can affect their safety, and factors that can interfere with the emotional and cognitive state. This dimension with 7 items is evaluated by a 5-point Likert ordinal scale ranging from very poor (1) to very good (5). Difficulties in caring tasks may arise from the unpredictability of the condition of the person being cared for as well as their lack of cooperation, but also from uncontrollable external factors, differences between different caregivers, heavy physical work or permanent care. It consists of 6 items that are evaluated by an ordinal scale that varies from not difficult (1) to very difficult (5). The resources pertaining to care are related to the caregiver's ability to achieve desirable care and may include self-skills and attitudes, but also the support of family and friends. This dimension has 7 items that are evaluated by an ordinal scale that varies between usually not able to make correct judgments (1) and is able to make correct judgments (3). The expectations of the caregiver refer to the degree of realism that the caregiver has in the performance of his/her role. It includes 5 items, evaluated by a nominal scale that varies between a realistic pattern (1 point) or unrealistic (0 points) pattern. The results were standardized so that each dimension had a final score ranging from 0 to 100.

The link to the forms in electronic format (Google Forms) was sent by email to each participant. The nurse through an interview completed the FCFI.

## **Participants**

The caregivers association invited 52 caregivers to participate in the study. In the period between recruitment and the beginning of the study, 19 caregivers dropped out, due to lack of availability, the death of the person cared for, or difficulty in accessing the platform.

The characterization of the 33 caregivers who participated in the second phase of the study is shown in Table 2. The participants were aged between 37 and 78 years, with an average of 53.5 (SD = 9.44) years. Most completed upper secondary education, and only 30.3% (10) completed higher education. Also, 30.3% (10) stated that they could not account for the hours spent, since they had to be fully available to provide care. The remaining participants refer to spending between 4 to 18 hours providing daily care. The vast majority (51.5%) stated to assume the role of caregiver because they had no other alternative.

Table 2  
Sociodemographic data of caregivers who performed the preliminary evaluation of the MOOC

Variable	%(n)
Gender: Female	73 (24)
Work status:	33.3(11)
Full-time	12.1 (4)
Part-time	54.5(18)
Does not work	
Relationship:	57.6(19)
Child	27.3(9)
Mother/Father	9.1(3)
Spouse	
Cohabits with family member: Yes	87.9(29)
Support from family/friends: Yes	72.7(24)
Dependence of the family member: Chronic disease	21.2(7)
Ageing process	30.3(10)
Mental disease	21.2(7)
Congenital deficiency	9.1(3)
Sequelae of accident/sudden event	18.2(6)
Dependency condition: gradual evolution	63.6(21)

## Data analysis

Quantitative data were analysed by SPSS version 28. Univariate analysis was performed through measures of central tendency and dispersion. The t-test for paired samples was applied for comparison between the median scores obtained in the knowledge test before and after the MOOC. Also, Pearson correlation was used to analyse the association between outcome variables (scale dimensions, knowledge test results and satisfaction questionnaire scores).

## Ethical considerations

The study had the approval of the Ethics Committees of the involved institutions (ADHOC\_1434/2020). The participants were informed of their right to withdraw from the study at any time.

## Results

Participants presented an average knowledge score before attending the MOOC of 14.94 (SD = 2.72) and after viewing the course of 16.52 (SD = 2.28), the differences being statistically significant ( $t(32) = 4.180; p < .001$ ), showing increased knowledge about the topics addressed. The questions with the highest number of incorrect answers were related to

personal protection attitudes when providing care, care in the prevention of pressure injuries, measures in the packaging, disposal of medicines, packaging of the mask and its safe use on public transportation.

The caregivers considered the questions to be easy and accessible but were still able to learn new content.

Through the analysis of the FCFI questionnaire, the vast majority of caregivers showed adequate knowledge to respond to the care challenges and good personal and social resources to accompany their family members. Few difficulties associated with the role of caregiver were also reported. The caregivers' expectations were rather dispersed but, overall, they were realistic and adapted to the situation (Fig. 1).

The FCFI correlation matrix shows a moderate correlation between knowledge and care resources ( $r = .56$ ;  $n = 30$ ;  $p = .001$ ) and a moderate but negative correlation between knowledge and difficulties ( $r = -.54$ ;  $n = 30$ ;  $p = .002$ ). No statistical significance was found for the correlation between knowledge and expectations.

