

SOCIAL INCLUSION IN A CEREBRAL PALSY THEMATIC NETWORK: ANALYSIS OF A COLLECTIVE BLOG

INCLUSÃO SOCIAL EM UMA REDE TEMÁTICA SOBRE PARALISIA CEREBRAL: ANÁLISE DE UM BLOG COLETIVO.

INCLUSIÓN SOCIAL EN UNA RED TEMÁTICA SOBRE PARÁLISIS CEREBRAL: ANÁLISIS DE UN BLOG COLECTIVO

Regina de Oliveira Heidrich

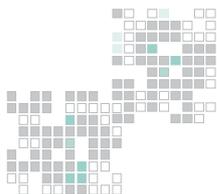
■ Docente na Universidade Feevale, mestrado em Desenho Industrial pela Universidade Estadual Paulista Júlio de Mesquita Filho (1998) e doutorado em Informática na Educação pela Universidade Federal do Rio Grande do Sul (2004). Coordenadora do curso de Design de 1998 a 2005. Atua como docente no mestrado de Inclusão Social e Acessibilidade. Tem experiência na área de Educação, com ênfase em Design inclusivo.

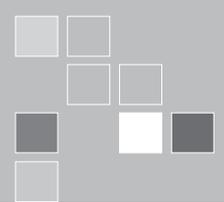
■ E-mail: rheidrich@feevale.br

Sandra Portella Montardo

■ É doutora em Comunicação Social pela Pontifícia Universidade Católica do Rio Grande do Sul (2004). Fez Estágio de Doutorado na Université René Descartes, Paris V, Sorbonne, em Paris (2003-2004). Atualmente é professora e pesquisadora da Universidade Feevale, nos cursos de Publicidade e Propaganda, no MBA em Comunicação Estratégica e Branding, no Mestrado em Inclusão Digital e Acessibilidade e no Mestrado em Processos e Manifestações Culturais, sendo que neste último é líder da Linha de Pesquisa Linguagens e Processos Comunicacionais. É membro do Conselho Científico Deliberativo da Associação Brasileira de Pesquisadores em Cibercultura (ABCiber).

■ E-mail: sandramontardo@feevale.br





ABSTRACT

The study investigated a thematic network about cerebral palsy (CP) in a collective blog. The goal was to identify the process of social inclusion by means of online interactions. Previous studies suggest the existence of blog and photoblog networks with different types of interaction, inspired by the characteristics of the disabilities of the participants themselves. These interactions are found to promote online socialization. The study investigated online social interactions about CP in a collective blog and the consequences in terms of social inclusion. We applied the method of netnography to select and collect blog data. Social Network Analysis (SNA) was applied to analyze online interactions. The study suggests there is evidence of strong and weak social interactions in the blog.

KEYWORDS: SOCIAL INCLUSION; DIGITAL INCLUSION; THEMATIC NETWORK; CEREBRAL PALSY; COLLECTIVE BLOG.

RESUMO

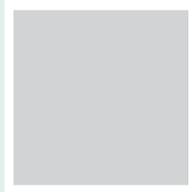
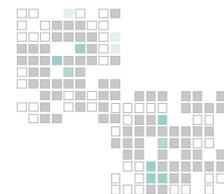
O estudo pesquisou uma rede temática sobre a paralisia cerebral em um blog coletivo. O objetivo foi identificar o processo de inclusão social através das interações digitais. Estudos anteriores sugerem a existência de redes de blogs e fotoblogs com diferentes tipos de interação, inspirados nas características das deficiências dos próprios participantes. Essas interações visam promover a socialização virtual. O estudo investigou as interações sociais virtuais em um blog coletivo sobre paralisia cerebral e suas consequências em termos de inclusão social. Aplicou-se o método da netnografia para selecionar e recopilar os dados do blog. A Análise de Redes Sociais foi aplicada para analisar as interações virtuais. O estudo sugere que existem evidências de interações sociais fortes e fracas no blog.

