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Online decentralized systems and the fight against pediatric cancer

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Abstract

This article discusses the use of Web 2.0 participatory online platforms in the specific case of pediatric oncology in the portuguese context. We present the initiative to build an online site for information about pediatric oncology, where initially was decided to adopt a rigid structure in the management of informational content, focusing on safety and quality of information. Looking to explore new possibilities of using the website by users, It was made a study about the context of web 2.0 in order to further contribute to an expanded awareness of the potential of the available resources from their universe of users. Finally, we proceed with the analysis of the efficiency of decentralized systems online to mobilize citizen action and solidarity through Web 2.0 applications, seeking to expand the critical reflection on the implications for the use of such funds with the specific case of Portuguese pediatric oncology.

Keywords: Internet, Web 2.0 participatory online platforms, social networks, pediatric oncology,

1. Introduction

This paper aims to contribute to applicable knowledge to the contexts of contemporary media network, specifically related to the pediatric cancer problem. It is part of an investigation which demonstrates the contribution of digital media design in the context of pediatric cancer

Within this investigation course, was developed and implemented the platform www.oncologiapediatrica.org, which was aimed to first confirm the hypothesis of the design multimedia can contribute to the information, support and sharing of testimonies from family, friends and patients in the fight against pediatric cancer. This platform is based on a centralized system, i.e. the organization, policy and management of information content of the site comply with a hierarchical pyramid structure. However, technological developments conducive to the flourishing of Web 2.0 and social networks now require a re-addressing the approach previously adopted in order to upgrade the project by this new reality.

To better understand this study, focused on emerging information management systems, horizontal and decentralized as are the social networks or blogs, it is necessary to present a synthesis of the first phase of research that preceded the current one.

In 2005, the Portuguese context, information about pediatric oncology available through web sites on the Internet which offer security and reliability to their users were scattered and insufficient> In this area was a large gap of national sites for parents or the general public. This made that anyone easily give up using this resource to look for information. In addition, this lack of offers made that the health professional themselves do not encourage parents to this type of query.

The publications produced by hospitals, institutes and associations were the main means of specialized information that general public had access. But a number of problems were identified, such as the Hospital of St. John Porto, where the latest version of the publication of support or clarification on the subject dates from 1993, and due to be outdated, was not even distributed. Moreover, due to economic factors as the cost of printing, the information tended to be more generic. The study then proposed the Internet use as a more economical and faster medium, allowing the publication of a greater number of more specialized and updated information (Martins, 2007). Thus began the project activities for the construction on the Internet of a portuguese reference website in pediatric oncology.

The site www.oncologiapediatrica.org was launched in March 2007, and its tendency was always of growing. In 2007, the average number of visits per day was 91.9, rising to 229.1 in 2008 and in 2009 to 274.8 visits.

A significant part of the research was developed in field work, in a direct contact with institutions, health professionals, researchers and families of children with cancer.

This study was developed during the period prior to the construction of the site having had a greater importance and influence than the initially expected. This fact has forced a significant prolongation of this period – about nine months.

The difficulties encountered while performing field work became relevant for the study because ultimately condition the project as a whole. We could refer, for example:

- To the difficulty in obtaining permits;
- To the inertia identified in some collaborative contexts;
- To the difficulty in the development of certain teamwork;
- To the apparent impossibility of obtaining a more diverse participation in the site.

It should be noted that these difficulties are not likely to be assigned to individual desires, but rather the result of deeper social issues.

The contact with health professionals has proved systematically difficult, especially with the medics, largely due to lack of availability. After all, the information collected was quite important to the study. It should also highlight the collaboration of nursing staff, especially in the orientation of the field work and in defining structure of the site.

The contact with the parents was done mostly during the field work stage in the São João hospital. There was the care to a previous preparation, relying mainly on the advice of a health professional.¹ The authorization to conduct interviews, and the selection of respondents, was always the responsibility of a health professional.