In addition, no statistical significance was found between the FCFI and the satisfaction scale or with specific knowledge of the MOOC.

The assessment of satisfaction with the use of technology following the TAM model is shown in Table 3.

Table 3  
Assessment of satisfaction with the technology used

	Minimum	Maximum	Median	M(SD)
1. Course duration	2	5	4	4.35(.80)
2. Material provided	3	5	5	4.58(.56)
3. Course content	2	5	4	4.35(.66)
4. Relevance of themes	4	5	5	4.68(.48)
5. Language used	3	5	5	4.42(.67)
6. Video image	1	5	5	4.45(.93)
7. Video sound	1	5	5	4.39(.96)
8. Subtitle size	2	5	5	4.52(.72)
9. Response to expectations	3	5	4	4.35(.61)
10. Contribution to improving knowledge	3	5	5	4.55(.57)
11. Contribution to improving skills	1	5	5	4.42(.81)
12. Likelihood of re-taking the course	1	5	4	4.39(.80)
13. Recommend the course	2	5	4	4.32(.65)
14. Overall assessment	1	5	5	4.45(.81)

The caregivers' assessments about the MOOC were mostly positive, suggesting its usefulness, clarity, and understandable information. Caregivers who usually expressed difficulties in understanding the information transmitted

by health technicians also shared this opinion. The course framework was considered appropriate, emphasizing the adequateness of the illustrative videos, the paused and clear timbre of voice, and graphics. Also, a special highlight was given to the added value of this type of resource in the everyday lives of people who need to make decisions about the care provided to the impaired person and that often do not know how to get adequate support. Participants also identified the benefits of this type of initiative, reporting that health services care about them thus contributing to an increase in their self-esteem and self-confidence.

The participants also gave several suggestions, which involved other initiatives such as the development of new modules, with new contents such as sensory and occupational stimulation; cognitive stimulation; management of affections and emotions; assertive communication with the impaired person and guidelines to improve resilience.

## Discussion

The Delphi technique was adopted to decide on the methodological options of phase 1 regarding the design of the course, for the selection of the contents on the COVID-19 prevention measures. In addition, the nominal group technique was used to validate the contents on the prevention of pressure injuries and falls. The Delphi technique was more adjusted to the selection of contents for which it is intended to create a guide for caregivers to implement in time of a pandemic (13). It is worth noting that since the beginning of the pandemic outbreak and in light of updated scientific evidence, the transmission and control of SARS-Cov-2 infection have gone through several adaptations at the personal, environmental level and in the provision of care to person with impairment for self-care activities. The valuable contribution of experts from the field of microbiology, infection prevention and control and public health was crucial to increase the rigour and validity of the contents worked. The nominal group technique proved to be more adapted for the development of content on the prevention of pressure injuries and falls since most colleagues shared the same research center and their geographic proximity facilitated face-to-face discussions (13). The remaining contents of the course were adequate, but not validated, since they had been addressed in the previous pedagogical evaluation processes, which resulted in a doctoral thesis and two master's dissertations (16–18). These measures ensured the development of contents based on the available scientific evidence, and tailored to the target population. It should be noted that most family caregivers who usually have low health literacy, are older and emotionally more affected by stress and overload associated with the care they provide (19–21), thus requiring the use of plain language (22,23). The pilot study aimed to test the MOOC validity and suitability to the target population. The combination of desk research with methodologies involving course recognition added more quality and effectiveness to the MOOC (24). The opinion of people with the profile of caregivers allows ensuring that the information, method and evaluation tools proposed are adapted to the target audience, being a procedure used in the evaluation of MOOCs (25–27).

Nowadays, MOOCs represent a product and a resource to achieve quality training, in a particular context of great social transformation associated with a pandemic (28). The European Commission emphasized the need to “rethink education”, with MOOCs being an important open and accessible training format (28). However, a set of recommendations need to be considered in the development of these MOOCs to ensure quality criteria (25,26,29). For the design and development of this MOOC all the items recommended to ensure its quality were considered: course overview and introduction, learning objectives, assessment and measurement, instructional materials, learning activities and learner interaction, course technology, learner support, and accessibility and usability, navigation, syllabus, instructor availability, and student input (30).

