Collaborative e-Health Environments: The enhanced role of health agents

Ambientes colaborativos de e-Saúde: o papel ampliado dos agentes de saúde

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Abstract

The literature has discussed the importance of the impact of Information and Communication Technology on health promotion, health education and applications to promote change in health behaviors, denominated e-Health promotion. The objective of this article is to describe Web 2.0 properties that should converge to a peer-to-peer collaboration platform, with the mediation of a health agent. This Web 2.0 system should provide a space where people may, not only receive information, but also exchange ideas and experiences about how to deal with the conditions resulting from the diseases caused by Zika virus, such as microcephaly. Microcephaly is a rare neurological condition in which the child's head and brain are significantly smaller than those of others at the same age and sex and may cause a number of genetic or environmental problems. The risk of a Zika epidemic is real, it mainly affects people in poor countries, and especially Brazil that has the social responsibility to face the challenge of supporting hundreds of families of children born with microcephaly. E-Health projects are often focused only on health service managers, practitioners and research partners. These projects are not of open access and, in Brazil, there is no public platform that serves non-specialized citizens. We suggest a design that includes the health worker, family and stakeholders as content creators, able to act peer-to-peer and bottom-up, which may be useful for developing countries with similar health contexts.

Keywords: Collaborative environments. E-Health. Health communication. Microcephaly. Web 2.0. Virus Zika.

Resumo

A literatura tem discutido o impacto das Tecnologias de Informação e Comunicação na promoção da saúde, na educação em saúde e nas aplicações para se promover a mudança nos comportamentos em relação a isso. O objetivo deste artigo é descrever as propriedades da Web 2.0 que devem convergir para uma plataforma de colaboração peer-to-peer, com a mediação de um agente de saúde. Esse sistema deve fornecer um espaço onde as pessoas podem não só receber informações, mas também trocar ideias e experiências sobre como lidar com as condições resultantes das doenças causadas pelo vírus Zika, como a microcefalia. A microcefalia é uma condição neurológica rara em que a cabeça e o cérebro da criança são significativamente menores do que aqueles da mesma idade e sexo, o

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Received on September 9, 2017, and approved on August 10, 2018.

Como citar este artigo/*How to cite this article*

Jorente M.J.V. *et al*. Collaborative e-Health Environments: The enhanced role of health agents. *Transinformação*, v.31, e170059, 2019. http://dx.doi.org/10.1590/2318-0889201931e170059

que pode causar uma série de problemas genéticos. O risco de uma epidemia de Zika é real. Ele afeta principalmente pessoas em países pobres, como o Brasil, que tem a responsabilidade social para enfrentar o desafio de apoiar centenas de famílias. Os projetos oficiais de e-Health geralmente se concentram apenas em gerentes de serviços de saúde, profissionais e parceiros de pesquisa. Sugerimos um design que inclua o agente da saúde, a família e as partes interessadas como os criadores de conteúdo, capazes de atuar peer-to-peer e bottom-up. Isso pode ser útil em países em desenvolvimento com contextos de saúde semelhantes ao brasileiro.

Palavras-chave: *Ambiente colaborativo. E-Health. Comunicação e saúde. Microcefalia. Web 2.0. Zika virus.*

Introduction

The literature has discussed the importance of the impact of Information and Communication Technologies (ICT) on health promotion (Eng, 2001; Eysenbach, 2001; Mukherjee, McGinnis, 2007), health education and applications to promote change in health behavior, denominated e-Health promotion (Knott, Weller, 2014; Skinner, *et al*., 2006). Some studies have evaluated quantitatively and qualitatively the impact of ICT on the promotion of e-Health[2] (Chou *et al*., 2013), while other studies explore peer-to-peer collaboration for health information sharing and dissemination. In exploratory searches in Brazilian, American and European governmental sites, it may be observed that information in websites promoting health (Cunningham *et al*., 2014; Showell; Nøhr, 2012; Sinha; Thankachan, 2012) is constructed top-down.

Official or governmental institutions create top-down e-Health platforms considering that the mere publicization of information itself could guarantee the health information will be accessed in such a way to guide decision making or knowledge construction.

According to the strategies of the latest Brazilian National Health Information and Informatics Policy[3] the purpose of e-Health is to:

> Promote the innovative, creative and transformative use of information technology to improve health work processes, resulting in an articulated National Health Information System that produces information for citizens, management, professional practice, knowledge and social control, guaranteeing measurable efficiency and quality gains by broadening access, equity, integrality and humanization of services and thus contributing to the improvement of the health condition of the population (Brasil, 2016, p.11).

