Integrative Review

Online information as support to the families of children and adolescents with chronic disease

Informações on-line como suporte às famílias de crianças e adolescentes com doença crônica

Información en línea, apoyo a los niños de las familias y adolescentes con enfermedad crónica

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ABSTRACT

Objective: To describe the use of online information as support to families of children and adolescents with chronic disease.
Methods: This is an integrative review conducted in August 2015, with an online search in the following databases: PubMed, Biblioteca Virtual em Saúde, Cumulative Index to Nursing & Allied Health Literature, and Science Direct.
Results: Twelve studies were selected from the 293 studies found in the databases. After analysis, the following two categories emerged: Potentialities of the use of online information by families of children and adolescents with chronic disease, and Weaknesses of the use of online information by families of children and adolescents with chronic disease.
Conclusions: The internet offers a wide range of information that helps families manage the care of children and adolescents with chronic diseases, but it also has characteristics that need to be analysed.
Keywords: Consumer health information. Internet. Chronic disease. Child. Adolescent.

RESUMO

Objetivo: Descrever o uso de informações on-line como suporte às famílias de crianças e adolescentes com doença crônica.
Método: Trata-se de uma revisão integrativa realizada no mês de agosto de 2015, com busca on-line nas bases de dados: *PubMed*, Biblioteca Virtual em Saúde, *Cumulative Index to Nursing & Allied Health Literature e Science Direct*.
Resultados: Foram selecionados doze estudos de 293 encontrados. Após análise, elencaram-se duas categorias: Potencialidades do uso de informações on-line às famílias de crianças e adolescentes com doença crônica e Fragilidades do uso de informações on-line às famílias de crianças e adolescentes com doença crônica.
Conclusões: A Internet oferece amplitude de informações que subsidiam as famílias no gerenciamento do cuidado às crianças e aos adolescentes com enfermidades crônicas, no entanto, ainda possui particularidades que precisam ser analisadas durante a utilização desta rede virtual.
Palavras-chave: Informação de saúde ao consumidor. Internet. Doença crônica. Criança. Adolescente.

RESUMEN

Objetivo: Describir el uso de la información en línea y apoyar a las familias de los niños y adolescentes con enfermedad crónica.
Método: Se trata de una revisión integradora realizada en agosto de 2015, con la búsqueda en línea, en bases de datos: PubMed, Biblioteca Virtual em Saúde, Cumulative Index to Nursing & Allied Health Literature y Science Direct.
Resultados: Un total de doce estudios de 293 encontrados. Tras el análisis se enumeraron dos categorías: Posible uso de información en línea para las familias de niños y adolescentes con enfermedad crónica y Debilidades de la información en línea para las familias de niños y adolescentes con enfermedad crónica.
Conclusión: Internet ofrece variedad de información que soportan las familias en la gestión de la atención de los niños y adolescentes con enfermedades crónicas, pero también tiene características que necesitan ser analizadas durante el uso de esta red virtual.
P**alabras clave:** Información de salud al consumidor. Internet. Enfermedad crónica. Niño. Adolescente.

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INTRODUCTION

Health related issues are one of the main concerns of human beings(1), and people are increasingly accessing the internet in search of information about their health or the health of a family member or friend(2-3).

When it comes to chronic disease, internet access is even more common since the anxiety and hope of finding an immediate diagnosis and/or innovative treatment are even greater. Moreover, users with chronic diseases can share their experiences and seek additional information or even experiences that help them cope with their pathology(4).

The internet is admittedly an important means to self-care because it provides information and can enable interaction between caregivers, health professionals, and individuals affected by a chronic condition(5). Similarly, families search for information to manage the healthcare of children and adolescents from several sources, such as books, magazines, conversations with friends, relatives, health professionals(6), participation in support groups, social media, and internet searches(7).

The internet allows the instant and simple exchanging of information and alternative treatment or diagnoses that can help reduce the anxiety of sufferers or their family members, and increase their confidence and understanding of a health condition before or after a medical consultation(6).