There are several reasons that led to this contact with parents:

- Contact directly with its reality;
- Know the real difficulties and anxieties of the parents;
- Know the kind of information they most look for and what the mains media used;
- Introduce the project;
- Find out how the site could eventually help them.

Most of the interviews proved to be very useful to the project, and beyond the significant collection of information we obtain significant incentives too, that worked as motivational factors of work. The interviews and information gathering was as soon as possible.

The field work was, with no doubt, fundamental in the investigation. It was the study period where most contacted, observed, recorded and discussed directly with the principal actors and audience of the project. There was a confrontation with unexpected difficulties and obstacles which forced several times to change the working methodology. It should be outlined that all the ethic rules initially agreed was done, protecting all those involved in field work: patients,

¹ Respecting the initially agreed and signed with the São João Hospital and the Ethics Commission, the contact with the parents was always guided and authorized by a health Professional. Of all those who have guided us, we highlight the nurse Maria Flores, responsible for nursing staff of the Unit of Pediatric Hematology and Oncology. Her information and advices were fundamental to the success of the interview.

parents and health professionals. There was also the careful to ensure that potential emotional implications not put at risk the seriousness required for the normal development of research.

Once collected the necessary data, it was defined and made available to approval the first content structure of the site. After the approval of the agents involved in the project, was given by completed the first part of the investigation work and started the second – the site construction.

Since the beginning, the structure of management information thought for the site was vertical, i.e. a hierarchical pyramid system. As a delicate subject which was intended to give security guarantees and content veracity to the web users, it was estimated that a system of centralized control was the best. The consensus on this option was total, by all entities and individuals who are interviewed. However, it should be noted that in 2006 the 2.0 platforms like social networks, based on a more horizontal logic already existed but had not, in Portugal, the prominence and popularity that began to be felt in mid 2008.

Although one of the major objectives was to create a cohesive space, which contributes to the development of a networking between the various institutions, health professionals and citizens – i.e. a horizontal relationship – the major concern of the study focused on safety and credibility of published content. Enable any citizen to freely publish an informative content was a risk.

However, as mentioned, it was found during field work a great difficulty in bringing together clinical content to the site. Same difficulties were experienced in the many attempts on the creating of a solid and organized human structure to work on the site, both within each institution, as the attempt to develop a collaborative network among the various institutions. This scenario left a climate of little optimism for the future of the project, since it was expected small contribution from health professionals.

The site success mainly resided in the various forums around. Although these forums are controlled – the contents are only published after approval – they are open spaces that visitors use to write messages such as news, testimonials, questions or anxieties. Such content, written by different people, unleashed unexpected dynamic on the site.

The need to raise awareness to the participation in the project was to be dissipating. The many voluntary contribution that were received from citizens led to gradually ceased to be a need to promote the site. Another important event was the community that spontaneously emerged and grew, mainly through the various forums around the site. Several of these members developed become near with the team behind the project, establishing an important and active voice in management.

As will be seen below, these positive results demonstrate that the initial strategy of develop a site with a hierarchical pyramid structure should be reconsidered and the difficulties encountered and examined during the investigation were reflected in the dynamics of the site

over the past years. In other words, we can affirm that these results and the growing popularity and the power of web 2.0 platforms requires that there be a reflection on the system more effective in mobilizing citizens and institutions of citizenship and solidarity actions, which contribute to alleviating the problem of the individual citizen that relates directly or indirectly with the pediatric cancer.

2. The power of citizens and social networks in the ecosystem communication

One of the technological developments that were highlighted in the context of the digital media , in recent times, were the web 2.0. applications. This term, appeared in October 2004 and authored by Tim O'Reilly, founder of O'Reilly Media, in a brainstorming session on MediaLive International. Since that date, has been popularized as the new trend of the internet (O'Reilly, 2005). Forms of communication such as blogs, wikis and the social networks are just some examples of reference.

Are technologies that facilitate the connection of society to the web, where anyone can publish and build freely informative contents according to their interests and needs. The Web 2.0 represents a significant technological development that enabled the emergence of new services, available through applications that become more interactive, sophisticated, with powerful tools and interfaces faster and easier to use. These vantages have come to enrich the user experience and interaction with collective.