Therefore, it is important to analyse the impact of the course on improving the specific knowledge regarding the provision of care person with impairment for self-care activities, during the pandemic. The average score obtained before the course was 75% of correct questions, which shows that knowledge before the course was already at a very positive level. After completing the course, the average score rose to 83%. Overall, the caregivers considered the course

contents to be accessible and easy. The pedagogical evaluation of the knowledge gained through the MOOC has been described as an aspect that deserves great attention (31). As in other types of training, there are many variables that influence the results. The perception of less difficult questions can lead to the notion of fewer gains. Conversely, the participants' perception of difficult questions may be pedagogically discouraging. Importantly, both external and internal motivation are decisive for a better willingness to learn; however, these factors have not been evaluated. Although the results show a significant gain in improved knowledge, further detailed analysis of the questions with the highest percentage of incorrect answers is needed. In the diagnostic assessment of knowledge before the course, six questions registered over 25% of incorrect answers. After the completion of the course, three questions still showed a high percentage of wrong answers.

The questions with the highest percentage of incorrect answers corresponded to the most difficult questions. For example, one question related to the care necessary to prevent pressure injuries, being the answer options: a) change position only when a reddish zone arises; b) keep the bed linen well-stretched; c) massage the reddish zones with alcohol; and d) use an alternating pressure mattress to avoid changing the family member's position. The correct validated answer was b); however, even after taking the course, a large percentage of the participants chose option d). The reference to a more differentiated technology prompted the choice of the answer, although the justification was not acceptable. During the course, it was emphasized that the major factor in the prevention of pressure injuries was related to the change of position that should occur every 2 hours. Another question with the highest number of incorrect answers referred to the safe use of medicines, with the following answer options: a) store the medicines in a dry and warm place; b) store the medicines in the bathroom; c) dispose of the medicines outside the expiration date; and d) all the previous options are incorrect, the latter option being correct. After taking the course, most participants chose the incorrect option c) dispose of the medicines outside the expiration date. However, the idea of delivering these drugs to pharmacies was emphasized so that their destruction was safe. Another question concerned the packaging of the face mask in use, when there was a need to remove it, for example to eat, referring to the need to: a) store it in a paper bag or envelope, which must be rejected when changing the mask; b) store it in a tissue bag, which must be washed when changing the mask; c) store it in a plastic bag with holes; which must be rejected when changing the mask; and d) all the above options are correct. The correct answer was the last hypothesis; however, most participants selected only the first option. This may have resulted from some contamination of information from other sources, because, at the time, it was the most widest recommendation released by the media.

The results found through the questionnaire to evaluate the acceptance of the MOOC following the TAM model, shows that the caregivers were satisfied with the course, considering it useful, with clear and understandable information. Similar results were found in other studies (27,32,33). Caregivers evaluated the course positively, and those who had low literacy acknowledged the usefulness of the course to the caregiver's role since it delivered clear and understandable information. Implementing digital support tools requires informal caregivers' empowerment in using this technology (34).

Participants referred to the adequateness of the course's framework, the illustrative videos, the paused and clear timbre of voice, and the graphics. The added value of this type of resource to people's lives was emphasized because it allows making more informed decisions about the care to be delivered and available resources. Participants also perceived that health professionals are attentive to their needs and care about them. This aspect contributes to self-esteem and self-confidence while playing the caregiver's role (34,35). However, balancing time for care and predisposition for viewing the course proved to be demanding for many caregivers, and nurses played a pivotal role in ensuring follow-up and continuity in the project.

Despite these obstacles, 81% of participants showed satisfaction with the online format of the course, especially during the pandemic time. Similar results have been found in other studies (27,36).

The less positive opinions referred to the MOOC contents found to be more suitable for people with a physical disability rather than a cognitive impairment. Guidelines including customized options could highly contribute to improving these courses (36).