However, despite being a useful tool, the internet is growing uncontrollably and can provide inaccurate, misleading, biased and unreviewed data, which makes it difficult to differentiate trusted from untrusted sources(2, 8).

In order to reduce any conflicts arising from unsubstantiated findings or reports viewed by users on the internet, health professionals must know the health-related websites and online tools available, and instruct users on the accuracy of the provided information(2).

The use of online healthcare information is a growing and little explored trend in the qualitative dimension and in understanding the impact of this trend on the care of children and adolescents with chronic illness, and all the related specificities and continuous demands. Therefore, health workers should incorporate the online universe in their practices as a way of responding to the needs of families and of recognising application in the management of chronic diseases.

In view of the aspects mentioned above, the guiding question for this study was the following: What scientific knowledge has been produced on the use of online information as support for the families of children and adolescents with chronic illness? In addition, the aim of this paper is to describe the use of online information as support for the families of children and adolescents with chronic illness.

METHODS

Research was based on the monograph entitled, "*Utilização de ferramentas de suporte on-line às famílias de crianças e adolescentes com doença crônica: uma revisão integrativa*"(9). An integrative review is an investigation that includes the analysis of relevant research and the synthesis of several studies to understand a particular subject(10). Similarly, this study was conducted according to the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses do-Prism(11), as shown in Figure 1.

This review consisted of six steps(10). The first step was to identify the subject and establish the research question mentioned above. The second step was to define the criteria for inclusion and exclusion. The inclusion criteria were primary studies, published in English and Portuguese, and available in full for free and online from the selected databases. The exclusion criteria were duplicate articles found in more than one database and studies that did not address the proposed theme. We did not use a timeframe to explore the knowledge produced to date.

The literature search was conducted in August 2015 on the websites PubMed, Virtual Health Library, Cumulative Index to Nursing & Allied Health Literature, Science Direct. The descriptors were associated as follows: "online health information OR consumer health information AND chronic diseases AND child". The obtained results are shown in Figure 1.

The third step consisted of defining the characteristics that would be extracted from the sample, namely: publication title, authors, year, country of origin of the study, journal, database, methodological approach, data collection technique, and purpose of the research. In addition, the studies were reviewed according to the level of evidence as proposed by Melnyk and Fineout-Overn(12). This assessment focuses on evidence classification systems characterised in a hierarchical manner, according to the methodological design.

In the fourth stage, we analysed the selected studies and defined two thematic categories: Potentialities of the use of online information for the families of children and adolescents with chronic illness, and Weaknesses of the use of online information for the families of children and adolescents with chronic illness. The fifth step consisted of the interpretation of the results and discussion, and the sixth step was the presentation of the integrative review(10).

