REVISTA DE ENFERMAGEM REFERÊNCIA
homepage: https://rr.esenfc.pt/rr/
ISSNe: 2182.2883

RESEARCH PAPER

Feeding a person: design and content development for a digital tool for care to dependent people

Alimentar pessoa: conceção e desenvolvimento de uma ferramenta digital para cuidar de pessoas dependentes

Alimentar a la persona: concepción y desarrollo de una herramienta digital de atención a personas dependientes

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Abstract

Background: Digital platforms are a resource in health.

Objective: The study aims to describe the design, development, and validation of the content of the *feeding a person*, for integration into a digital platform, designed to support family caregivers.

Methodology: The production of content was carried out by a focus group that, based on the literature and through the plain language methodology, designed the material to be included in the platform. The material produced was validated by 15 experts using the Delphi technique and subsequently subjected to evaluation by 8 caregivers.

Results: Dentition, dietary needs, hydration, care before, during, and after feeding the person, changes in swallowing, and special situations were the contents identified according to the needs of caregivers. The information has been refined until the final structure and contents presented a simple language, logical organization, appropriate to the little differentiated population with low health literacy.

Conclusion: The contents were considered facilitators of informed decision-making by caregivers of people with impaired self-feeding.

Keywords: activities of daily living; health education; e-Health tools; caregivers; self-care

Resumo

Enquadramento: As plataformas digitais são um recurso na saúde.

Objetivo: O estudo pretende descrever a conceção, desenvolvimento e validação dos conteúdos do tema alimentar pessoa, a integrar numa plataforma digital, destinada a apoiar familiares cuidadores.

Metodologia: A produção de conteúdos foi realizada por um grupo focal que, baseado na literatura e através da metodologia *plain language*, desenhou o material a incluir na plataforma. O material produzido foi validado por 15 peritos recorrendo à técnica Delphi e posteriormente submetidas a avaliação de 8 cuidadores.

Resultados: Dentição, necessidades nutricionais, hidratação, cuidados a ter antes, durante e depois de alimentar a pessoa, alterações da deglutição e algumas situações especiais foram os conteúdos identificados para dar resposta às necessidades dos cuidadores. A informação foi refinada até que a estrutura e os conteúdos finais apresentassem uma linguagem simples, organização lógica, adequada à população, pouco diferenciada e com baixa literacia em saúde.

Conclusão: Os conteúdos foram considerados facilitadores para uma tomada de decisão fundamentada por parte de quem cuida de pessoas com compromisso no autocuidado alimentar-se.

Palavras-chave: atividades de vida diária; educação em saúde; ferramentas da e-saúde; cuidadores; autocuidado

Resumen

Marco contextual: Las plataformas digitales son un recurso en la sanidad.

Objetivo: El estudio tiene como objetivo describir el diseño, el desarrollo y la validación de los contenidos del tema *alimentar a la persona*, para ser integrados en una plataforma digital destinada a apoyar a los cuidadores familiares.

Metodología: La producción de contenidos la realizó un grupo focal que, con base en la literatura y a través de una metodología de lenguaje claro, diseñó el material para incluirlo en la plataforma. El material producido lo validaron 15 expertos mediante la técnica Delphi y posteriormente fue sometido a la evaluación de 8 cuidadores.

Resultados: Dentición, necesidades nutricionales, hidratación, cuidados antes, durante y después de la alimentación de la persona, trastornos en la deglución y algunas situaciones especiales fueron los contenidos identificados para dar respuesta a las necesidades de los cuidadores. La información fue depurada hasta que la estructura y los contenidos finales presentaron un lenguaje claro, una organización lógica, adecuada a la población, poco diferenciada y con baja alfabetización en la salud.

Conclusión: Se consideró que los contenidos facilitaban la toma de decisiones fundamentadas por parte de quienes cuidan a las personas con un compromiso en el autocuidado alimentarse.

Palabras clave: actividades de la vida diaria; educación en salud; herramientas de la esalud; cuidadores; autocuidado

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Received: 14.08.19
Accepted: 08.01.20

How to cite this article: Fontão, A. M., Lumini, M. J., & Martins, T. (2020). Feeding a person: design and content development for a digital tool for care to dependent people. *Revista de Enfermagem Referência*, 5(1), e19054. doi: 10.12707/RIV19054.

