REFACS

Digital media and caregivers of people with cancer: health communication and psychosocial support

Mídias digitais e cuidadores da pessoa com câncer: comunicação em saúde e apoio psicossocial

Medios digitales y cuidadores de personas con cáncer: comunicación en salud y apoyo psicosocial

Ana Carolina de Oliveira Santana[1]
Heloísa Cristina Figueiredo Frizzo[2]
Gleiciane Aparecida Teodoro[3]
Vitória Helena Maciel Coelho[4]
Elaine Leonezi Guimarães[5]

This is a qualitative, descriptive, observational cross-sectional research. It was carried out in the year of 2018, with the help of virtual ethnography. It aims to understand how social media addresses topics related to caregivers of people with cancer, and how they are shared on the internet. The collected data were structured and analyzed through the following thematic units: *Health Information and Psychosocial Support Space*, and *Support to Caregivers*. 15 digital media were created, featuring seven typologies. *Health Information* refers to information on types of cancer, treatments, diagnoses, and care management including health care, quality of life and social rights. *Space for psychosocial support and caregiver support* refers to digital media where the family member/caregiver can seek warmth, help and support during the process of caring for the sick person. The results revealed a deficit of information, welcoming environments and guidance for the person executing the tasks of a caregiver.
Descriptors: Medical oncology; Caregivers; Social media; Health communication; Psychosocial support systems.

Esta é uma pesquisa de natureza qualitativo-descritiva e observacional de corte transversal, feita por meio da etnografia virtual e realizada em 2018, com o objetivo de compreender como as mídias sociais abordam temáticas relacionadas a cuidadores de pessoas com câncer, e como estas são compartilhadas na internet. Os dados coletados foram estruturados e analisados por meio das unidades temáticas: *Informação em Saúde e Espaço de Apoio Psicossocial* e *Suporte aos Cuidadores*. Levantou-se 15 mídias digitais, caracterizando-se sete tipologias. *Informação em Saúde* refere-se a informações sobre tipos de câncer, tratamentos, diagnósticos, e manejo de cuidado, incluindo cuidados em saúde, qualidade de vida e direitos sociais. *Espaço de apoio psicossocial e suporte ao cuidador* refere-se às mídias digitais onde o familiar/cuidador possa buscar acolhimento, apoio e suporte durante o processo de cuidar do ente adoecido. Os resultados revelaram um déficit de informações, ambientes de acolhimento e orientações durante a vivência do papel de cuidador.
Descritores: Oncologia; Cuidadores; Mídias sociais; Comunicação em saúde; Sistemas de apoio psicossocial.

Esta es una investigación descriptiva cualitativa, observacional de corte transversal, mediante etnografía virtual, realizada en 2018, con el objetivo de comprender cómo los medios sociales abordan las cuestiones relacionadas con los cuidadores de personas con cáncer y cómo se comparten en Internet. Los datos reunidos se estructuraron y analizaron a través de las unidades temáticas: Información en Salud y Espacio de Apoyo Psicosocial, y Soporte a los Cuidadores. Se analizaron 15 medios digitales, caracterizando siete tipologías. Información en Salud se refiere a informaciones acerca de los tipos de cáncer, los tratamientos, los diagnósticos y la gestión de la atención, incluida la atención en salud, calidad de vida y derechos sociales. Espacio de apoyo psicosocial y soporte al cuidador se refiere a los medios digitales donde el familiar/cuidador puede buscar refugio, apoyo y soporte durante el proceso de cuidado del familiar enfermo. Los resultados revelaron un déficit de informaciones, de ambientes acogedores y de orientaciones durante la experiencia del papel de cuidador.
Descriptores: Oncología médica; Cuidadores; Medios de comunicación sociales; Comunicación en salud; Sistemas de apoyo psicossocial.