PALAVRAS-CHAVE: INCLUSÃO SOCIAL; INCLUSÃO DIGITAL; REDE TEMÁTICA; PARALISIA CEREBRAL; BLOG COLETIVO

RESUMEN

El estudio investigó una red temática sobre la parálisis cerebral (PC) en un blog colectivo. El objetivo fue identificar el proceso de inclusión social a través de las interacciones en línea. El estudio investigó las interacciones sociales en línea acerca de CP en un blog colectivo y sus consecuencias en términos de inclusión social. Se aplicó el método de netnografía para seleccionar y recopilar los datos del blog. El Análisis de Redes Sociales (ARS) se aplicó para analizar las interacciones en línea. El estudio sugiere que hay evidencias de interacciones sociales fuertes y débiles en el blog.

PALABRAS CLAVE: INCLUSIÓN SOCIAL; INCLUSIÓN DIGITAL; RED TEMÁTICA; PARÁLISIS CEREBRAL; BLOG COLECTIVO.



Introduction

The present study analyzed a thematic network about cerebral palsy (CP). The data for the thematic network was drawn from comments posted on a blog about CP. Projects such as the “Social inclusion via online socialization of people with special needs” assess the promotion of social inclusion (SI) of people with disabilities¹ and of their families in online social networks. The project aimed to identify the patterns of socialization that emerge from these networks. The achievement of social inclusion by means of digital inclusion (DI) was addressed in a study that reviewed different concepts of social inclusion and their relation with digital inclusion (Montardo & Passerino, 2007). Social inclusion is the promotion of autonomy for individuals who are at a disadvantage in relation to other social groups (Azevedo & Barros, 2004; Ladeira & Amaral, 1999; Sposati, 2006). Social inclusion is a permanent, though not necessarily continuous, process. It is a process in which people may be simultaneously included in some situations and excluded in others. Digital inclusion, in this context, may be understood as a component of social inclusion (Warschauer, 2006). It helps to promote the autonomy of its users in their search for financial independence, human development, equality, and quality of life (Sposati, 2006).

Previous studies carried out by our group analyzed thematic networks to identify processes of social inclusion of people with different types of disabilities and of their families. Montardo and Passerino (2010a) investigated online interactions associated with autism and Asperger syndrome. The authors defined three types of user interac-

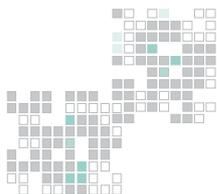
¹ According to the Brazilian Office for the Integration of People with Disabilities (Coordenadoria Nacional para Integração da Pessoa Portadora de Deficiência - CORDE), the term to be used is “person with disability”, and not “person with special needs” or “person with deficiency” because of a petition issued by people with disabilities themselves. However, the term “people with special needs” in the title of the project also refers to the elderly, which justifies its use.

tions: interactions promoting social inclusion (users who post and comment); interactions benefiting from social inclusion (readers); and interactions that were a combination of both. The blogs formed an extension of the Parents Association. Montardo (2008) investigated a social network of parents of children with Down syndrome; the interactions between the parents occurred primarily in photoblogs. The author found that pictures posted on the blog helped reveal characteristics of the disability and helped people who had met in person recognize each other. The study suggested the photoblog assisted the promotion of social inclusion of people with Down syndrome and their families. Yet another study investigated a network of blogs about hearing impairment. The blogs were managed by people with hearing impairment and by professionals who worked in the field (Montardo, 2010b). For people with disabilities, the use of information technology promotes equality with their peers; the technology can help to overcome motor and communication impairments (Heidrich, 2004).

In the present study the interactions in a blog about cerebral palsy were analyzed according to the following questions: (1) What are the patterns of socialization observed among CP patients and professionals? (2) Are the blog interactions suitable to support online socialization between users and readers? And (3) is it possible to identify a thematic network in the social network?