These study positive results portray the commitment of a group of carers who take their role seriously, are committed to their best preparedness, and are aware of their social duties and responsibilities. E-learning, especially web-based courses, is a new way to provide better learning, counselling and support in healthcare (33). In addition, the research team involved in the development of the MOOC is committed to the project and has raised awareness of the need to make adaptations in the teaching-learning process, both in an academic context and with caregivers. Similar results are corroborated by other studies (7,8,33). However, it remains necessary to include the acceptance and usability of digital technologies (37).

The results found through the FCFI demonstrated that caregivers present adequate knowledge and resources to care for their family members, not showing difficulties in the inherent tasks. This finding might be explained by the fact that this sample was recruited from a caregivers' association, whose one of the objectives is to empower and support people in the caring process. These associations can be a valuable resource for the empowerment of the family caregiver, because peer support helps people to feel better able to manage situations, seeking help and counselling (38,39).

The existence of a multidisciplinary team, and the important role of the nurse, is likely to support the excellent preparedness to the caregiver's role. A recent study identified that nurses perform a set of important activities with the caregiver, related to the identification of support needs, practical education, support in decision-making on treatment, and emotional support (39).

In our perspective, other factors that might have contributed to these results are related to the close kinship of caregivers to the impaired person, which allows greater proximity between the dyad, the person who cares and the recipient of care. The gradual dependency condition also allows setting the pace of the adaptation to the new caregiver role, leading to fewer difficulties in care.

Although more dispersed, the results also demonstrated that caregivers have realistic expectations regarding the performance of their role. Again, the sharing of different experiences among the various elements of the group of caregivers and the support of health professionals can lead caregivers to achieve mastery in care, and help them meet physical, emotional and comfort needs, among others. This sense of self-competence can also promote resilience in the caregiver (39).

### **Limitations of the study**

The present study has some limitations mainly related to contextual and temporal aspects. Due to the pandemic, a convenience sample was recruited from a caregiver' association. We believe that the caregivers who agreed to participate in the study were the most motivated to learn and develop skills, which may partially explain the positive outcomes, also evidenced before the taking of the course. Moreover, since these caregivers were part of an association it is likely to have contributed to the good preparedness for the role. Further studies should focus on a random sample with community participants. Problems and technical failures in the platform that supports the course were identified during the study, likely to have a negative impact on the overall assessment, but are external to the research team.

## **Conclusion**

The COVID-19 outbreak was a challenge for health professionals and challenged these professionals to seek new strategies to provide optimal care. The changes that occurred, namely the limitations in health services outreach and

social isolation, led to the use of new technologies to respond to the educational needs of the population, and in particular of family caregivers. For example, the development of online MOOCs allowed empowering family caregivers to provide better care during the pandemic.

The produced positive results have contributed to an increase in knowledge of family caregivers of home-dwelling impaired person. The MOOC received positive feedback from participants who integrated the preliminary phase of the project, being considered a useful tool for informal caregivers with basic digital literacy.

This process enabled the course to be made available on the NAU platform. Caregivers were poorly prepared for the performance of their role, specifically regarding protection measures in the context of a pandemic, severely impacting the health and well-being of the most vulnerable people and with an additional burden to the Portuguese National Health Service. Therefore, this MOOC constitutes an important tool to raise awareness and provide better training to informal caregivers. Similarly, the course can be used as an indirect resource to support health professionals and allied professionals who work under unprecedented stressful conditions.

Importantly, the development of this MOOC was a gratifying challenge and investment for all involved.

## **Declarations**

### **Competing interests**

Not applicable for that section

### **Ethics approval and consent to participate**

This study was conducted in accordance with the principles of the Declaration of Helsinki. The participants were provided with verbal and written information concerning the study, and they all provided signed informed consent to participate. The study was submitted and approved by the Ethics Committee of the higher education institution (ADHOC\_1434/2020 flow).

### **Consent for publication**

Not applicable for that section

### **Availability of data and materials**

The datasets generated and analysed in the present study are not publicly available; however, they are available from the corresponding author upon request.

### **Authors' contributions**

MJL, MRS, BS, TM – study design conceptualization, data analysis and manuscript writing.

All authors provided feedback on the draft manuscript, made the manuscript revision and approved the final version.