On the other hand, technologies cannot be expected, no matter how well implemented they may be, to present the solution to the problems of competence in understanding the information shared in these environments. These problems present themselves to the information scientist as a challenge in the elaboration of efficient strategies, especially in situations aggravated by adverse contexts, in which educational, psychosocial and/or cultural background gaps may be interposed to the pressing information needs of the communities of interest.

If this dramatic situation is no doubt a reason for concerns, it also defies Communication and Information Science researchers to find, in this light, a fertile soil to work in treating information so that it reaches people to share ideas and experiences to provide a digital place of dialogue and aid in several aspects that one involved in this context must cope with.

Within this perspective, in the Brazilian context, we understand that the answer may be found in a program officially deployed by the Ministry of Health in Brazil in 1991, that created the so-called Program of Community Health Workers (CHW), part of the construction of the Brazilian unified health system brought by the 1988 Constitution, which instituted a new public job named Community Health Worker. The Program is intended to search for alternatives to improve the health conditions of people in their own communities.

[2] Technology that supports health care providers in the management of chronic diseases and continuing care (Hendriks, *et al*., 2015).

[3] Translation by the authors.

Today, the Community Health Worker (CHW) professional is one of the most studied by universities throughout the country. This is due to the fact that CHWs are transiting through both spaces – government and community – and mediate this dialogue. The CHW has a very important role in the reception of the individuals and families, since he/she is a member of the team that is part of the community, which allows the creation of bonds, providing direct contact with the team.

Community Health Agents (CHA) and Agents to Combat Endemics (ACE) could perform the mediation between the technologies and affected families or stakeholders. They are important workers within the Unified Health System (SUS).

The CHA regularly visits the homes, with the role of guiding people in relation to their health, referring them to the health care center or other places of care whenever necessary. The ACE promotes actions of health education in the community and informs the population about the risks of diseases, the digital communication channels should favor to speed up the communication process between the ACE and the population. In addition, ACE also visits homes and other sites aiming to prevent and control diseases such as dengue, malaria, leishmaniosis and Chagas' disease.

Currently, according to the Ministry of Health, Brazil counts on a quantitative of 89,708 ACE (Brasil, 2016), therefore the need to qualify the field activities developed by agents to combat endemic diseases is highlighted. We also highlight the opportunity to explore new channels and mechanisms for sharing and dialoguing with the objective of integrating primary health care actions to improve the qualification of these agents in the use of technological platforms. Leadbeater and Wong (2010) argue that disruptive innovation is found among the peripheral social agents because they always have to cope with more difficult situations, which make the risks associated with radical innovations seem smaller. For the collaborative Web environment that we propose, it is important to listen to the population through a direct path and establish a truthful relationship with health professionals and agents.

In this context, considering the ineffectiveness of top-down strategies of communication, the article describes strategies based on Web 2.0 possibilities in its potential for collaboration, that effectively promotes information sharing in a horizontal way. For this, this article views the possibility of horizontal communication as follows: (1) firstly, the system must be designed institutionally, *i.e.*, top-down, aiming the peer-to-peer at the end; (2) the system should then be open to contributions both by Health Workers and by non-specialized individuals; (3) the system should be built previewing the training of Health Workers together with the environment design; (4) the trained Health Worker should prepare non-specialized individuals to manage the information in the system; (5) once the individuals are trained, they can share significant information among them.

The objective of this article is, therefore, to describe the need and procedures for mediation of a health worker that should converge to a peer-to-peer collaboration platform. For that, this Web 2.0 system should provide a space where people may, not only receive information, but also exchange ideas and experiences about how to deal with the conditions such as microcephaly with which families must live in a continuous and chronic manner.

Microcephaly in Brazil and Brazilian Community Health Workers

Although Brazilian initiatives in public policies on racial equality and women's health have been a reality, i.e., the country's policies targets citizens, it is observed that, when it comes to digital environments identified as networks of collaboration in health technology and information, in general, they are aimed at health professionals, researchers, and health service managers, without a perspective of information sharing within the digital environment system.

On the other hand, what is observed in websites for information on disabilities is that they are governmental initiatives with relatively simple language, aimed at lay audience, but merely informative, with linear Web 1.0 features, which do not meet the needs of individuals and there is no space for interaction or peer-to-peer information exchange. Paradoxically, the greatest contribution of the current development phase of the Web, in the context of the growth and potential of the Internet, is precisely the possibility of information exchange and empowerment of individuals who decide to play a decisive role in clarifying their health and wellness needs. According to Chou *et al*. (2013, p.6), "[…] peer-to-peer health exchange parallels a main finding in online support group studies where sharing personal advice dominates over sharing knowledge and guidelines". Still according to the author, future interventions could include more complex approaches to disseminate guidelines or information combining system-generated content and content generated by peers or users relating their personal experience.