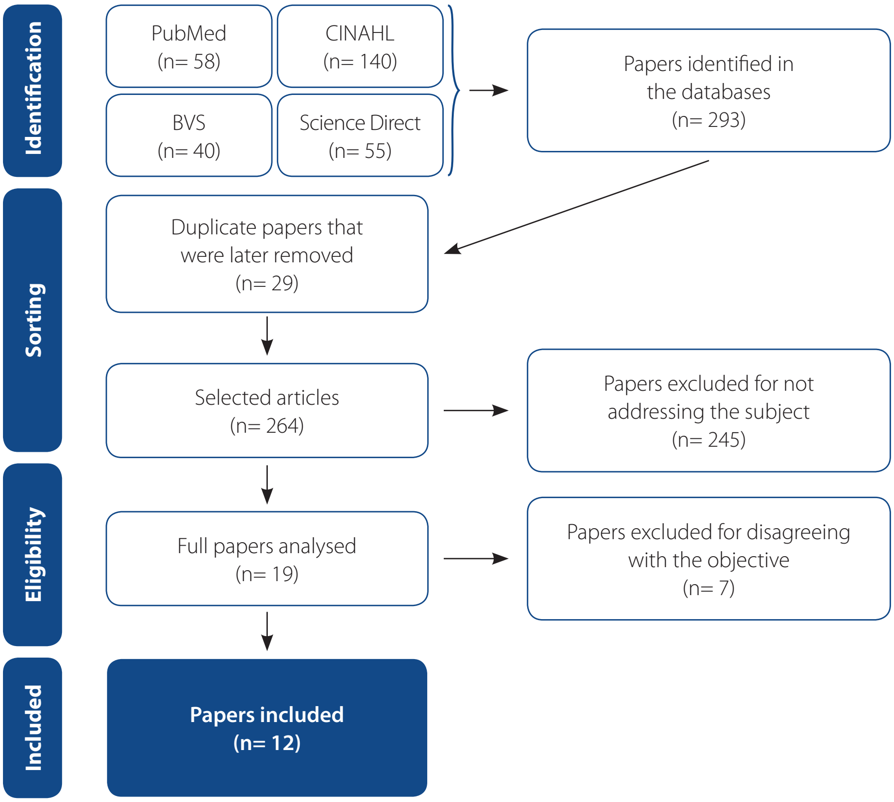

Figure 1 – Flow chart of the sample selection for the integrative literature review, prepared using PRISMA(11)

Source: Research data, 2015.

RESULTS

Of the 293 publications found, 12 papers were eligible for this investigation. Of the total number of studies and the searched databases, 58 were found in PubMed, of which 51 did not address the subject and seven were selected for the sample. In BVS, 40 studies were found, of which 27 were duplicates, 11 did not address the subject, and two were selected. In CINAHL, 140 papers were found, of which two were duplicates, 137 did not address the study proposal, and one was included in the sample. In Science Direct, 55 articles were identified, of which 53 did not address the subject in question, and two were selected for the study. Therefore, the universe of papers consisted of 12 studies, as shown in Chart 1.

The period of publication of the articles was from 2008 to 2015; five articles published in 2014, two in 2013, and one in 2008, 2009, 2011, 2012 and 2015. No publications were identified in previous years. All the identified studies were published in foreign journals; five were from North America, three from the United Kingdom, two from Sweden, one from Canada, and one in Italy. With regard to methodology, six articles adopted the quantitative approach and six adopted the qualitative approach. In the level of evidence assessment, nine studies of the sample had level VI, one had level VII, and two were evaluated as level II.

The topics covered in the selected studies were as follows: two studies address the use of a tool to assess websites(23-24); six address the development, use, evaluation, and/or application of software for computers and smartphones(14, 16-17, 19, 21-22); two deal with the attitude and behaviour of health professionals and parents of children and adolescents when accessing online portals(18, 20); one paper compares the effectiveness of direct access to an online platform with regard to the consultation of health workers(15); and another demonstrates how the characteristics of parents influence searches of health information online(13).

The analysis of the selected studies revealed positive and negative aspects of the use of online information for the families of children and adolescents with chronic illness, which resulted in two categories: Potentialities of the use of online information for the families of children and adolescents with chronic illness, and Weaknesses of the use of online information for the families of children and adolescents with chronic illness.