Introduction

Feeding is influenced by psychosocial, cultural, religious, and economic factors. Aging brings with it alterations that can affect the food habits of a person. Changes in ingestion, chewing, swallowing, digestion, and absorption (due to decreased intestinal motility and digestive juice production), in association with sensory changes (taste and smell) and possible alterations in the mouth (less saliva and altered dentition), can lead to decreased nutritional intake and, consequently, to malnutrition, gravely affecting the health status of the person (Souza, Martins, Franco, Martinho, & Tinôco, 2016).

When the person is no longer able to start and finish the necessary tasks to feed because of impairment or dependency, the help of a caregiver is fundamental. Despite the limitations, it is essential to involve and encourage the person to participate in the process to be as independent as possible in this basic activity of daily living. Helping does not mean replacing. The objective can also be to regain independence or retrieve the ability to self-feeding with the support of adaptive strategies (Fontão, 2017). This study aims to present the development and validation of content related to this topic to be integrated into a digital platform designed to support family caregivers.

Background

Self-feeding ability is one of the last skills that the dependent person loses (Costa, Fonseca, & Lopes, 2012). However, many older people have their self-feeding skills compromised, leading to their institutionalization and increasing healthcare costs (Costa et al., 2012).

Osborn and Marshall (1993) refer that the refusal to eat, dysphagia, nasal regurgitation, prolonged swallowing time (sometimes associated with food accumulation in the mouth), the non-closure of the mouth after food placement, or behavioral changes associated with eating (head-turning in the opposite direction, spoon eating, food spitting) are some of the difficulties that the caregivers of dependent people face. Many of these difficulties are associated with a previous diagnosis of dementia, leading to a decreased capacity to recognize the foods, confusion related to the perceived need for food, forgetting about how to use cutlery, and the difficulty in swallowing or chewing (Liu, Watson, & Lou, 2014).

Feeding is a self-care activity. Impaired self-feeding may be related to motor, cognitive-behavioral, and emotional alterations (Fontão, 2017). The motor changes translate into the disabilty to perform technical activities such as opening containers, bringing the food to the mouth, preparing and organizing the food on the plate. The cognitive-behavioral changes are frequent after a stroke or brain hemorrhage and are characterized by a disability to perceive the need for food, recognize the foods, or remember how to use cutlery. These changes may also be because of dysphagia, sequelae of brain pathologies such as stroke, Alzheimer's disease, Parkinson's disease, with changes in the structures involved in swallowing, loss of muscle mass, changes in the oral cavity, or decreased sense of taste and smell, resulting from the aging process itself (Fontão, 2017). Depression is referred to as the most frequent emotional change, conditioning the search for food and the pleasure of feeding (Fontão, 2017).

The choice of meals, the food constraints of the diet, and the refusal to eat (with subsequent gradual weight loss) can be frustrating for caregivers (Fontão, 2017). Family caregivers feel satisfied when they know that they provide adequate care to the dependent person. In some situations, family caregivers seek health professionals to guide them with useful and adapted solutions according to the situation and the needs of each person, to ensure a correct food intake (Cichero, 2018; Fontão, 2017).

The new technologies are an increasingly available health resource, gradually changing the nature and how care is provided (Fontão, 2017; Thimbleby, 2013). The use of the internet and new technologies in health care has been implemented in various contexts, contributing to the sustainability of health systems (Thimbleby, 2013). For the family caregivers, the internet is increasingly becoming an effective response by directly making different available contacts of support groups or websites of specific information for each diagnosis or to clarify doubts or answer to a simpler problem (Landeiro, 2015; Landeiro, Martins, & Peres, 2016a; Landeiro, Peres, & Martins, 2017; Lindberg, Nilsson, Zotterman, Söderberg, & Skär, 2013).