Chou *et al*. (2013, p.8) lists some questions that must be reflected on:

> Is the intervention a space where health messages are 'pushed' out for the audience's response and commentary, and, if so, how is audience feedback incorporated into ongoing message design? Alternatively, does the intervention involve the audience as cocreators of content? If so, how might health promoters moderate this content to ensure accuracy and appropriateness?

We acknowledge that the implementation of a Web 2.0 tool for horizontal information sharing faces several empirical problems related to content management, for example, but these issues will not be addressed at this stage of design conception.

As Health Workers are a new category of workers formed by and for the community, acting and making part of the health services provided in the communities, with attributions (1 to 8) established by law in 2006 (Brasil, 2006), this article suggests expanding the attributions they perform physically to attributions performed in digital environment, creating scalability and contributing for solutions of problems. The suggestion to expand the Health Workers' role in the digital environment is described below along with the physical attributions established by the law:

a) "To describe the families in a defined geographic base or micro area".

Using this attribution, the Worker could map the occurrence of microcephaly cases, digitally. Our suggestion is that the e-Health system on the Internet should bring a geolocation resource, in which the health agent should be trained to act on.

b) "To enroll all people in his/her micro area and constantly update records".

In this context, within the georeferencing resource, the Health Worker should be able to insert information, so that when anyone browsing the georeferencing button, a window should display public information about services (and private information about the condition of the patients that can be publicly displayed) nearby the area of the affected person.

Another feature to be filled by the Health Worker is the possibility to update confidential information, as well as new information about the development, characteristics, symptoms and relevant information that could be made public.

c) "To guide the families regarding the health services available that they are entitled to".

Guiding the affected individuals and families demands instructing these people on how to manage information on the system and how to insert/upload new information.

d) "To carry out programmed activities as well as activities of spontaneous demand".

To help identify spontaneous demand activities, the suggestion of this article is that the e-Health system integrates a software for online chat. Business software for synchronic chatting with customers are quite common

both in Brazil and around the world. Public institutions may also take advantage of this service to offer a possibility of online synchronic interaction.

Mibew Messenger is an open source and free, which is in line with the governmental guidelines to use open source and free software, for instance. Its main features are: real-time chat, unlimited number of operators, visitors and multi-language chats, it is executable on the institution's server; chat button provides status online and offline (displays a message when the attendant is offline); chat window presents an optional form prior to the chat, window customization, possibility to send chat by e-mail, audible and visual alert to each new message; operator skills include automatic messages, click tracking to get to your website, chat history with search, page change notification, active chat view, administrator can take over the chat, daily statistical reports.

e) "To follow, through home visits, all the families and individuals under his/her responsibility. The visits shall be scheduled along with the health team, considering the risks and vulnerability in such a way that families with greater need are visited more often, maintaining the average of one visit per month as reference".

Accompanying the on-site visit, the resource should have an area to register the follow-up and scheduling of that visit. This feature, being networked, facilitates the logistics of the schedules, in addition to facilitate the access to other healthcare professionals to this system and information.

f) "To develop actions that seek integration between the health team and the population enrolled in the Health Care Center of the micro area, considering the characteristics and aims of the follow-up of individuals and social groups or collectivity".

The integration happening digitally complements the activities to integrate the health team and the population through the interaction brought by a chat software, and other apps, for instance.

In designing the e-Health system, there is a decision to be made about this attribution: either there will be the convergence of another system/tool, or it will interoperate with commercial platforms, such as Facebook. An example is Eurordis (<http://www.eurordis.org/pt-pt>), a platform aimed at rare diseases in Europe: converging to Eurodis, the RareConnect platform (<https://www.rareconnect.org/pt>) aggregates possibilities for finding discussion groups, sharing stories, join a community, Webinars etc. The communities in RareConnect were created in collaboration with patients/families groups that offer resources such as: moderators, bonds with specialists or provide trustworthy information.

g) "To develop activities of health promotion, prevention and health care through home visits and individual and collective education actions at home and in the community, such as actions to eradicate *Aedes aegypti's* breeding sites, malaria campaign, among others, maintaining the team informed, especially regarding the risk situations".

These actions, implemented on-site, could also take advantage on the digital environment with hangouts, video lectures, podcasts, YouTube channels and radio programs.

h) "To be in permanent contact with the families, developing educational actions, aiming at the promotion of health, the prevention of diseases and the follow-up of people with health problems, according to the team's planning".