1. Occupational Therapist. Uberaba, MG, Brazil. ORCID: 0000-0003-2095-7603 E-mail: carolina.deolsantana@gmail.com
2. Occupational Therapist. Specialist in Health Informatics. Master in Medical Sciences. PhD in Sciences. Adjunct Professor by the Graduate Program in Psychology (*Programa de Pós-Graduação em Psicologia - PPGP*) at the Universidade Federal de Triângulo Mineiro (UFTM), Uberaba, MG, Brazil. ORCID: 0000-0002-7661-0353. E-mail: heloisa.frizzo@uftm.edu.br
3. Psychologist. Master's student in Psychology at PPGP at UFTM, Uberaba, MG, Brazil. ORCID: 0000-0002-3871-3626 E-mail: gleicianetheodoro@hotmail.com
4. Physical therapist. Master in Bioengineering. PhD in Medical Sciences. Adjunct Professor at UFTM, Uberaba, MG, Brazil. ORCID: 0000-0003-1799-2256 E-mail: vitoria.coelho@uftm.edu.br
5. Physical therapist. Specialist in Physiotherapy in Child Neurology. Master and PhD in Physical therapy. Adjunct Professor at UFTM, Uberaba, MG, Brazil. ORCID: 0000-0002-8450-1261 E-mail: elaine.guimaraes@uftm.edu.br

INTRODUCTION

The Instituto Nacional do Cancer - INCA (National Cancer Institute) points out cancer as a public health problem, especially in developing countries, related to multifactorial causes. Such causes include risks of an environmental nature, genetic factors, lifestyle and harmful habits, such as poor diet; alcohol use; cigarette and others[1]. Based on the document produced by the World Health Organization (WHO), it is estimated that, in the coming decades, the impact of cancer on the population corresponds to 80% of the more than 20 million new cases estimated for 2025[1].

Cancer is one of the most feared pathological processes due to its degree of aggression, the suffering generated and the invasive treatment used to fight it[2], its diagnosis and its repercussions impact on the family complex. The family has a significant role in the process of diagnosis and conduct of treatment[3]. In particular, the caregiver, a person of extreme importance at all times, who becomes the link for understanding the patient as a whole, receiving care, guidance and support from the entire team.

The companion or caregiver of a cancer patient may have kinship relationships or not, and commonly faces changes in their life routine, moving away from work, abdicating theor professional life, distancing themself from their daily activities, and even their functions in favor of the person diagnosed with cancer[4,5]. In this situation, it is considered that this form of care can often generate changes in the caregiver's biopsychosocial status, such as fatigue, distress, physiological disorders, loss of participation and occupational and social roles, causing changes in daily life of these people.

The act of taking care of a sick person can cause a high level of stress, which tends to create an its own illness in the long run. Thus, it is important to consider the need to develop fundamental strategies for the search for the biopsychosocial well-being of the caregiver, aiming to promote the improvement in the quality of life of these people.

Based on this, and living in the age of information and digital communication, the internet has established itself as a valuable source of health information, ranging from advice on a healthy lifestyle to the treatment of diseases, allowing easy access to this information would transform individuals into more active and trained collaborators in the management of their own health.

Accessibility, associated with mobility and communication free from geographical barriers, all of which are on a global scale, points to a new cultural configuration, creating numerous forms of social interaction, reconstructing and reconfiguring patterns of online relationships, as is the case with virtual communities[6].

Contemporary society has sought the use of information and communication technologies (ICTs) to improve quality of life of people in situations of illness, contributing to the construction of affective bonds that, once consolidated, can offer social support[7,8].

Considering the importance of ICTs, as virtual means to share information and guidance about the management of physical, psychological, cognitive and social conditions of one's family member, as well as the exchange of experiences or giving/receiving support for the experience of caring, The present study aimed to understand how social media addresses themes related to caregivers of people with cancer, and how they are shared in different virtual spaces.

METHOD

This is a qualitative-descriptive and observational cross-sectional research, which used virtual ethnography as an exploration method[9]. The study scenario was the cyberspace, in which systematic observation of online spaces such as websites and blogs and the like related to oncology was sought, as a means of analyzing content related to caregivers of people with cancer.