1. Cerebral palsy (CP)

The words *cerebral* and *palsy* are used to describe a health condition, a physical disability; however, for a long period of time people with CP were associated with *invalids* (Andrade as cited in Heidrich, 2004). Cerebral palsy is associated with a form of brain damage, and is characterized by difficulty in control of voluntary muscles and of movement of the body. The word *cerebral* in *cerebral palsy* refers to the brain (central nervous sys-



Cerebral palsy is the result of a nonprogressive lesion or poor brain development that exists since childhood (...) CP is still mistaken for mental retardation despite the marked differences between the two conditions.

tem, CNS), and the word *palsy* refers to disorders of body movement. Cerebral palsy is not a disease. It is a unique medical condition that affects mostly children. Cerebral palsy may be a prenatal condition or affect children during or after birth. Most cases of cerebral palsy are caused by lack of oxygen to the brain. CP is caused by brain lesions or trauma before, during or after childbirth or, in rare cases, in the early years of childhood. According to Andrade (2006), CP is an umbrella term for several types of physical disabilities associated with body movement. A child's ability to walk and to control posture and body balance is affected by problems in the connections and communication between the brain and the muscles. CP affects only the brain but is associated with sequelae that may result in additional problems during childhood (depending on the area of the brain that is affected, and the extension and location of the lesion).

Cerebral palsy is the result of a nonprogressive lesion or poor brain development that exists since childhood. The motor dysfunction is characterized by unusual posture and movements resulting from an abnormal muscle tone. The lesion that affects the brain when it is still immature interferes with the normal motor development of the child. (Bobath, 1989, p.11).

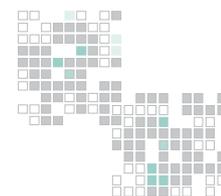
According to Santos (2004), the incidence of cerebral palsy in developed countries is 1.5 to 2.5 per 1,000 live births. However, there are studies reporting an incidence as high as 7.0 per 100 (including all forms of CP). There is no conclusive, reliable study about the incidence of CP in Brazil. The incidence rates reported vary according to the diagnostic criteria in each study. However, it is hypothesized that Brazil has a high incidence rate of CP because of poor prenatal care services.

In early childhood, motor development is extremely accelerated. Typically-developing children quickly learn to roll on the floor, crawl, walk, run, feed themselves, and dress and undress themselves. These motor tasks require the development of manual skills and of balance. The same is true for children with CP. However, their pace of development is slower. The severity of CP may completely hinder the development of specific motor skills. CP may be associated not only with delay in motor skill development but also with severe impairment in motor development, depending on the type of brain lesion. As children with CP become more active, abnormal posture and body movement become more frequent. Motor impairment in children varies according to the type of CP. The most well-known types of CP are: quadriplegia, spastic diplegia, hemiplegia and athetosis (Bobath, 1989).

CP is still mistaken for mental retardation despite the marked differences between the two conditions. Children with cerebral palsy may present cognitive impairment and learning disabilities as a consequence of CP (Werneck, 1997). Mental retardation, however, is characterized by difficulties in social interaction; patients with moderate to severe mental retardation have learning disabilities and limitations in communication, and are often unaware of their surroundings.

Andrade (2006) described some of the impairments and disorders that result from brain damage in CP. They vary according to the severity of the lesion. Below is a brief description of the most frequent impairments and disorders that may manifest in CP:

- **Epilepsy:** Seizure or epileptic discharge of variable intensity in patients with CP; different forms of



epilepsy may occur. Epilepsy is more common during preschool years. The prognosis for CP patients indicates development of additional problems.

- **Mental retardation:** Associated with selected cases of CP. Frequently leads to misconceptions and prejudice about the potential of CP patients. It is critical to diagnose the different degrees of mental retardation in each child and to seek adequate, specialized medical follow-up.

- **Visual impairment:** In CP patients it is associated with poor eyesight, strabismus, and refraction disorders. Impairment with optimistic prognosis if diagnosed and treated at an early stage.

- **Learning impairment:** Children with CP may present learning difficulties. This does not mean that they will not be able to learn. Special education, social inclusion in regular schools, technological resources (such as computers and other electronic devices that serve as stimuli), and innovative means of communication and learning should be made available to patients.

- **Speech and eating difficulties:** As a result of brain damage, CP patients present difficulties with verbal communication and difficulties to feed themselves.