In this new generation of World Wide Web, the leadership is directed toward the community, which is provided with more power. Therefore, the success of an application 2.0 is essentially the activity of this community:

The Web 2.0 is the shift towards internet as a platform, and an understanding of the rules for success in this new platform. Among others, the most important rule is to develop applications that leverage network effects to become better the more they are used by people, taking advantage of collective intelligence (O'REILLY, 2005 apud COUTINHO, 2009).

From the mid 1980s, anyone with sufficient technical knowledge was potentially able to enter in the internet development. According to Castells "*these multiply contributions emerged a whole series of new applications never planned before, since the e-mail to MODEM, passing by banner ads and chat rooms arriving, finally, the hypertext*" (Castells, 2001, p.46). This was crucial to the rapid evolution of the internet.

However, twenty years later, with the emergence of social platforms, a new door was opened. The individuals without computer skills also began to have a voice in the conduct of technology. The support of the citizens for this type of platform was a large mass, attending to an emancipation of these in the internet – for example, through social network like Facebook or Twitter.

This phenomenon led Rosental Alves², a renowned expert in cyber-journalism, considering that *“the social networks of which the citizen belongs are more important than CNN”* (ALVES, 2009). These networks have caused a great impact in the media. According to this researcher, live it is an authentic *“digital revolution”*, where the media lose the *“control over information, contrary to networked individuals who gain power”* (ALVES, 2009).

To Alves, what should be understood are the gravity, depth and seriousness of the paradigmatic changes that the communications are suffering as a result of the digital revolution. Due to technological advances, people are changing the way of communicate. He warns that even the media who do not understand this new world of communication, are doomed to die (ALVES, 2009).

Social networks like Twitter usually obey to a horizontal information structure. That is, there is no one at the top or the bottom of the pyramid, because it simply does not exist³. Thus, the social communication organs and citizens appear at the same level, without any hierarchical organization or distinction. Both broadcast informative content based on the same rules, benefits limitations.

The media are about to change, tending to a horizontality. I.e. walks to a democratic transversal mode which the access to the publication of information is global, no longer being limited to a qualified group, as with traditional media.

The fact that we publish first on the web does not mean that the message lose value when goes to the television, to the radio or newspaper (ALVES, 2009). Currently it was another dynamic. All ways are part of this ecosystem that is constantly changing, a model of network communication. A communication model which does not replace the earlier models, but articulates it, producing new forms of communication and also enables new ways of facilitating empowerment and, consequently, communicative autonomy (Cardoso, SPAIN; ARAÚJO, 2009).

This emergence of horizontal systems and communicative autonomy has also verified in the area of pediatric oncology, and with notable results. It must therefore reflect on this system and understand what may be, in this context, the consequences.

3. From the vertical system to horizontal system

As stated above, the site www.oncologiapediatria.org was developed according to a vertical structure, in which the power of informational management is centralized. In this way, This has ensured the site's policy regarding the veracity of the information, for example, the clinical information, reducing the chance of publication of inappropriate content

² Rosental Alves is a researcher and professor of online journalism at the University of Austin, Texas.

³ In some social networks – which apparently is not the case of Twitter – it will be able to discuss the platform policy management. Sometimes, the managers, publish contents and tools that influence and/or constrain the activities of users and, consequently, the dynamics of the network.

On the other hand we believe that the quest for security increases the risk of making the space of interaction with the site too restricted. Taking into account certain difficulties in the obtaining of information contents and overall dynamics of the site, so the hypothesis of experimentation with a more open system started to gain body.

The difference between the vertical and horizontal system, focuses primarily on information control. The difficulty lies in leveling this same control in order to get the best of both worlds: the freedom and security. The major challenge is to understand how can be developed a clear and safe space, where citizens build their network. How to mobilize institutions and citizens in citizenship actions and social solidarity? Taking into account the developed works which is focused mainly in the portuguese context, it is believed that the most likely answer will be more toward a system of information management horizontal and decentralized.