The research was carried out in 2018, with the following inclusion criteria: a) Electronic

sites (blogs, personal sites and similar) that address issues related to oncology and caregivers of people with cancer; b) Posted between the years of 2014 and 2019; c) Sites by Brazilian authors, written in Brazilian Portuguese.

Data collection occurred through the insertion of the researcher in the virtual environment, with the analysis script constructed for research, elaborated with the following items: 1) Descriptors, which were the keywords used in the research; 2) Nationality; 3) Title; 4) Content, what was offered on the website; 5) Main target audience was family members and people with cancer; 5) Last page update; 6) Characterization of content related to caregiver.

In this preliminary stage, an electronic search was performed in virtual spaces using the descriptors/keywords: *família*, *cuidador*, *cuidar* and *cuidado* (oncology, cancer and family/caregiver). After this search, the data were organized and analyzed according to *Title* and *Content* covered, with a total of 36 sites. Sites, blogs and similar that offered medical services and/or product sales were excluded. The data were organized in a table by *Title*; *Characterization* and *thematic units*.

After the preliminary stage, the electronic sites found were explored through the search tab using the descriptors/keywords: *família*, *cuidador*, *cuidar* and *cuidado* (family, caregiver, care and caring). The collected data were structured and analyzed through thematic units.

The collected material was analyzed from the content analysis, which consists of three stages: pre-analysis; exploration of material; treatment of results obtained and interpretation[10]. The present study did not need approval by a Research Ethics Committee since it used information in the public domain, according to guidelines provided for in resolution 510/2016.

RESULTS

The understanding of data allowed systematization of thematic units: *Health Information* and *Psychosocial Support*. The thematic unit: *Health Information* was subdivided into two subunits, namely: *Management of the person with cancer* and *Caregiver care*.

Chart 1 presents the description of the thematic units, of the subunits, respectively characterized, in addition to the identification of the digital media found. The thematic unit: *Health information: management of the person with cancer* refers to informative content on different types of cancer, treatments, diagnoses, and also to the care management of the person with cancer, regarding care with medication, food, quality of life, social rights, positioning of a person who is restricted to bed, and pain control resulting from treatment, among others.

The digital media classified as *P1*, (*Blog do câncer, Viva um dia de cada vez e seja feliz*, and *Encontrando Dr. Hodgkin*) are presented in a blog format, offering exchanges of information between the creator of the online space and visitors of the page. In this profile, there are tools available that allow asynchronous online interaction, allowing the user to establish a communication process with another user at different times (Chart 1).

In *P2*, digital media were selected in a website format, whose purpose is to disseminate information about cancer and consequent management/treatments. In these spaces there are restricted options for tools that allow exchange of information between users and authors of the respective media. The only space available for this is the e-mail address for contact (Chart 1).

In this profile, the media *Oncoguia* and the *Instituto vencer o câncer* were found, of which information regarding cancer disease and its subtypes, types of exams, treatments, reports of the patient's daily life and innovations in studies offered in both texts and videos are offered.

The social media classified as *P3* is available on the social network Facebook®, called *Luta contra o câncer*. According to its creators, the perspective of this virtual space is to report the experience of a person who had cancer. It is a place to promote exchanges, information and experiences related to being diagnosed with cancer. The thematic unit of *Health Information: caregiver care* refers to content on guidance to caregivers, related to the importance of taking care and reports of experiences about the caregiver process and role (Chart 1).

P4 and *P5* are online spaces in website formats. The digital media classified as *P4* offer asynchronous online interaction, which are: *Falando sobre oncologia*, *Oncoguia* and *Casa do Pedro*, and seek to provide discussions and guidance for people with cancer and family members/caregivers through measures that must be taken related to the disease.

In *P4*, the *Oncoguia* space offers information on oncology-related content, both for patients and caregivers. In this space, when accessing the tab *De familiar para familiar* (From family member to family member), the visitor is directed to the family member page, where categories such as *De paciente para família* (From patient to family member) and *Espaço do familiar* (Space of the family member) are available, offering tips and guidelines on how care should be performed when contemplating both involved (Chart 1).