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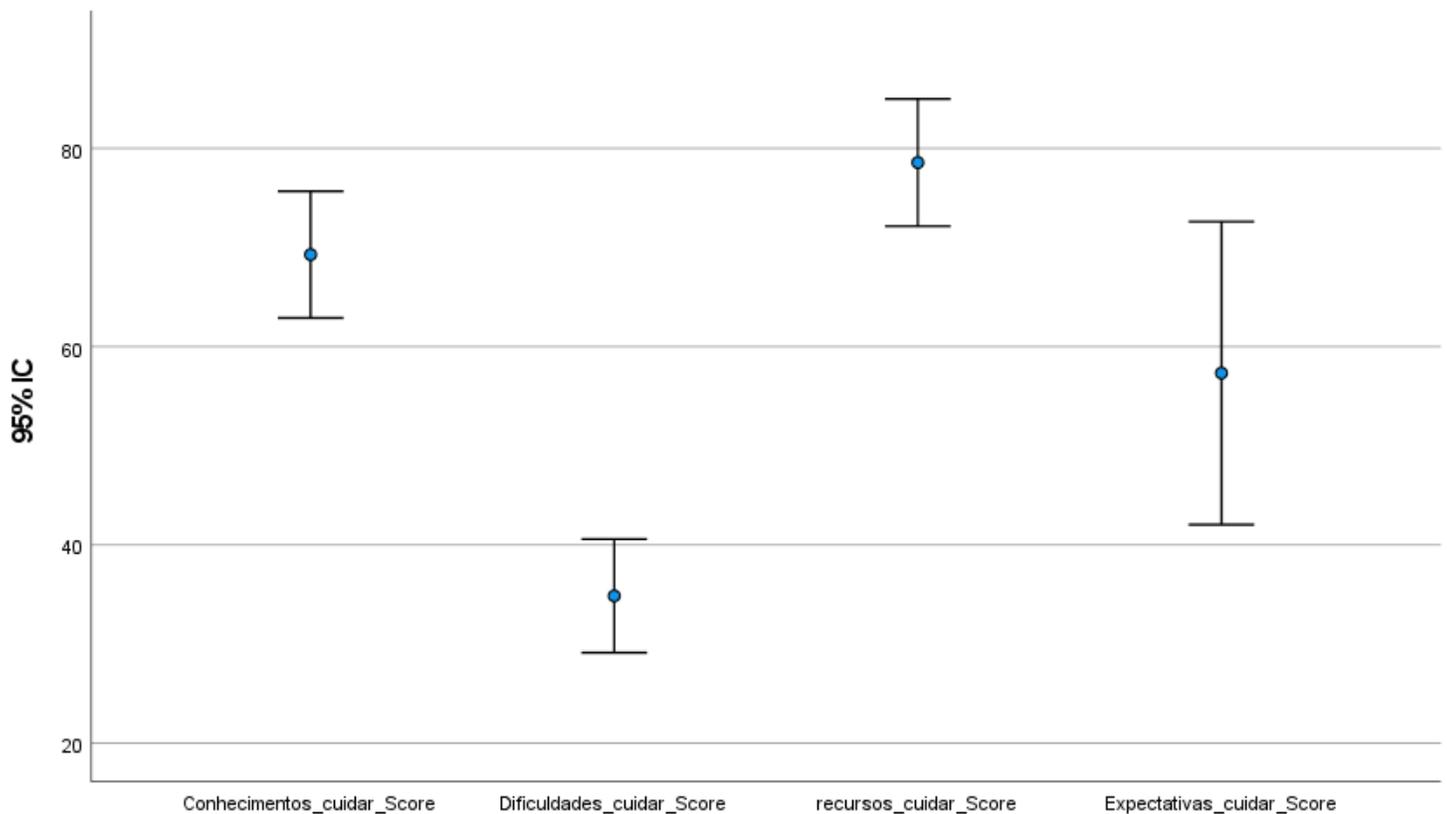
## References