As stated by Ori Braffman and Rod Beckstrom, is important in clarifying, that a decentralized system is not the as anarchy. There are rules and regulations, although not imposed by anyone individually. Instead, power is shared by all (BRAFFMAN; BECKSTROM, 2008, pp. 22-23).

This idea of distributed power, which these two authors mention in the book "The Starfish and the Spider", is a good starting point to demonstrate that the decentralized organizations can be, in many cases, quite powerful.

The Information and Communication Technology (ICT) have been the primarily responsible for increasing the production, dissemination and circulation of information in contemporary societies. For Castells, these technologies have changed the main economic, social, political and cultural activities from around the globe, forming what the author calls the "*network society*" (CASTELLS, 2007). The author adds that the internet development provides support material suitable for the spread of networked individualism as dominant form of sociability (CASTELLS, 2001, p.161). This global communication system has proved to be, by its flexibility and power of communication, a privileged terrain for the construction of individual and collective projects based on interests and values of each (CASTELLS, 2001).

For Cardoso, the users have become the leading innovators in the network society, however, he stresses that the users are also very different from each other and innovate in specific areas, those where communication is seen as more important to them (CARDOSO, 2009).

This is also observable in the health field, as evidenced by Rita Espanha:

The individual health and its daily management have never involved so much information like today. Large amounts of information about health and medicine are available from several sources – these sources are health professionals, experts of various kinds, public and private institutions or groups of patients or consumers – through a multiplicity of informative channels, both from the media or as a basis for local or interpersonal, interacting with doctors and other health professionals, families, friends, coworkers, etc.. This constant flow of information encourages the individual to be responsible for their health and their

family every day (KIVITS, 2004). In this context of general information about health, the use of the internet has proved to be central (ESPANHA, 2009, p. 2).

For Espanha, the internet has been a major cause of increased flow of generalized information about health and one of the ways that individuals use more. In the United States, and taking into account the data of WIP (World Internet Project, University of Southern California) the search for medical information on the internet is the seventh most common activity. In 2004, 50.6% of American internet users said they had accessed health information. In Portugal, has also observed a significant increase in search for health on the internet⁴ (ESPANHA, 2009, pp. 2-3).

4. Pediatric oncology – a case study

Currently in Portuguese oncological universe, contrary to what it was in 2005, it can find a set of official reference sites that provide credible information useful and updated to citizens.

The Portal of Portuguese Oncology (Portal de Oncologia Português – POP⁵), developed by JRS Pharmarketing and the Info Cancro⁶ website, by Roche, are two good examples. Both have very complete information and are an important contribution to clarify questions concerning this disease. But the institutional websites about cancer are generally informative and less open to citizen participation indeed – typically provide little more than small forums of opinion, with no great importance – as happens in the two examples above. There is therefore a major trend for the existence of information sites and too little to share and exchange of content. Despite of the recognized potentialities of the web 2.0 platforms and their growing popularity, there is not, by the institutions within the health area, a large investment in these participatory and collaborative tools.

There is a gap of institutional spaces of public utility related to cancer that helps to approximate the citizens of these institutions, through a greater interaction. However, in addition, there has been taking a heavy growth of communities connected to pediatric oncology on the internet. They are above all visible in web 2.0 platforms and in social networks. These sites are used for several approaches, ranging from simple sharing of testimonies, in the personal blog, to the creating of solidarity movements in social networks such as the popular Facebook. Campaigns like “*Help Aline Coelho*”, “*Together for Teresa*”, “*Helping Afonso*” or “*Helping Marta*”, are just some examples and with results quite surprising and remarkable. These campaigns that born, mainly in order to sensitize the society to the voluntary registration in the Bone Marrow Bank. Donors has been a phenomenon of civic mobilization and solidarity, through the internet.

⁴ According to data from the National Statistics Institute (Instituto Nacional de Estatística – INE), collected between 2003 and 2007, presented by the author.