While in *P5* (*Cantinho do cuidador* and *Quem cuida do cuidador enquanto ele cuida do outro?*) consists on digital media that offer guidelines related to the management of caring for an ill person, and about the importance of the family/caregiver taking care of their mental health, favoring the caregiver's well-being. In these spaces, there are limiting options for interaction between users and creators. The only space available is the e-mail address for contact and a space for comments (Chart 1).

The thematic unit *Space for psychosocial support and caregiver support* refers to contents and spaces for the family member/caregiver to seek refuge, help and support during the process of caring for the sick person.

Digital media classified in *P6* are virtual spaces in the format of websites, with limited options for tools that allow interaction between users and authors of the respective media (Chart 1). It presents as an available space the indication of an e-mail and a place for comment. In these virtual environments, users are offered a place where they can read and/or write (via e-mail or comment) publications about other people's experiences of caring for a person with cancer, and emphasize the importance of caring for others it is necessary to take care of oneself.

Social media classified in *P7* are available on the social network Facebook®, being spaces that allow asymmetric interaction between users and between users and the creators of the pages. The page *Câncer-grupo de apoio a familiares, responsáveis e cuidadores de pacientes* is a space created to support caregivers of people with cancer, where users tell about their experiences and/or offer care to someone who is going through the process of care for or mourning a family member with cancer. The page *Venci a leucemia* was created to tell the story of Lucas, a child who fights against the disease daily, and in this place there are exchanges of experiences, support and welcome between users and the creator of the page (Chart 1) .

In the results presented, it can be observed that, in the content offered to the caregiver in digital media related to oncology, there is a prevalence of health information, focused on the care of the person in illness. It is also observed that there are limitations of information to care with the caregiver, where only one third of the spaces found offer places where the caregiver can seek welcoming and/or support about the care experience.

Chart 1. Description and characterization of thematic units, sub-units, and characterization of the researched digital media. Uberaba, 2018.

Thematic Units	Sub-unit	Characterization	Digital Media
Information in Health	**Management of the person with cancer**	Social media in blog format that offer exchange of information related to technologies offered for cancer treatment; promotion and prevention actions; research developments and dissemination; description of symptoms related to the manifestation of cancer; Routine exams and treatments. **(P1)**	- Blog do câncer - Viva um dia de cada vez e seja feliz. (Desafiando o Câncer). - Encontrando Dr Hodgkin
		Social media in website format that offer information regarding cancer and forms of treatment; Defense of civil rights of people with cancer and their families/caregivers; Information on health care through integrative and complementary practices. **(P2)**	- Oncoguia - Instituto Vencer o Câncer - Falando sobre Oncologia
		Social media classified as pages or communities that offer information related to cancer and allow interaction between network users, contributing to the exchange of experiences lived when falling ill with cancer. **(P3)**	- Luta contra o Câncer
	Caretaker care	Social media that offer guidelines related to the care that should be taken for the person who has cancer. And they bring reports of experiences written by caregivers of people with cancer. **(P4)**	- Oncoguia - Casa do Pedro
		Social media that offer guidance to the caregiver, related to the importance of taking care of mental health when caring for someone who is ill. **(P5)**	- Cantinho do cuidador - Quem cuida do cuidador enquanto ele cuida do outro?
Space for psychosocial support and caregiver support		Social media that offer space for the caregiver, where someone can tell their story serving as inspiration for other people who are going through the same process. These spaces also prioritize the search for quality of life and well-being of the caregiver. **(P6)**	- Oncoguia - Quem cuida do cuidador enquanto ele cuida do outro?
		Social media classified as pages or communities that offer spaces for caregivers of people in illness to exchange information, seek and offer support and listening regarding the care process. **(P7)**	- Câncer: Grupo de Apoio à familiares, responsáveis - Cuidadores de pacientes Venci a Leucemia

Chart 2 presents descriptions of social media according to health information.