2. Material and methods

Netnography applied to a collective blog

Jorn Barger coined the term “weblog” in 1997 to describe a set of Internet sites that collected and published interesting web links (Blood, 2000). Starting in 1999, the development and improvement of online publication tools have increased the popularity of weblogs and made it easier to publish and maintain sites. Knowledge of the HTML language is no longer necessary to publish and maintain Internet sites. As a result, blogs were increasingly adopted by several users, and adapted for several types of use. The tool that allows users to post comments was added some time later. Posting comments is one of the distinctive characteristics of blogs. It enables interaction between

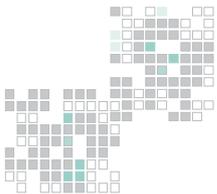
readers and authors (Amaral, Montardo, & Recuero, 2009).

Blogs may be described as: (1) Structural blog: describes its structure, including posts and comments; (2) Functional: focuses on communicative and social functions; and (3) Cultural: focuses on the use of blogs as live storage space of human experience (Amaral et al., 2009). Blogs may be used as means to different ends. Nonetheless, blogs share the characteristic that posts and comments enable socialization between writers and readers (Bruns & Jacobs, 2007; Amaral et al., 2009).

3. Use of netnography to analyze blogs

Goetz and Lecompte (1988) defined ethnography as an analytical reconstruction of scenarios and cultural groups that takes into consideration the beliefs, practices, artifacts and knowledge shared by a particular culture. Ethnography delves into the subject investigated and group of study. Batzán (1995) underscores the descriptive feature of ethnographic studies, which aim to achieve a global understanding of the culture being investigated. Hine (2005) defines ethnography as systematic organization of data collected from the experience of face-to-face observation and that captures “community performance.” Goetz and Lecompte (1988) write that the recreation of the scenario and the choice of method are fundamental for the study. Anthropologist Lévi-Strauss (1975) distinguished between three stages of anthropological studies. Ethnography is the empirical instance, the first stages of research (observation, description, and field work), is followed by ethnology, which is the preliminary synthesis of data. Both ethnography and ethnology are subsumed in anthropology.

According to Hine (2005), the Internet may be understood both as a cultural context and a cultural artifact. This understanding supports the utilization of virtual ethnography to study the groups formed online. In this same vein, Schnei-



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Kozinets (2002) suggested an adaptation of ethnography, called netnography. The author also proposed the caveats and research opportunities that follow, since web groups are usually analyzed from a distance. The application of netnography methods to the study of blogs (Montardo & Passerino, 2006) in combination with social network analysis (SNA) (Montardo & Passerino, 2010a) is described elsewhere. Below is a description of the method based on netnography and SNA.

Netnography is a necessary step in the early stages of the study. It defines sample selection and data collection for the thematic network. Our search for online social networks maintained by patients with CP allowed for the discovery of communities in the Orkut social network, and of blogs. Considering that others have investigated online interactions about CP in Orkut communities (Politi, 2009), the present study investigated a collective blog. To our knowledge, blogs have not yet been investigated as an online resource for interactions about CP. This type of blog is owned by more than one person. (More than one user has administrative access.) In general, there is a common theme under discussion, which is shared by each of the bloggers. The present study investigated a blog with a thematic network about CP, and whose participants are either CP patients or knowledgeable about CP.

The blog originated from a community in the Orkut social network. The purpose of the Orkut group was to organize discussions and information about CP, and make the discussions and the information available to other people. The blog

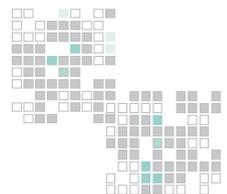
successfully provides posts that include videos, photos, links to other sites, and tags that characterize the posts. (These tags identify testimonies from parents, teenagers, and adults with CP). The tags were a novelty, they were not found in the previous analyses of thematic networks.

The researcher posted a comment on the blog to explain the purposes of the study, and to request permission to carry out observations of the blog. A link was added which lead to our University's website and to the curricula vitae of the people involved in the project. Bloggers who gave their consent to participant in the study were emailed a copy of the study's consent to disclosure of information form.