Reference	Year/Place of study/Journal/ Database	Methodological approach/Level of evidence	Objective
Stern et al.(13)	2011/United States of America (USA) Journal of Family Issues/ CINAHL	Quantitative/Level VI	Explore how the parental status, gender, and interaction between these two variables influence a range of aspects for the search for online health information.
Swallow et al.(14)	2014/United Kingdom/JMIR_ *Research Protocols*: JMIR *ResProtoc*/ PubMed	Quantitative/Level II	Evaluate the feasibility of a randomised clinical trial of Online Parent Information and Support in terms of recruitment and retention of mothers and fathers, data collection procedures and psychometric performance of the study measures on the target population, and investigate the trends of change of results measures in a small-scale randomised clinical trial in parents of children with chronic kidney disease stages 3-5.
Armstrong et al.(15)	2015/USA/JAMA Dermatology/ PubMed	Quantitative/Level II	Compare the effectiveness of access to an online model for tracking dermatologic care in children and adults with atopic dermatitis with personal visits at the consultation room.
Stinson et al.(16)	2014/Canada/ Pain Research & Management/ PubMed	Qualitative/Level VI	Evaluate the healthcare needs of adolescents through an online self-management programme for chronic pain in adolescents called *iCanCopewithPain*™.
Fore et al. (17)	2013/ EUA/ JMIR Research Protocols: JMIR ResProtoc/ PubMed	Qualitative/Level VI	Describe how the project Metas Dirigidas ("GDD") was employed to understand the context and objectives of potential participants in a system that conceptualises a health-learning programme in a network of collaborative care for chronic diseases (C3N), specifically for paediatric inflammatory bowel disease.
Byczkowski et al.(18)	2014/ EUA/ Health Informatics Journal/ PubMed	Quantitative/Level VI	Understand the perception of parents of children with chronic diseases (diabetes, juvenile idiopathic arthritis and cystic fibrosis) on the usefulness and value of information available on the website intended for patients with chronic illness.
Swallow et al.(19)	2012/United Kingdom/Journal of Advanced Nursing/PubMed	Qualitative/Level VII	Present the report of a protocol for studying the creation and evaluation of an information pack for parents and online support for the home care of children with chronic kidney disease stages 3-5.
Nordqvist et al. (20)	2009/Sweden/ Journal of Medical Internet Research/ PubMed	Qualitative/Level VI	Explore the attitudes of paediatric health professionals in relation to the introduction of a local web portal for young patients with type 1 diabetes that offers interactive educational devices, social networking tools, self-service information, and locally produced treatment.
Timpka et al.(21)	2008/Sweden/ BMC Medical Informatics and Decision Making/ PubMed	Qualitative/Level VI	To address the potential for developing web 2.0 services for young people with a chronic disease.

Chart 1 – Characterisation of the papers included in the review (continue)

Reference	Year/Place of study/Journal/ Database	Methodological approach/Level of evidence	Objective
Swallow et al. (22)	2014/United Kingdom/BMC Nephrology/VHL	Qualitative/Level VI	Explore the views of parents, patients, and professionals about the content of the information proposed by the web-application Online Parent Information and Support (OPIS) for the care of children with chronic kidney disease.
Lam et al. (23)	2013/USA/Patient education and counseling/ Science Direct	Quantitative/Level VI	Assess the quality, readability, and social impact of websites for adolescents diagnosed with osteosarcoma.
Cerminaraet al.(24)	2014/Italy/Epilepsy & Behavior/ Science Direct	Quantitative/Level VI	Assess and analyse the quality of online information about children with epilepsy and its treatment in English-speaking countries to identify shortcomings and recommend changes in online health resources for children's epilepsy.

Chart 1 – Characterisation of the papers included in the review (conclusion)

Source: Research data, 2015.

In the first category, the potentialities of the use of online information to support children and youths with chronic disease were: search for online information, both sexes, in families with chronically ill children, which serves as relief for the parents since they verified that the symptoms and behaviours of their children are appropriate for the age and provide knowledge for the family members to discuss treatment with the physician(13); source of complementary knowledge(17); supports caregivers due to the dynamism, flow, and possibility of exchanging information(18, 20); helps parents cope with chronic diseases(14, 16, 19-22); attracts teenage audiences(16); contributes in self-care(17-18); has positive results in online therapeutic follow-up, as in the consultations at the doctors' offices(15); and although the internet is widely accessed, health professionals continue to be the main source of information(20).

In the second category, the weaknesses of the use of online information to support the parents of children and adolescents with chronic diseases were: difficulties in understanding the information(14, 19); the "digital divide" (limited knowledge of different languages, use of high-cost electronic devices, and access for the low-income population)(16, 19-21); restriction of online therapeutic models to populations in specific chronic conditions(15); low quality(23-24) and reliability(24) of the available content; low availability of data for adolescents(23); deficit of skills of health professionals to identify and conduct the use of online support tools(20-24), and ignorance of legal regulations on online communication(20).