Chart 2. Description of social media according to health information. Uberaba, 2018.

Information in Health	Profile	Digital Media	Description
Management of the person with cancer	P1	Blog do Câncer	It addresses the following themes: "Technology; Treatment; Prevention; Search; Myths and Truths about cancer ", where similar discussions are available in specific tabs.
	P1	Viva um dia de cada vez e seja feliz (Desafiando o câncer)	It is a blog and a page on Facebook that reports the daily life of a person with cancer and offers information regarding diagnosis, symptoms, tests, rights and others.
	P1	Encontrando Dr. Hodgkin	Blog with information about lymphoma, treatments, symptoms and diagnosis.
	P2	Instituto Vencer o Câncer	Website of the Instituto Vencer o Câncer, which is a non-profit foundation that seeks to disseminate issues relevant to health in Brazil and worldwide; inform, support and welcome patients and family members in the face of a cancer diagnosis and treatment, share information related to prevention, nutrition, physical activity, patient rights and integrative medicine with the population, encouraging the search for quality of life.
	P2	Oncoguia	Website of a non-governmental institution that offers information to cancer patients and guidance for better living through quality information projects and actions, health education, support and guidance for patients and caregivers promoting discussions regarding the defense of social rights, treatments and others, both for the person with cancer and for the caregiver.
	P2	Falando Sobre Oncologia	Site created by a doctor who promotes discussions on oncology, relating ethics between doctor and patient, quality of life and science.
	P3	Luta contra o Câncer	Facebook page created by the developer and curator of a digital space to tell about her fight against cancer, recreating her routine and daily life, self-care and health care, in addition to promoting exchange of information and interaction with digital users regarding the management of the disease and treatments.
Caretaker care	P4	Oncoguia	Site that offers support and guidance to the patient and caregiver, reports of experiences of caregivers of people with cancer.
	P4	Casa do Pedro	Blog that tells the story of Pedro, a child who fights cancer. It was created by Pedro's mother, who is a digital media curator. This provides guidance on the necessary care when dealing with a child with cancer and reports her experience as the mother of a child in the process of becoming ill.
	P5	Cantinho do cuidador	The Cantinho do Cuidador digital channel is a blog, created with a focus on caregivers and family members of cancer patients, in order to ease the limitations, concerns and facilitate the Caregiver's daily life. The initiative to create this blog space was intended to alleviate difficulties faced by caregivers of cancer patients. It is also found on a Facebook® page.
	P5	Quem cuida do cuidador enquanto ele cuida do outro?	Guide caregivers about the importance of taking care of themselves in order to be able to take care of someone else, so that they themselves do not get sick.

DISCUSSION

The use of the internet and ICTs through websites, blogs and the like, can ease the burden of care. Activities developed in these spaces produce social interactions, contributing to the establishment of support network and to the search for new meaning in life and occupations[8]. The ICTs present in most fields of human activity, including the health area, allow dissemination of the use of the internet, providing a marked growth in access to information with benefits for the education of the patient and family[11].

In the thematic unit *Health Information*, digital media were found to offer informative content on different types of cancer, treatments, diagnoses, research and innovations related to the theme. In addition to guidance on care with medication, food, positioning of a person who is restricted in bed, management and control of pain resulting from treatment, quality of life, well-being, guidance on social rights of the person with cancer and family/caregiver, guidelines related to the role of caregiver, and others.

The internet is the most complete and complex source of information today. With its thousands of health-related sites, it allows individuals to access all types of information, from diagnostic searches to the purchase of medicines, through therapeutic guidance, without forgetting personal pages and virtual communities, making it possible to obtain information anytime, anywhere, easy and fast[12].

It is observed that the internet is a means of disseminating information and guidelines, referring to diseases and treatments, addressing from disease prevention to the promotion of healthy habits, well-being, nutrition, hygiene and services, contributing in the educational area, therefore, the quality of information is a fundamental aspect to be evaluated[13].