⁵ Available in <http://www.pop.eu.com>

⁶ Available in <http://www.infocancro.com>

The first major Portuguese phenomenon was the "Helping Marta". In January 2009, Marta, a 4 year old child, was diagnosed with acute myeloblastic leukemia. With all the treatment possibilities exhausted, the only solution would be to get a compatible marrow donor (RAMOS, 2009). Since then, family and friends joined forces and launched an online campaign to get a donor for this child. The people discussed and sent new forms of aid, forming a strong chain of solidarity, through various ways, including the site of the movement on the Facebook.

In May of that year, a suitable donor was found for Martha. Although not known whether there was a direct relationship between the movement and appearance of the donor, highlights the effectiveness of these campaigns in the mobilization of citizens. The campaigns of solidarity generated in social networks have contributed greatly to the increase of registered in the Portuguese Bone Marrow Donors Registration.

In order to enhance the website www.oncologiapediatrica.org and test it in a horizontal system, in September 2009, was created a project page on the social network Facebook. The experience has been positive. In their six months of operation, confirmed the great momentum that this type of system can create, especially when it comes to a network such as Facebook, with over 350 million users in the whole world⁷ (RIBEIRO, 2009). The contributions on the site are freely made by many visitors to it. In the vast publications made by many users (more than five thousand) was not recorded any insulting, provocative or disrespectful (MARTINS, 2009). Facebook, beyond to its great popularity, has also been a testament to how these new decentralized social platforms can contribute to the construction of a social fabric with a larger solidarity and civic mobilization. It should be noted that these networks are not designed to explore clinical content, such as cancer.

5. Conclusions

The decentralized systems online have transformed the world of information and communication, which has never been horizontal. This transformation affects not only the universe of communication. The most varied spheres of society, such as politics, economy, education or the health are also directly or indirectly affected.

As seen, the increasing freedom of access to information related to oncology and the global interaction that is achieved on the network, are benefits recognized and very exploited by the citizens. This means that the individual has more autonomy and responsibility in their decisions. The intelligence and collective wisdom that Tim O'Reilly and Rosental Alves tell us,

⁷ The data are referred to December 2009 and was presented by Javier Olivan, responsible for the internationalization service of the Facebook, in an interview to the Public Journal on December 16th of that year. He added that in Portugal there are over one million active users of this network, but as his own remarks: "(...) what is most impressive is the speed which Facebook is gaining users in Portugal. In September had only half a million. That is, in three months the number of users doubled. If compared with the beginning of this year, when there were only about 100000 profiles, the number of Portuguese users increased ten times" (Ribeiro, 2009).

has been growing in many online communities, especially in social networks. Should one continue to look at this new manifestation suspiciously like a parallel reality and marginal? Certainly not. The significant increase in the National Registry of Bone Marrow Donors is an indication of the importance of these networks. These privileged ways for mobilizing citizen action and social solidarity are also spaces very searched for the collection, sharing and exchanging of information.

The large institutions and healthcare organizations can no longer limit to communicating; they also need to learn to interact. Thus the National Health System and its professionals will be better prepared for this new reality in which the user tends to be more informed. It is known, however, it is impossible for institutions to monitor the huge set of information that develops in many online communities and respond to all requests.

The potential of an open network seem to be evident. Relatively to safety, the doubts are bigger and one of the main issues to consider in future research. Despite the efficacy of these more generalist and popular applications, like *Facebook*, *YouTube* or the *Orkut*, in issues related to pediatric cancer, is believed that the new models can be studied with a design, tools and services appropriately thought for this purpose.

These horizontal models, developed specifically for pediatric cancer, may be a strong contribution to:

- The agglutination, interaction and mobilization (online) from different citizens and institutions that currently are scattered;
- The production of dynamic and plural content;
- The self-sustaining and self-regulating network creation;
- The development of more personalized solidarity action;
- Consequent optimization of the universes of knowledge and action in this area.

It is believed that this model, which intends to validate the field of Portuguese pediatric oncology, could be extended to other contexts of the area of cancer and general health.

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