The INTENT-CARE, interactive platform of support to caregivers, is a project in line with the European Innovation Partnership on Active and Healthy Aging and aims to be a repaired and integrated solution for support to aging (Landeiro, 2015). This project was developed in three stages: diagnosis, design and implementation of the interactive tool, and evaluation.

The interactive tool is a free online platform (http://pope.esenf.pt/intentcare), intended to provide information to people who care for dependent family members, with a view to complement the guidance given by health professionals and promote their empowerment. According to Landeiro et al. (2016a), it is an intuitive, reliable, and easy-to-use tool, whose interactive design allows a rapid response to the needs of the user, aiding in the decision-making process and the selection of the most relevant information. The content was developed focusing on the basic daily needs and allows overcoming the difficulties, regardless of the clinical diagnosis of patients.

This platform is supported by the viewing of procedure demonstration videos and documental audio files. This study aims to create a new theme for this technological resource that integrates the following areas of self-care: positioning, transferring, showering, dressing and undressing, and nasogastric tube feeding.

Research question

What information should be provided in a free online platform designed to support family caregivers regarding the *feeding content*?

Methodology

The methodology used by this study was composed of three distinct phases (depicted in Figure 1): exploratory phase (identification of needs through interviews with caregivers and nurses), production of content (using a focus group), and content validation to be integrated in the platform (using a panel of experts and through the Delphi technique, and a group of caregivers of people with commitment to self-feeding).

The exploratory phase was based on a study conducted by the second author (Landeiro, 2015), who identified the needs and ranked the significant difficulties that caregivers faced when providing care to their dependent family members. This qualitative study preceded to the development of the platform Cuidar de Pessoas Dependentes (INTENT-CARE). The family caregivers were selected using an intentional sample, indicated by family health nurses of a local health center of northern Portugal. The inclusion criterion was to be the caregiver of a dependent family member with impaired self-care , to have more than 18 years of age, and to accept being interviewed. The interview was used for data collection, focusing on the difficulties and needs perceived by family caregivers. The saturation of data determined the sample.

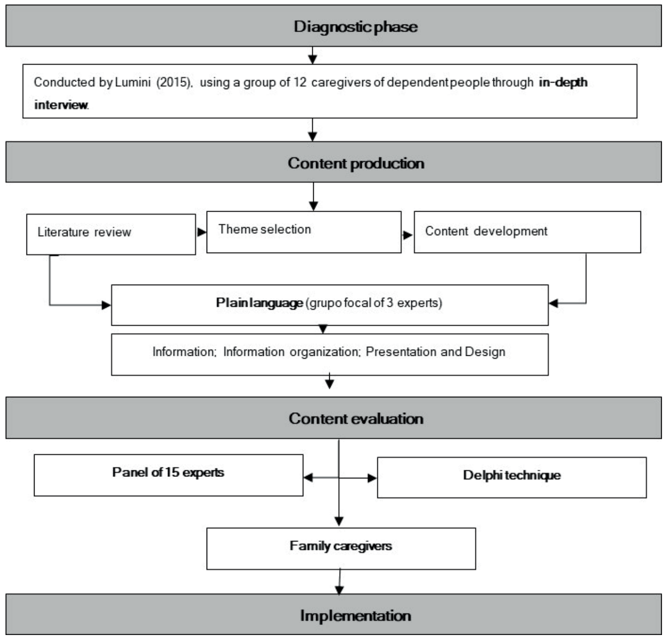

Figure 1. Design of the study.

The process of content production began with the construction of a plan, outlined by the authors, in accordance with the needs established previously and the scientific evidence. The design of the platform mentioned above was used as a basis so that the new contents were consistent and adjusted to the model used. After their development, the contents were analyzed according to the recommendations of the plain language methodology, in four steps: adaptation to the target population, language and style, organization, layout, and design (Rudd, 2012). Thus, the development of content was based on a simple, concise language, free of double meanings and with terminology appropriate to a target population with low health literacy. The theme was organized into sub-themes. According to the structure of the platform, each sub-theme corresponds to a page. At the end of each page, there is a hyperlink to the next related topic. The most specific information was meant to appear in boxes that the reader expands if its reading is deemed appropriate.