The internet is an excellent source of consultation, however, in most cases, the data present in the network are not available and structured in such a way that the user can retrieve and transform into useful information, according to their needs[14].

Seeking better qualification of the available information, ten criteria were suggested to assess the sources of quality of the information. These being: 1) to evaluate the identification information; 2) consistency of information; 3) information reliability; 4) adequacy of the source; 5) links, internal links and external links; 6) ease of use, to explore/navigate; 7) font layout and media used; 8) perceived restrictions; 9) user support; 10) other observations perceived as: use of source and consultation options in other languages[15].

There was a prevalence of digital media, in which the information offered does not meet most criteria for evaluating quality information, namely: *Viva um dia de cada vez e seja feliz, Encontrando Dr. Hodgkin, Luta contra o câncer, Casa do Pedro, Falando sobre oncologia* and *Quem cuida do cuidador enquanto ele cuida do outro?*, not showing reliability in the information, adequacy of the source, ease of use and other perceived restrictions of information. There were four sites that met the criteria for evaluating quality information: *Oncoguia*, *Instituto vencer o câncer*, *Cantinho do cuidador* and *Blog do câncer*, as they presented identification of the records, adequacy of the source, consistency of information, reliability of the information, ease of use and user support.

The caregiver, in addition to searching for health information on the internet, can use it as a support network mechanism, where they can share and or exchange experiences through the process of caring for a family member. In cyberspace, it is possible to meet people online and offline with similar experiences, as it can be seen through the sharing of processes experienced by those people and their search for psychosocial support[8].

In the thematic unit *Space for Psychosocial Support and Caregiver Support*, were selected four digital media that offered content and spaces, so that the family member/caregiver could seek refuge and support during the treatment process of the sick person, namely: *Oncoguia*, *Instituto vencer o câncer*, *Cantinho do cuidador* and *Blog do câncer*. These media were divided into profiles regarding the types of interaction and the format of the selected space.

Regarding the burden of caregivers, lack of support for self-care stands out, the increase in demands for care, the rupture of family routine, in addition to suffering, weariness, feelings of helplessness, feelings of abandonment, family disturbances, isolation and vulnerability[16,17]. Given this reality, there is a limited support for caregivers also on the internet.

In turn, caregivers experience many challenges, including unmet needs in areas of relational support, such as maintaining long-term relationships and emotional support[18].

There are difficulties in asking for help to maintain hope about the future, expressing one's feelings by sharing experiences, having a partner or friends who understand how difficult this role is, clarifying doubts and anxieties about the future, having time to go to a religious temple or church, express their feelings about the strong emotions experienced in the care process, such as anxiety, guilt and fear[18,19]. The situation of the main caregiver of cancer patients is stressful, as it creates the need for adaptations, in addition to the illness of the loved one, as well as the imminence of death, events that can generate various feelings that contribute negatively to the performance of their role of caring or make it difficult[20].

Health professionals need to develop proposals to raise awareness and recognition by the caregiver, of the importance of taking care, avoiding physical and emotional damage, and, consequently, excessive stress and the risk of falling ill. However, there is a shortage of national publications related to interventions, programs and technological resources that can be offered to the family/caregiver, indicating the need for more research to support effective actions to support the family of the person with cancer[20,21].

Thus, the reflections presented in the study seek to sensitize health professionals to appropriate the internet as a resource for practice and intervention in professional practice, considering the internet as a means of interlocution with the user, patient and caregiver.

CONCLUSION

This research presents contributions related to the process of caring for a person with cancer, seeking to subsidize and enhance the creation of spaces of support and virtual support for this population, pointing out the scarcity of information and guidance in the available thematic virtual environments, about the management of physical, psychological, cognitive and social conditions of caregivers of people with cancer.

In particular, the restricted virtual spaces that provide the exchange of experiences and support for the care experience stand out. Even so, the study made it possible to understand how the sharing of themes related to caregivers occurs in spaces destined for oncology on the internet, which can contribute to a better understanding of the care process, and enhance the creation of virtual spaces of support and support to caregivers of people with cancer.