DISCUSSION

The identified studies refer to the need for the professional appropriation of online care and information models given the broad expansion of internet and online tools. This issue leads to two distinct points: on the one hand, the internet allows the dissemination of information, whether through free content or online services, that can help families care for children and adolescents with permanent conditions, while on the other hand, quality content is not always available, part of the population has limited internet access, and the online service models apply to specific audiences.

The papers found are mostly related to chronic diseases. However, they can be used to discuss different diseases and promote health during the other stages of the life cycle.

The potentialities of the use of online information for families of children and adolescents with chronic illness

Care for children and adolescents with chronic illness is complex for the family since it demands a wide range of actions to meet the needs of sufferers(25). In some cases, the families must use technologies that require specific technical skills(26).

These different caregiving demands and little knowledge of the disease, especially with respect to prognosis, can cause insecurity in the families(27). Therefore, these families need to access reliable information that can reduce these insecurities and support care for the child or adolescent with chronic illness, and this information can be found online.

The family members of these sufferers search for information to acquire knowledge and adopt the appropriate care practices for their children(7) that complement the care provided by the healthcare professionals(16, 26). In a study conducted in the United States to examine the use of the internet to search for health-related information according to sex and the parental status, it was found that men and women with children search for information in a similar way, and both feel relief with the data found because they discover that most of the symptoms and behaviours are normal among children(13). Furthermore, the internet promotes access to information, and provides a huge amount of online content health-related issues(28).

The information available on the internet improves care and provides knowledge on clinical interventions and self-care(17-18). It also gives people the confidence to talk and question health workers about findings(13). These benefits create the initial conditions to transform the relationship between medical professionals and users or caregivers, without reducing the authority, social prestige, and knowledge of these professionals(1, 29).

Communication and information technologies are believed to contribute to the success of a health system(17) and lead to the emergence of a new model of care in which individuals take control of their health by connecting with online communities and support networks(3). Consequently, health professionals need to reorganise care by including the virtual dimension to support family members in the care for children and adolescents with permanent conditions.

The internet allows the creation of online models for therapeutic follow-up of people with chronic diseases. A study conducted in the USA compared the effectiveness of the physical consultation with the online consultation among children and adults with atopic dermatitis, and found that patients who consulted the online model showed significant improvements – as did the ones who did physical consultations – resulting in the comfort of both parties without the need to travel to major centres in search of assistance(15).

The exchange of supplementary information between professionals and patients/caregivers through the online model promotes a network of support for these families with the integration of the health team that is jointly responsible for the systematic care of the family that assumes the role of caregiver.

The dynamism of the internet provides a flow of simultaneous communication and becomes an instrument of support to caregivers in decision making and reduces family stress, which only benefits the child and/or adolescent(18, 20-30).

In addition to the content available on the internet and online services, in order to cope with the chronic condition, parents, children, and adolescents use applications that focus on the specific pathology(14, 16, 19-22). These tools allow them to expand their health education and manage their own condition as considered convenient(31). It is also attractive mostly to adolescents since they are the most active users of these applications(16). The use of these technological innovations may not be entirely suitable for health professionals since they require qualifications to support and strengthen the use of these resources for healthcare.

Thus, professionals involved in the development of online support tools can expand their knowledge, and ensure that important topics related to chronic disease are addressed and that interventions proposed on the internet are effective, which benefits the professionals, families, and the children and adolescents with chronic diseases(32).

The inclusion of the internet in the professional practice goes beyond the recognition that patients and family members use online content, it also englobes the evaluation of this content to improve the quality of care. However, it is necessary to recognise the current challenge of linking the knowledge of professionals to information found online by users(33), and the use of other available resources, such as online models of assistance and applications.

