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The Intersection of Self-Directed Learning, Communities of Practice, and Social Networking: How Learners Respond to a Lack of Information

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Abstract: This discussion will focus on the concepts of self-directed learning and how the insufficiency of awareness about pediatric stroke, along with a scarcity of resources, affects the parents’ ability to gather information. Results indicate that the use of social networking and the formation of communities of practice were the outcomes.

Introduction

Self-directed learning is often undertaken as the result of a health crisis. Medical crises fuel an immediate need to know on the part of the patient and caregivers. Sometimes, however, the motivation to learn is present but the learning resources are difficult to come by, making the search for information seemingly impossible. This is true in the case of pediatric stroke, and those who survive face significant physical and cognitive consequences. Despite this, according to the literature little is available in the way of treatment guidelines, making parents’ self-directed learning a challenge. When parents pursue understanding through customary avenues such as the internet, books, journals, and of course the medical community they struggle. Learners are left to turn to other parents who are seeking, or who have, knowledge of the same nature, and a community of practice may result to fill the void. Social networking, and in this case, social media, are the vehicles through which learning occurs.

While the term “self-directed” seems to imply independence, in the abundant literature on the topic of SDL many writers (Knowles, 1975; Tough, 1971) have discussed how this manner of learning does not occur in isolation. Other human beings are resources or serve as collaborators in learning. This collaboration between and among learners may result in the creation of a community of practice. Communities of practice are generated when people share some form of expertise that fellow members of the group recognize; they learn from one another, involve themselves in relationship building through assisting one another with information, and engage in a shared practice through their experiences, stories and tools. From this, a knowledge base is built (Wenger, 2006).

The purpose of this session will be to describe an ongoing research project designed to explore how the parents of children who have experienced a stroke have attempted to inform themselves about the cause, treatment, and outcomes of the stroke. This is exploratory research, so participants will be encouraged to consider how the findings of the initial phase of research have implications for educators of adults and health educators in the medical community, to provide suggestions for furthering this research, and to identify how this might inform their own practice.

Method and Data Sources

A phenomenological approach was employed to investigate this subject. Interviews were conducted with parents whose child suffered a stroke, the criteria being simply this: that the stroke occurred during the previous 5 years and that it was considered perinatal (in-utero; at or before 28 days of life) or childhood (occurring between 1 and 18 years) (American Heart Association, 2011). Participants were identified through the Children’s Hemiplegia and Stroke Association (CHASA), a non-profit organization that through online and personal support groups connects individuals and families who have a child living with hemiplegia,
hemiparises, or hemiplegic cerebral palsy, often caused by stroke. Data was collected during an annual retreat held by CHASA. Semi-structured and open-ended interviews were conducted with seven participants, all mothers.

**Results and Conclusions**

Findings from this study reveal a frustration on the part of parents regarding the sometimes delayed diagnosis of stroke, the lack of a standard treatment protocol, and the void of information related to how the stroke will affect the child long-term. While parents behave as self-directed learners and try to manage their quest for understanding and knowledge, there is simply a dearth of information about pediatric stroke; their learning comes from their own experiences and from what knowledge they glean from the medical community. Out of necessity parents move from the status of novice to subject matter expert, with their primary resource being other parents.

Most dialogue occurs online, and a repository of knowledge has been created by members of various web-based groups which serve as a principle resource for parents. Many find themselves as a part of this community of practice, exchanging information with others who are experiencing the same problem and living with the same challenges that change and evolve as the child grows and develops. In the context of this research, self-directed learning is explored as a process. A community of practice evolves when parents realize they themselves are, or are becoming, an important resource and their lived experiences serve to inform others. Their engagement results in knowledge creation, cooperative problem solving, and the documentation of ideas. Social media and networking make it possible for parents to communicate and build this community of practice.

**Implications for Practice**

The findings from this study have the potential to advance the discussion of patient education and the gaps that exist when there is a lack of awareness surrounding certain health problems. Web-based resources are often regarded as lacking in validity and are perceived as unpopular among some health practitioners. However, the study results underscore the potential value of social networking and social media in this context, and the positive impact they can make on families and patients who strive to make informed decisions about their healthcare.

**References**

American Heart Association (December 15, 2011). Heart disease and stroke statistics-2012 update: A report from the American Heart Association. Dallas, TX. Retrieved from [http://circ.ahajournals.org/content/125/1/e2.full](http://circ.ahajournals.org/content/125/1/e2.full)