Limitations of the present study should be considered, such as the scarcity of evidence-based studies on the use of ICTs in this theme, which allow adequate appropriation of knowledge regarding the disease, when caring and the caregiver. Thus, given the importance of using ICTs today, it is necessary to expand studies related to the theme, so that health professionals can better understand this phenomenon and develop effective strategies for implementing actions in their professional practice, offering information and guidance of quality to the caregiver and the cancer patient.

REFERENCE
1. Ministério da Saúde (Br), Instituto Nacional de Câncer José Alencar Gomes da Silva (Brasil), Coordenação de Prevenção e Vigilância. Estimativa 2016: incidência de câncer no Brasil [Internet]. Rio de Janeiro: INCA; 2015 [cited in 19 Dec 2019]. 122p. http://www.inca.gov.br/bvscontrolecancer/publicacoes/edicao/estimativa_2016.pdf
2. Gomes ALZ, Othero MB. Cuidados paliativos. Estud Av. [Internet]. 2016 [cited in 19 Nov 2020]; 30(88):155-66. DOI: http://dx.doi.org/10.1590/s0103-40142016.30880011
3. Gomes MLP, Silva JCB, Batista EC. Escutando quem cuida: quando o cuidado afeta a saúde do cuidador em saúde mental. Rev Psicol Saúde [Internet]. 2018 [cited in 19 Nov 2020]; 10(1):3-7. DOI: http://dx.doi.org/10.20435/pssa.v10i1.530
4. Ribeiro SL, Schwartz E, Feijó AM, Santos BP, Garcia RP, Lise F. Incidentes críticos experienciados no tratamento da doença oncológica. R Enferm Cent O Min. [Internet]. 2015 [cited in 19 June 2020]; 5(3):1805-19. DOI: https://doi.org/10.19175/recom.v5i3.898
5. Oliveira JM, Reis JB, Silva RA. Busca por cuidado oncológico: percepção de pacientes e familiares. Rev Enferm UFPE [Internet]. 2018 [cited in 20 Dec 2019]; 12(4):938-46. DOI: https://doi.org/10.5205/1981-8963-v12i4a231359p938-946-2018
6. Melo MC, Vasconcellos-Silva PR. Uso de comunidades virtuais no suporte a portadoras de câncer de mama. Ciên Saúde Colet. [Internet]. 2018 [cited in 20 Dec 2019]; 23(10): 3347-56. DOI: htpps://doi.org/10.1590/1413-812320182310.14612018
7. Mota DN, Torres RAM, Guimarães JMX, Marinho MNASB, Araújo AF. Tecnologias da informação e comunicação: influências no trabalho da Estratégia Saúde da Família. J Health Inform. [Internet]. 2018 [cited in 20 Dec 2019]; 10(2):45-9. Available from: http://www.jhi-sbis.saude.ws/ojs-jhi/index.php/jhi-sbis/article/download/563/330
8. Frizzo HCF, Bousso RS, Ichikawa CRF, Sa NN. Mães enlutadas: criação de blogs temáticos sobre a perda de um filho. Acta Paul Enferm. [Internet]. 2017 [cited in 20 Dec 2019]; 30(2):116-21. DOI: https://doi.org/10.1590/1982-0194201700019
9. Aguiar JG. A pesquisa etnográfica online em tempos de cultura da convergência. Rev Observ. [Internet]. 2019 [cited in 23 Nov 2020]; 5(6):109-31. DOI: https://doi.org/10.20873/uft.2447-4266.2019v5n6p109
10. Taquette SR, Minayo MC. Análise de estudos qualitativos conduzidos por médicos publicados em periódicos científicos brasileiros entre 2004 e 2013. Physis [Internet]. 2016 [cited in 15 Nov 2020]; 26(2):417-34. DOI: https://doi.org/10.1590/S0103-73312016000200005
11. Zanferrari PM, Corrêa CC, Wen CL, Berretin-Felix G. Desenvolvimento e aplicação de instrumento administrativo para orientação das pesquisas em telefonoaudiologia. Rev CEFAC [Internet]. 2016 [cited in 12 Nov 2020]; 18(2):459-69.
 DOI: https://doi.org/10.1590/1982-0216201618218815
12. Nettleton S, Burrows R, O'Malley L. The mundane realities of the everyday lay use of the internet for health, and their consequences for media convergence. Soc Health Illn. [Internet]. 2015 [cited in 10 Feb 2020]; 27(7):972-92. DOI: https://doi.org/10.1111/j.1467-9566.2005.00466.x
13. Biruel EP. Websites para diabéticos: uso da internet como instrumento de educação em saúde [Internet]. [dissertação]. São Paulo: UNIFESP; 2008 [cited in 10 Feb 2020]. 92p. Available from: http://repositorio.unifesp.br/handle/11600/24269
14. Tomaél MI, Valentim MLP, organizadores. Avaliação de fontes de informação na internet. Londrina, PR: EDUEL; 2004. 155p.
15. Tomaél MI, Catarino ME, Valentin MLP, Almeida Júnior OF, Silva TE, Alcará AR, et al. Avaliação de fontes de informação na internet: critérios de qualidade. Inf Soc. [Internet]. 2001 [cited in 10 Feb 2020]; 11(2):13-35. Available from: https://www.brapci.inf.br/index.php/article/view/0000001061/11e5b3ce0702bd4dfab28d67b6cd339d