1. WHO. Urgent need to take preventive measures in the fight against COVID-19 the focus of WHO/Europe advocacy campaign [Internet]. 2021. p. 14. Available from: <https://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/news/news/2021/11/urgent-need-to-take-preventive-measures-in-the-fight-against-covid-19-the-focus-of-who-europe-advocacy-campaign>
2. WHO. Supporting older people during the COVID-19 pandemic is everyone’s business [Internet]. 2020. p. 230. Available from: <https://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/news/news/2020/4/supporting-older-people-during-the-covid-19-pandemic-is-everyones-business>
3. Barbosa KTF, Oliveira FMRL de, Fernandes M das GM. Vulnerability of the elderly: a conceptual analysis. *Rev Bras Enferm.* 2019;72(Suppl 2):337–44.
4. Simões Â. Da vulnerabilidade à invisibilidade: os idosos institucionalizados durante a pandemia COVID-19. *Higeia* [Internet]. 2021;45–56. Available from: <http://hdl.handle.net/10400.11/7517>
5. OPSS. Acesso aos cuidados de saúde. Um direito em risco? *Nascer e Crescer.* 2015;24(4):147–8.
6. Portugal AA. Associação Portuguesa de familiares e amigos dos doentes de Alzheimer [Internet]. 2020. Available from: [https://alzheimerportugal.org/pt/news\\_text](https://alzheimerportugal.org/pt/news_text)
7. Ramos Junior A, Lopes Munhoz O, Rossato Badke M, Mara Caetano da Silva L, Cremonese L, Bastos Cogo S. O Social em Questão-Ano XXIII-nº 48-Set Experiência de enfermeiros docentes frente ao contexto da pandemia da COVID-19.
8. Mishra L, Gupta T, Shree A. Online teaching-learning in higher education during lockdown period of COVID-19 pandemic. *Int J Educ Res Open.* 2020;1:100012.
9. Kennedy J. Characteristics of Massive Open Online Courses (MOOCs): A Research Review. *J Interact Online Learn* [www.ncolr.org/jiol](http://www.ncolr.org/jiol) [Internet]. 2014;13(1). Available from:
10. Rudd RE. Guidelines for creating materials. *Evaluation* [Internet]. 2001;1–5. Available from:
11. Wallner C, Alpen S, Adolf M. Media Literacy Competencies for Navigating Media Cultures: Findings of a Comparative Study in Southeast Asia International Association for Media and Communication Research. 2017; (July):1–26.
12. Boateng GO, Neilands TB, Frongillo EA, Melgar-Quifonez HR, Young SL. Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. *Front Public Heal.* 2018;6(June):1–18.
13. McMillan SS, King M, Tully MP. How to use the nominal group and Delphi techniques. *Int J Clin Pharm.* 2016;38(3):655–62.
14. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS Q Manag Inf Syst.* 1989;13(3):319–39.
15. Shyu YIL. Development and testing of the Family Caregiving Factors Inventory (FCFI) for home health assessment in Taiwan. *J Adv Nurs.* 2000;32(1):226–34.