The Delphi technique (Scarparo et al., 2012; Silva & Tanaka, 1999) was used to validate the content developed. The structure of the tool was explained parameter by parameter and grouped by areas in a grid of analysis, which was sent to the experts. Ten recognized researchers (with research and publications) in the areas of gerontology, family health, family caregivers, long-term care, and health technologies, integrated in a research unit and five nurses working in medicine wards in a central hospital of Porto pointed out, for each assessment unit, the level of concordance (1 = *strongly disagree*, 2 = *strongly disagree*, 3 = *neutral*, 4 = *agree,* and 5 = *strongly agree*) regarding the importance and adequacy of the information, considering its applicability to family caregivers. Also, each expert was asked to justify his/her assessment, providing suggestions for correction and reformulation of the content. The document sent by email to the experts included a page with the title of the study, the description of the objectives and research methods, instructions for its completion, and the safeguard of confidentiality and anonymity in data processing and dissemination. A deadline of 2 weeks was defined for the forwarding of responses.

It was agreed that, for each analysis item, that it obtained at least one evaluation below 4, there would be no consensus and, thus, this information should be removed or reformulated (in accordance with the suggestions and comments added by the panel of experts for later validation). A database was created with the levels of concordance, comments, and suggestions of experts, and a second version was remade and forwarded again. After two rounds, there were no suggestions or comments, and the final format of the technological tool was accepted consensually by the panel of experts.

With the purpose of assessing whether the content and functionality of this theme in the platform were adequate for the target population, the technological tool was presented, explored, and evaluated with family caregivers of dependent people hospitalized in three services of a central hospital of Great Porto. The inclusion criteria were that the participants should accept to participate in the study, be 18 years old or older, and have digital skills to use the platform, and also the family member should present self-feeding commitment. At this stage, eight caregivers used the tool and completed the questionnaire. The questionnaire was made available in the platform and was based on a Likert scale, scored from 1 to 9, in which the lowest value corresponded to a negative parameter qualification (e.g., difficult, annoyed, confused) and the highest value to the best qualification (ex. easy, simple, interesting), allowing evaluating the terminology used, the clarity and adequacy of the information, the relevance, design and functionality. The ethics committee of a hospital in central Porto authorized the study (reference 2016.079-067-DEFI/065-CES). The rules of conduct, according to the Declaration of Helsinki of the World Medical Association, were ensured. The anonymity of participants and confidentiality in the processing and analysis of data were also ensured (including the possibility of refusal to participate or withdrawal from the study).

Results

The caregivers' narratives were analyzed, reporting various difficulties in service accessibility, lack of family support, and lack of support at hospital discharge and patient's transition to home. The lack of knowledge about dehydration prevention, diet adaptation to dysphagia, strategies to use in case of refusal to eat were also identified as problems for the caregivers.

As for the production of content, the focus group drew up a grid with information concerning the seven dimensions: Introduction, Dentition, Dietary needs, Hydration, Feeding, Changes in swallowing, and Special situations (Table 1), responding to the needs identified in the exploratory phase.

Table 1
Specification of the contents for development regarding feeding the person proposed by the focus group

Dimensions	Contents
Introduction	Concept of oral feeding. Importance of autonomy promotion.
Dentition	Teeth function. Oral hygiene care (brushing technique). Denture care.
Dietary needs	Function of carbohydrates, protein, fats, fiber, vitamins, and minerals, and water. Meal suggestions. Nutritional supplementation.
Hydration	Recommended daily intake. Main complications of dehydration. Managing comorbidities.
Feeding	Care before, during, and after feeding the person.
Changes in swallowing	Dysphagia. Warning signs and symptoms. Changes in food consistency.
Special situations	Refusal to eat. Feeding adaptive techniques.