16. Borges EL, Franceschini J, Costa LHD, Fernandes ALG, Jamnik S, Lopes SI. Sobrecarga do cuidador familiar: a sobrecarga de cuidar de pacientes com câncer de pulmão, de acordo com o estágio do câncer e a qualidade de vida do paciente. J Bras Pneumol. [Internet]. 2017 [cited in 12 Nov 2020]; 43(1):18-23. DOI: https://doi.org/10.1590/s1806-37562016000000177

17. Floriani CA, Schramm FR. Cuidador do idoso com câncer avançado: um ator vulnerado. Cad Saúde Pública [Internet]. 2006 [cited in 16 Mar 2020]; 22(3):527-34. DOI: https://doi.org/10.1590/S0102-311X2006000300007

18. Fernandes CS, Angelo M. Family caregivers: what do they need? An integrative review. Rev Esc Enferm USP [Internet]. 2016 [cited in 10 Apr 2020]; 50(4):672-8. DOI: http://dx.doi.org/10.1590/S0080-623420160000500019

19. Tsai P-C, Yip P-K, Tai JJ, Lou M-F. Needs of family caregivers of stroke patients: a longitudinal study of caregivers' perspectives. Patient Prefer Adherence [Internet]. 2015 [cited in 12 May 2020]; 9: 449-57. DOI: https://doi.org/10.2147/PPA.S77713

20. Ferreira MLSM, Mutro ME, Conde CR, Marin MJS, Meneguin S, Mazzetto FMC. Ser cuidador de familiar com câncer. Cienc Enferm. [Internet]. 2018 [cited in 12 Nov 2020]; 24:6. DOI: http://dx.doi.org/10.4067/s0717-95532018000100206

21. Sanchez KOL, Ferreira NMLA, Dupas G, Costa DB. Apoio social à família do paciente com câncer: identificando caminhos e direções. Rev Bras Enferm. [Internet]. 2010 [cited in 20 June 2020]; 63(2):290-9. DOI: https://doi.org/10.1590/S0034-71672010000200019

CONTRIBUTIONS
Ana Carolina de Oliveira Santana, **Heloísa Cristina Figueiredo Frizzo** collaborated in the design, to data collection and analysis, writing and review. **Gleiciane Aparecida Teodoro**, **Vitória Helena Maciel Coelho** e **Elaine Leonezi Guimarães** participated in writing and review.