4. Results and discussion

Between December 2006 and January 2009 the blog had 36 posts and 427 comments (mean = 11.9 comments per post; maximum 25 comments for any single post). The blog is owned and maintained by 23 parents of patients with CP and four patients with CP. In our opinion, the blog shows a high level of activity due to the common interest between writers and readers.

Data was organized into posts, comments, social links, and social capital. The posts and comments were from CP patients or their parents. These posts contained personal accounts of the cause of CP in the patient. Medical malpractice during delivery was the most frequently reported cause of CP, both in Brazil and abroad. Other posts included information and suggestions about the treatments available for some of the consequences of CP (cognitive and social capital), and manifestations of sympathy and support about issues associated with CP (relational and social capital).



The question that arises is whether the presence of a link between two blogs necessarily represents the creation of a tie?

And if yes, what type of tie is it?

The four adults with CP who contribute to the blog wrote mostly about their social and professional lives. The discussion about social inclusion in schools is also highly frequent.

To identify online social interactions of people with CT and their families the first step was to analyze the structure of the blog. We searched for software that would allow for representation of a thematic network about autism and Asperger syndrome in the light of a perspective of social inclusion. The search results yielded systems that only identify quantitative aspects of the networks (Benkenstein, Montardo, & Passerino, 2007). These systems did not meet the needs of our study. Therefore, we investigated the origin of this type of software and assessed the limitations of theories of social network analysis (SNA) in relation to the representation and analysis of thematic networks.

Recuero (2005) evaluated the shortcomings of systems of quantitative analyses and proposed an Internet SNA model with three major components: Organization, Structure, and Dynamics. Organization is associated with the social interactions in a group. Structure relates to the results of the interactions in the group, in terms of social ties and social capital. Dynamics addresses the changes in a thematic network over time. The present study focused on the component "Structure." The evaluation of this component presupposes the analysis of social ties and social capital, since our goal was to establish a representation of the thematic networks and the types of connections that constitute them.

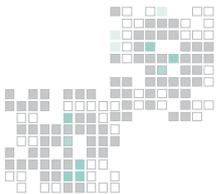
Social ties are social interactions (Recuero, 2005). These interactions may be relational (voluntary) or associative (involuntary, associated

with belonging). To investigate the process of finding employment, Granovetter (1973) recommended "The strength of the weak ties" (1973), which Barabási (2003) named one of the most influential texts about networks ever published in sociology. Granovetter showed that what happens at the macro level of sociology is associated with what happens at a micro level (individuals). Acquaintances, and not friends, were the ones who made new job recommendations.

Barabási (2003) identified in Granovetter's theory (1974) a vision of society that was constituted of small groups within which everyone knows each other. Society is formed by several connections between people within a cluster of groups of role players with strong connections between them, and these groups have weaker connections to other clusters. These weaker ties are the bridges to the outside world. In new, strange places people often obtain information from different sources instead of their closest friends (Barabási, 2003).

Granovetter (1974) defines strong ties as those that show a linear relation between time, emotional intensity, intimacy (mutual trust) and reciprocity of services for role players in the same cluster. Weaker ties are characterized by irregular interactions in terms of frequency and intensity. Weaker ties represent a strong alternative source of information and, therefore, represent an opportunity of mobility within a society.

Granovetter (1974) did not investigate online social networks. The question that arises is whether the presence of a link between two blogs necessarily represents the creation of a tie? And if yes, what type of tie is it? Drawing on Granovetter (1974), are links in a thematic network enough to characterize the relation between two blogs as



a strong tie? Since the ties between blogs may be established by more than one link between just two role players (in blogroll, in posts, and in comments), is it possible to have strong and weaker ties between the same two players in a thematic network? How to identify Granovetter's (1974) characteristics of time, emotional intensity, intensity (mutual trust) and reciprocity of services, in a thematic network?