16. Landeiro M. Tecnologias educacionais interativas: contributo para o desenvolvimento de conhecimentos dos familiares cuidadores. 2015.
17. Dias AM. Contributo de uma ferramenta tecnológica interativa no suporte a familiares cuidadores de pessoas dependentes com compromisso no autocuidado alimentar-se. 2017.
18. Dias B. Desenvolvimento de conteúdos sobre a gestão do regime medicamentoso para a ferramenta interativa INTENT CARE. 2019;80.
19. Soleimaninejad A, Valizadeh-Haghi S, Rahmatizadeh S. Assessing the eHealth literacy skills of family caregivers of medically ill elderly. *Online J Public Health Inform.* 2019;11(2).
20. Wang K, Gao X, Sun F, Bishop NJ. eHealth Literacy and Caregiver Burden Among Chinese Caregivers of Older Adults With Cognitive Impairment: Does Education Matter? *J Appl Gerontol.* 2021;40(12):1837–45.
21. Bangerter LR, Griffin J, Harden K, Rutten LJ. Health information-seeking behaviors of family caregivers: Analysis of the health information national trends survey. *JMIR Aging.* 2019;2(1):1–10.
22. van der Giessen JAM, Ausems MGEM, van Riel E, de Jong A, Fransen MP, van Dulmen S. Development of a plain-language guide for discussing breast cancer genetic counseling and testing with patients with limited health literacy. *Support Care Cancer.* 2021;29(6):2895–905.
23. Sagi D, Spitzer-Shohat S, Schuster M, Daudi L, Rudolf MCJ. Teaching plain language to medical students: improving communication with disadvantaged patients. *BMC Med Educ.* 2021;21(1):4–11.
24. Witthaus G, Inamorato dos Santos A, Childs M, Tannhäuser A-C, Conole G, Nkuyubwatsi B, et al. Validation of non-formal MOOC-based learning. An analysis of assessment and recognition practices in Europe (OpenCred) [Internet]. JRC Science for Policy Report. 2016. 1–105 p. Available from: <https://ec.europa.eu/jrc%0Ahttp://publications.jrc.ec.europa.eu/repository/bitstream/JRC96968/Ifna27660enn.pdf>
25. Clafin SB, Gates R, Maher M, Taylor B V. Building a successful massive open online course about multiple sclerosis: A process description. *J Med Internet Res.* 2020;22(7):1–12.
26. Manallack DT, Yuriev E. Ten Simple Rules for Developing a MOOC. *PLoS Comput Biol.* 2016;12(10):4–7.
27. Padilha JM, Machado PP, Ribeiro AL, Ribeiro R, Vieira F, Costa P. Easiness, usefulness and intention to use a MOOC in nursing. *Nurse Educ Today.* 2021;97(April 2020).
28. Cabero-Almenara J, Barragán-Sánchez R, Palacios-Rodríguez A, Martín-Párraga L. Design and Validation of t-MOOC for the Development of the Digital Competence of Non-University Teachers. *Technologies.* 2021;9(4):84.
29. Spyropoulou N, Pierrakeas C, Kameas a. Creating Mooc Guidelines Based on Best Practices. *EDULEARN14 Proc* [Internet]. 2014;6981–90. Available from: <http://library.iated.org/view/SPYROPOULOU2014CRE>
30. Nie Y, Luo H, Sun D. Design and validation of a diagnostic MOOC evaluation method combining AHP and text mining algorithms. *Interact Learn Environ.* 2021;29(2):315–28.
31. Storme T, Vansieleghe N, Devleminck S, Masschelein J, Simons M. The emerging pedagogy of MOOCs, the educational design of technology and practices of study. *J Comput Educ.* 2016;3(3):309–28.
32. Bragagnollo GR, de Camargo RAA, Guimarães MDN, Dos Santos TS, Monteiro ELM, Ferreira BR. Development and validation of an interactive educational technology on spotted fever. *Rev Lat Am Enfermagem.* 2020;28:1–13.
33. Kurz A, Bakker C, Böhm M, Diehl-Schmid J, Dubois B, Ferreira C, et al. RHAPSODY - Internet-based support for caregivers of people with young onset dementia: Program design and methods of a pilot study. *Int Psychogeriatrics.* 2016;28(12):2091–9.
34. Klimova B, Valis M, Kuca K, Masopust J. E-learning as valuable caregivers' support for people with dementia - A systematic review. Vol. 19, *BMC Health Services Research.* BioMed Central Ltd.; 2019.

35. Moreno PA, Garcia-Pacheco JL, Charvill J, Lofti A, Langensiepen C, Saunders A, et al. ICarer: AAL for the Informal Carers of the Elderly. In: Studies in Health Technology and Informatics. IOS Press; 2015. p. 678–80.
36. Biliunaite I, Kazlauskas E, Sanderman R, Andersson G. Process Evaluation of Internet-Based Cognitive Behavioral Therapy Intervention for Informal Caregivers. *Front Med.* 2021;8(November):1–14.
37. Krick T, Huter K, Domhoff D, Schmidt A, Rothgang H, Wolf-Ostermann K. Digital technology and nursing care: A scoping review on acceptance, effectiveness and efficiency studies of informal and formal care technologies. *BMC Health Serv Res.* 2019;19(1):1–15.
38. Willis E, Semple AC, de Waal H. Quantifying the benefits of peer support for people with dementia: A Social Return on Investment (SROI) study. *Dementia.* 2018 Apr 1;17(3):266–78.
39. Varik M, Medar M, Saks K. Launching support groups for informal caregivers of people living with dementia within participatory action research. *Action Res.* 2021;

## Figures



**Figure 1**

Variation of standardized scores assigned to each dimension of the FCFI