The introduction presents the theme, defines concepts, and reinforces the role of caregivers to the person with impaired self-feeding, always enhancing their autonomy. It was considered appropriate to address the function of teeth and the most frequent problems related to their absence or dental prosthetics and oral hygiene care. Using the food wheel, a list of the roles and composition of each food group was developed, taking into account the dietary needs. The recommendation that the platform should complement the information conveyed by health professionals (basic idea of the platform) was reinforced by the need to evaluate and monitor the dietary needs of the person to adjust the diet (taking into account possible comorbidities, namely heart, renal, or metabolic disease). Examples of healthy and balanced meals were considered useful content to be integrated, as well as the role of food supplements and the need for proper hydration (using adaptive strategies such as the use of gelatin or the addition of food thickener or use of gelled water). Various strategies to handle cases of dysphagia were listed, being relevant to develop the different etiologies, warning signs and symptoms (mainly associated with respiratory complications), and the need to change the consistency of food. The recommendations of the ACSS (Ministério da Saúde, Administração Central do Sistema de Saúde, 2011) were followed in the operationalization of the *feeding the person* procedure, explaining and justifying the activities that implement it. Finally, regarding the special situations, cases of refusal to eat were discussed, and the available adaptive strategies related to self-feeding were presented.

The validation of the content was carried out with recourse to experts and through the Delphi technique. The mean age of researchers was 51.3 years, and the majority was female and a mean time of professional activity of 20 years. Regarding their academic qualifications, eight had a Ph.D., two had a master's degree, and all had a postgraduate course in nursing (four in the area of the Medical-Surgical Nursing, three in Rehabilitation Nursing, and three in Community Nursing). The clinical practice experts had a mean age of 30.9 years, and the majority were female. The mean time of professional activity in clinical practice corresponded to 9.6 years. Regarding their academic qualifications, four had an undergraduate degree in nursing and a master's degree. All nurses had postgraduated in Medical-Surgical Nursing and Community Nursing.

The panel of experts focused on the need to simplify and adequate the terminology used and suggested syntactical and lexical changes in the contents so that using more commonly known and simple phrases were used. Concerning dietary needs and hydration, the experts considered it was essential to highlight other pathologies other than the cardiac and renal diseases (in particular diabetes).

The majority of experts also reinforced the need to stress even more the interventions (what to do), reducing some theoretical explanations, as well as the inclusion of practical cases that implement the suggested interventions: types of foods to eat (according to the different nutritional content); outlining a flowchart of actions in case of unexpected situations (complications related to dysphagia, refusal to eat).

The dimensions Feeding by mouth, Changes in swallowing and Special situations were unanimously identified as relevant and pertinent for inclusion in the structure of interactive digital tools (agreement between the values by the experts). The dimensions Dentition and Dietary needs obtained the lowest level of agreement, and more detailed information about the function of the dentition and more technical information about the nutrients, their functions in the body, dosages, and recommended portions of different food groups were eliminated. The specific content validated by the experts has been integrated into the platform (http://pope.esenf.pt/intentcare).

The eight caregivers who completed the questionnaire for the evaluation of the platform, specifically for the topic under analysis, were mostly female, with ages ranging between 38 and 61 years. The results of the analysis of the questions asked to the caregivers are described in Table 2.

Table 2

The minimum and maximum values obtained, means, and standard deviations of the parameters evaluated for family caregivers

	Minimum value	Maximum value	Mean (*DP*)
Font size	6	9	8.0 (1.0)
Quantity of information	7	9	7.8 (0.9)
Order of information	7	9	8.0 (0.8)
Clarity of information	7	9	7.9 (0.8)
Easy use of the tool	7	9	8.2 (0.8)
Easy exploration of the tool	7	9	8.0 (0.8)
Reliability of information	7	9	8.2 (0.8)
Absence/presence of errors of the tool	9	9	9.0 (0.0)
Quality of pictures	6	9	7.8 (0.9)
Relevance of the tool	6	9	7.7 (1.6)
Overall assessment of the tool	7	9	8.4 (1.1)

Note. SD = Standard deviation.

Regarding the font size (*difficult/easy to read*), the quantity of information (*inadequate/adequate*), and the order of Information (*confusing/clear*), the caregivers have evaluated these parameters positively.