The questions about content may be analyzed in the light of social capital, one of the areas of SNA, and a category in the model proposed by Recuero (2005). Social capital is related to connections, and is based on reciprocity and trust (Recuero, 2005). A comparison of the definitions by Putnam (2000) and Bourdieu (1983) suggested that social capital is a set of resources of a certain group, and it is acquired by sharing individual resources. Social capital may be utilized by all members of the group even if individually, and it is based on reciprocity (Recuero, 2005). The contents of messages should thus be taken into consideration.

Bertolini and Bravo (2004), as cited in Recuero (2005), defined five types of social capital: relational, normative, cognitive, trustworthy (social environment), and institutional. The types of social capital may also be grouped into first-level (relations, norms and rules, and knowledge) and second-level (trust in the social environment and presence of institutions) social capital.

In this model, social ties and social capital are part of the network structure. Latter studies by the same author investigated social capital in online social networks of different types (software, blogs, and photoblogs). Social ties, however, were not investigated. This may be due to the fact that the networks analyzed did not have a specific, common theme.

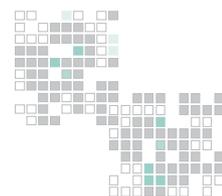
Due to the characteristic of a thematic network there are necessary adaptations in order to analyze characteristics of social inclusion (Recuero (2003) suggested that thematic networks may originate

from blogs, that is, a relationship between bloggers may be established using the tools for comments and posts in their blogs). Consequently, the investigation of a network of blogs of people with disabilities and their families presupposes identification of the context, in addition to the analysis of the content of posts and comments. That was the premise of the present study.

Following analyses of the social capital of role players in the network (posts and comments), we identified the type of social ties in the network. Our results suggested there were strong and weak ties in the network (Granovetter, 1973; 1983). The characteristics of the ties were analyzed together with the type of social capital.

We found that strong ties are established when a blog post finds resonance in the comments of others for that post. In other words, if a blogger's posts focuses on providing information (cognitive, social capital), and the feedback for the post is of the same type, there is a strong tie between blogger post and feedback. In turn, if the replies for this type of post (cognitive, social capital) are actually requests of or offers for support (relational, social capital), there is a weak tie. The opposite is also true. Posts that focus on relational, social capital and whose replies focus on the same type of information represent strong ties; if the replies focus on cognitive, social capital, there is a weak tie.

It was our hypothesis that strong ties would define social interactions that support social inclusion in the blog. However, we found that weaker ties were just as important as the strong ties. The difference lies in who is the agent of social inclusion in a thematic network (by means of posts or comments in their own blogs), and in who is the beneficiary (reader comments). These characteristics are not mutually exclusive. Relational, social capital was found predominantly in the posts by parents of people with CP. These users were also responsible for most occurrences. However, we also found instances of allocation of cognitive,



social capital; particularly in posts by people with CP. Posts with relational characteristics were predominantly about the struggle of overcoming social stigma and seeking social inclusion. The bloggers reported achievements in different fields of social life.

Our study suggests there were strong social ties in the network, which resulted from finding resonance between posts and comments. It also suggests there was some overlap between relational (voluntary) and affiliation (belonging) ties in the blog. This finding may be explained by the fact that the blog was maintained by voluntary work. The owners of the blog have the time and energy to update it, and they identify with the topics. These characteristics allow them belong to a group associated with a specific condition. The analysis of second-level social capital suggested there is trust in the social environment. This may be because the blog encouraged collective participation and comments by authors and other readers.

Conclusions

The CP thematic network extends beyond the object of the study and is part of a larger social network (Orkut). It is possible that blogs reach more people than social networks because blogs are listed in and may be found through search engines, and do not require readers to have usernames and passwords. Consequently, a collective blog has greater potential for social inclusion. This is corroborated by finding constant updates and blogs receiving a greater number of comments. We conclude that the blog represents a thematic network since the topic of posts and comments was limited to topics associated with CP. We did not identify social stigma in the blog, but there was reference to this type of social situation. These instances were invariably followed by testimonies suggesting ways to overcome prejudice. In conclusion, blog users, by means of strong or weak ties, promoted and enjoyed social inclusion via instances of relational and cognitive social capital.

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