Although the internet is a modern and expanding source of information, some families use the traditional model of acquiring information. Certain studies show that patients and caregivers still obtain information about their health condition and therapy from health professionals(1-2, 7, 20, 28). This can be attributed to limited internet access and the non-preference of family members to this type of technology.

Weaknesses of the use of online information for families of children and adolescents with chronic illness

The internet as a source of information has weaknesses and peculiarities and should therefore be used with caution(28). Many sites, platforms or applications related to healthcare have outdated or incomplete information, without authorship or origin, or containing language that is inappropriate for the target audience. Others provide highly technical information for the general public that does not substantially differ from the content provided to professionals(8, 34). To involve users and help them understand the information, online platforms can use illustrations, videos and gamification techniques.

One of the major weaknesses found is possible difficulties in reading and understanding the information(14, 19); in this case health literacy is thought to facilitate a conscious and critical understanding and use of information in the scope of healthcare(35).

Regarding the inadequacy of the available content in online healthcare resources, some data is influenced by commercial interests(8) and most of this information is not edited or structured(36).

Moreover, the information that appears on the first search pages of the internet is often backed by the financial investments of the platform, and does not always rank first because these websites are more frequently accessed or contain appropriate information.

Even with the exponential use of the internet, there is still the so-called "digital divide"(16, 19, 21, 37), which is defined as having access to the internet but not making use of it for a number of reasons(38). Firstly, there is a language barrier that prevents users from understanding the available information. Secondly, users need electronic devices that are generally expensive and inaccessible for low income populations, and they lack the knowledge of the tools, sites, and the organisation of the virtual environment to use the internet(8).

The virtual tools available include online models, which should be used discriminately and by specific persons. These models require the correct selection of the patient and disease, which is only applicable in cases of online assistance, to protect the health of patients(15). In addition to the online format, patients should attend physical consultations to verify the data that is submitted virtually. Therefore, the internet becomes an additional, contributory tool that must be correctly and sensibly used by health workers and patients.

Another weakness is the quality of the information that supports youths with chronic illness. Also, the content that targets this population is usually scarce, although it is provided in social networks that engage users(23). A study that evaluated sites about infant epilepsy found little reliability or quality in the provided information, reinforcing the importance of improving the tools that offer content on pathologies with the help of healthcare professionals and experts(24).

Also on the topic of health professionals, some studies found that these workers can lack the skills to identify and guide the use of online support information(20, 24), and they are unaware of the legal aspects that permeate online communication with patients(20). Therefore, it is crucial for health workers to be updated on the available health-related websites, and acquire the skills to determine the credibility of the information provided(2) since it can be misunderstood and compromise treatment(33).

CONCLUSIONS

The current expectation of available and accessible data and applicable models for the online care of children and adolescents with permanent diseases that accompany worldwide technological advancements is undeniable. Visibly, investments are being made to support the expanding accessibility, quality and effectiveness of information, and the identification of weaknesses can help improve the provision of online information.

Although the diversity and number of website is steadily growing, it is essential to improve the quality of health information available online. We suggest the use of evaluation criteria in the preparation of content and the involvement of healthcare experts in the development of tools to ensure the provision of quality information with a theoretical basis. We also stress the need to expand online information and support for youths with chronic diseases.

Research on this subject regarding the Brazilian scenario is still limited, and there are gaps in the care model related to online support for the families of children and adolescents with chronic illness, and how this model is used. Further research is needed to shed additional light on technological changes and how users and health professionals are making use of these innovations to improve healthcare.

For professional healthcare management and practice, it is important to recognise the need to articulate common knowledge, professional knowledge, and this new online access to health-related content for the benefit of the families of children or adolescents with chronic illness. Currently, the use of this online information is often submerged in the provided healthcare.

In this digital age, it is necessary to rethink the use of the internet in professional training as an element that creates and recreates care spaces and shares information, which implies the acquisition of knowledge and the development of new skills to incorporate care technologies.

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