Collaborative Web 2.0 aspects of an e-Health environment

To be in permanent contact with the families, this study suggests it should also be done through mobile Internet. Chou *et al*. (2013, p.6) also concerns digital divide. The authors recommend that initiatives should take into account "the literacy demand, message comprehension, relevancy, and trust of information source, and determine intervention effectiveness for audiences with limited literacy". In the Brazilian case, it is necessary to consider the

federal government initiatives until the beginning of 2016, for dissemination of information, however this study points out that the Internet via mobile is the best way to share information in e-Health context in the country.

Chart 1 summarizes the actions this study suggests the Agents may carry out digitally, within their functions defined by law.

The boundary between Web 1.0 and 2.0 was centered on the understanding of the Web as a platform (Sáez-Vacas, 2007; O'Reilly, 2005). This means that, unlike boundary delimitations of a place, the Web has come to be situated as a gravitational center, as a set of principles that congregates, around itself, digital environments with properties, such as affordances.

The design of the new Web 2.0 features has gathered around its gravitational center an exponentially increasing number of environments that, from 2002, have characterized the platform for the dynamism, fluidity and openness, allowing the emergence of new affordances. For this mediation to be effective, the Collaborative Web (Web 2.0) properties must be efficiently applied and optimized in the construction of the system, or the system should interoperate with a commercial software such as the examples in the third column of Chart 2.

Chart 1. Mediation performed by the Community Health Worker in the digital environment.

	Community Health Worker actions	Mediation performed by the CHW in the collaborative Web environment
1	To describe the families in a defined geographic base or micro area.	Map the occurrence of Zika and microcephaly, digitally.
2	To enroll all people in his/her micro area and constantly update the records.	Update the confidential information, as well as new information about the development, characteristics, symptoms and relevant information that could be made public.
3	To guide the families regarding the health services available that they are entitled to.	The worker should insert this guidance and information digitally.
4	To carry out programmed activities as well as activities of spontaneous demand.	Interact with the individuals through a chat software with synchronic messages or other asynchronic possibilities.
5	To follow, through home visits, all the families and individuals under his/her responsibility. The visits shall be scheduled along with the health team, considering the risks and vulnerability in such a way that families with greater need are visited more often, maintaining as reference the average of one visit per month.	During the on-site visit, the resource should have an area to register the follow-up and scheduling of that visit.
6	To develop actions that seek integration between the health team and the population enrolled in the Health Care Center of the micro area, considering the characteristics and aims of the follow-up of individuals and social groups or collectivity.	Mediation and Integration actions within the micro area in the digital environment should be carried out either interoperable with commercial services or designed with programmed convergences to interact within the system.
7	To develop activities of health promotion, prevention and health care through home visits and individual and collective education actions at home and in the community, such as actions to eradicate *Aedes aegypti's* breeding sites, malaria campaign, among others, maintaining the team informed, especially regarding the risk situations.	Dissemination and mediation of educational activities creating events in the Web, Hangout (Gmail), Life event (Facebook), Periscope (App), Instagram (Live), Podcasts and others.
8	To be in permanent contact with the families, developing educational actions, aiming at the promotion of health, the prevention of diseases and the follow-up of people with health problems, according to the team's planning.	According to the team's planning, maintain updated information and inform patients through mobile Internet.

Source: Elaborated by the authors (2017).

Chart 2. Properties the e-Health system should incorporate. (2017)

	Mediation performed by the CHW in the collaborative Web environment	Properties or affordances of Web 2.0	Examples of resources/digital environments that incorporate these properties
1	Map the occurrence of Zika and microcephaly, digitally.	Interactivity	Google Maps Google Drive Flickr
2	Update the confidential information, as well as new information about the development, characteristics, symptoms and relevant information that could be made public.	Continuous reconfiguration + Content retrieval	Creative Commons + Search engines such as Google, advanced search resources
3	The worker should insert this guidance and information digitally.	Connection and interoperability	Data Mining environments
4	Interact with the individuals through a chat software with synchronic messages or other asynchronous possibilities.	Continuing reuse + Internal mutability of the system	*Meebo Messenger*, open software, documentation and code in accordance with W3C + Creative Commons, intellectual property issues
5	During the on-site visit, the resource should have an area to register the follow-up and scheduling of that visit.	Responsivity	All environments that adapt and respond to Tablets e Smartphones
6	Mediation and Integration actions within the micro area in the digital environment should be carried out either interoperable with commercial services or designed with programmed convergences to interact within the system.	Connection and interoperability + Interaction	WhatsApp, Life event (Facebook), Instagram (Live)
7	Dissemination and mediation of educational activities creating events in the Web, Hangout (Gmail), Life event (Facebook), Periscope (App), Instagram (Live), Podcasts and others.	Reliability and welcoming of the individuals' needs	Hangout(Gmail), Life event (Facebook), Periscope (App.), Instagram (Live), Podcasts and other informational Websites such as Wikipedia, Youtube, Vimeo TED talks
8	According to the team's planning, maintain updated information and inform patients.	welcoming of creativity in interaction	Integration of platforms and databases - ensure continuing update

Source: Elaborated by the authors (2017).