The results concerning the clarity of information and easy use of the tool show that the caregivers considered the tool to be very consistent and containing very clear information. Also, the tool was considered intuitive, easy to use or explore, with reliable information, and excellent quality of pictures. The obtained scores presented an evident ceiling effect. Overall, the caregivers considered the tool to be interesting, adequate, and highly useful in learning how to care for family members. Only one caregiver suggested that could be useful the inclusion of videos showing the consistency of food and adaptive materials.

Discussion

The hospitalization constitutes, for the person and his/her caregiver, a transitional period in which they are not yet responsible for the care and feel great support and appreciation by nurses. However, when the patient returns home, the caregivers take on the responsibility of care, inevitably feeling insecurity and lack of confidence (Landeiro, Martins, & Perez, 2016b).

The family caregivers present constraints and incompatibilities to reconcile their time with extensive participation in training programs. Thus, interactive technology tools can be a mediation strategy in this process (Landeiro et al., 2017). Information and communication technologies can provide qualified information directed at those who use them to complement and never replace the interventional role of health professionals (Lindberg et al., 2013). On the other hand, the development of skills and resolution of problems inherent to the care process should be promoted (Landeiro et al., 2017; Landeiro et al., 2016b; Landeiro, Freire, Martins, Martins & Peres, 2015; Lindberg et al., 2013).

The increased number of dependent people at home requires, from professionals, greater investment and planning to maximize the use of resources. The emergence of the internet as a resource for families in the access to information increasingly justifies the development of research in this area so that there is a real perception of how this resource can be adapted specially to the needs of each person (Thimbleby, 2013).

This study aims to contribute to this area of care, as it focused on the design and construction of the contents of the *feeding* for integration into a platform designed for caregivers. It will impact nursing care considerably and follow the technological advancement and the current requirements of the cared-for people (Lumini, Araújo, & Martins, 2018). For this purpose, methodological decisions were taken that focused on the design, content, and structure of a relevant dataset in this area. The literature review about the theme and the search for the best scientific evidence, as well as the model adopted for the construction of content (plain language), ensured a structured communication style, suitable to a population with low health literacy, with expression and linguistic accuracy, associated with an information organization and a profoundly detailed design. The validation of content was carried out by the Delphi technique. This method ensured the collaboration of a group of experts in the analysis and reformulation of the content of the theme, which otherwise would be difficult to obtain. The choice of the experts was based on the theoretical domain of the related topics and experience in clinical practice, resulting in an extended and detailed field of knowledge and sensitivities.

In this sense, the methodology used in the production of content invested in the transfer of knowledge produced by the scientific evidence for use in the daily practices of caregivers who provide care to people with impaired self-feeding.

The result was a set of information on how to feed a person with impaired self-feeding, based on the best available evidence, adapted to the specific needs of family caregivers, suitable to various literacy levels. The caregivers have agreed that the material developed and integrated into the platform is useful, easy to use, allowing quick answers adapted to their needs and difficulties when dealing with people with impaired self-feeding. This material can also give continuity to the information transmitted by health professionals, building a second line of care, in a perspective of continuity and complementarity.

The authors believe that the reduced sample of caregivers who completed the final questionnaire constitutes a limitation of the study.

Conclusion

Impaired self-feeding is described as one of the areas of self-care in which people lose independence in their performance later in life. This study, based on the needs expressed by caregivers, particularly in post-discharge moments, aimed to build recommendations on how to interpret and solve situations of impaired self-feeding. The tension felt by families in their process of preparation for discharge hinders effective and efficient learning, and it is necessary to reinforce the information given by professionals where new health technologies appear as an additional feature. Indeed, family caregivers regard the educational technologies increasingly as a complement to the information provided by health professionals, which defines this partnership as crucial for an improvement in their care practice. The authors believe that the description of the process of design, development, and validation of a theme, integrated into a platform designed for caregivers of dependent people, using a scientific methodology, contributes to more meaningful nursing for people and society in this field. The technological tool developed with specific thematic content focused on self-feeding was considered an asset to the family caregivers of people with impaired self-feeding.

Author contributions

Conceptualization: Fontão, A. M., Lumini, M. J., Martins, T.
Data curation: Lumini, M. J.
Writing – original draft: Fontão, A. M.
Writing – review & editing: Lumini, M. J., Martins, T.

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