Chart 2 exemplifies the properties or affordances the e-Health digital environment should converge in order to be effective, in line with the attributions the health agent already assumes by law. The suggestion of this paper does not assign more duties to the health agent, on the contrary, from our point of view, the implementation of such platform could facilitate the agent's work by gathering, in one environment, all the information necessary to perform his/her work. The suggestion of this paper is that the support used to collect information from the families they serve changes from analogic to digital.

The project focused on affordances provides the development of a platform characterized by properties that facilitate the access and use of digital resources. Affordance may be understood as how much potential the shape or interface of an object present so it is manipulated in the way it was intended to. Gibson (1986) defined the Theory of Affordances, where he asserts that the perception of affordances is holistic, what we perceive of an object is its affordances, not its properties or dimensions. "For example, one will perceive that one can walk forward when

one sees a solid, opaque surface that extends under one's feet. The affordance is walkability and the information that specifies walkability is a perceived invariant combination of a solid, opaque surface of a certain size relative to oneself" (McGrenere; Ho, 2000, p.2). Affordances may also be considered as a tool that aims to understand how the individual interacts with objects and how to effectively enhance this interactivity.

Conclusions

The process of improving cognitive capacity in human beings is articulated with concepts, methods and means corresponding to their needs and abilities woven into systems to solve problems and meet the challenges of life. Technologies, as potentiators of these three instances – concepts, methodologies and means – are, therefore, in line with information in their moments of search, creation, storage, retrieval, and use. The computer is a technological object, because its construction and its vocation for communication already consolidated by habits presupposes the convergence of knowledge of scientific laws defined by several areas of knowledge. According to this development, over the past 50 years, exponential growth has been witnessed both in computing capacity and in its own dissemination – computers and Post-PC devices and their applications and systems are practically everywhere as a emblematic innovation of the 20th and 21st centuries.

When technology progresses, its complexity also progresses, even in the so-called everyday technology, whose complexity is masked or filtered by the interfaces due to the facilitation of its use by lay public. The accumulation of functions and their convergence in a device translates such complexity, so that a Post-PC device, such as a smartphone or a tablet is currently much more complex than mainframes or even the first personal computers from which they inherited elements of this complexity.

At present, much of the population has one (if not two or more) of these devices, mostly constructed in a continuous way in relation to the previous digital technologies, still not assimilated in the change from the analogical paradigm to the digital one.

Innovation is the behavioral change of Health Workers as producers and consumers of processes, methods, devices, products and/or services. Much of what we may define as innovation involves ICT and its transformation into artifacts and experiences that respond to the market demands of an interconnected economy of information and knowledge.

The main barriers identified in the literature (Brender *et al*., 2000; Kaplan, 2001; Morris *et al*., 2002) refer to insufficiently developed standards (identification, presentation, communication and representation of clinical data), conflict of interests with private medicine, scarcity of resources for investments and fear of professionals in exposing their clinical behavior. In the most diverse e-Health applications, from systems and websites for health based on self-health applications and sites, we highlight the offer of information systems on a wide variety of medical specialties and the controversies over the efficiency of these systems for improving people's health.

In order to reach the goal established by the national policies, health information and informatics must be treated as a strategic macro function of the Brazilian Unified Health System management. In this way, it will be possible to break the merely instrumental vision of this field, which is essential for the continuous improvement of health policy in the country. In the context of the new paradigm, the planning, definition, implementation and evaluation of health information systems will be carried out in a participatory manner, taking into account the needs of users, health professionals, service providers and managers of the three levels of government: federal, state and municipal.

Training these Health Workers is a complicating factor, however, the worker must be convinced, believe and understand the benefits brought by the technologies, and thus embrace the idea, because the e-Health system itself will not solve all problems; therefore, it has to be hybridized to the subject that represents the official institutions in a common effort to cope with the reality of people.

Contributors

M.J.V. Jorente study conception and design, writing, review and approval of the final version of the manuscript. N. Nakano literature review, writing and translation of the manuscript. M.C. Padua literature review and writing of the manuscript. A.R. Silva literature review and writing of the manuscript.

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