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A Sense of Community: Building a Collective Conscious Framework through Virtual Communities when a Child is diagnosed with Cancer

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ABSTRACT
Cancer is the number one cause of disease-related deaths among children. According to the American Childhood Cancer Organization (2010), physicians diagnose approximately 12,400 children up to the age of 19 years with cancer each year. The overall survival rate for children living 5 years after diagnosis of cancer is 80% (National Cancer Institute, 2009). The once taken-for-granted world no longer exists when a child is diagnosed with cancer. For parents, the experience of the taken-for-granted world can be a time of isolation from the rest of the world. Grandparents similarly have shared emotions and experiences. How does one family cope effectively while another cannot? This study uses a qualitative research method to explain the social reality of the lived experiences of grandmothers who have grandchildren diagnosed with cancer. It is through virtual communities where these women build a sense of community.

Keywords
Virtual communities, social networking sites, social support, social capital, photo elicitation, lived experience model, phenomenology.

INTRODUCTION
Virtual communities are communities in which the primary mode of interaction is electronic communication. Using computer-mediated communication to form virtual communities strengthen our ties to the social world (Putnam, 2000). We are no longer bound by space or time; therefore, people who share the same interests or goals can form virtual communities.

The once taken-for-granted world, the world of the familiar, no longer exists when a child is diagnosed with cancer. According to Schutz and Luckmann (1973), “What is taken for granted within the prevailing lifeworldly situation is surrounded by uncertainty” (p. 9). Grandmothers search for social interaction when a grandchild is diagnosed with cancer. Social interaction is the reality of everyday life shared with others (Berger & Luckmann, 1966).

It is through social interaction and social capital that virtual communities begin to exist. The long term survival of virtual communities requires bridging social capital. Social capital has been defined many ways. The best definition can be found where social capital refers to social networks norms of reciprocity, mutual assistance, and trustworthiness (Putnam, 2000; Putnam, Feldstein & Cohen, 2003; Rose, 2000). Building social capital is difficult depending on the type of social capital. Bonding social capital also conceptualized as “birds of feather flock together” or inward-looking is the easiest social capital to build (Putnam, Feldstein & Cohen). Putnam, Feldstein & Cohen refer to bridging social capital as outward-looking which ties individuals or groups across a greater social distance which is the case of the study of grandmothers and their grandchildren who have been diagnosed with cancer.

The concept of social capital dates back to 1916 when Lyda Judson Hanifan was a state supervisor of rural schools in West Virginia. He described social capital as a tangible substance that count for most in the daily lives of people such as the cultivation of good will, fellowship, and social intercourse among those that make up a social unit. Pierre Bourdieu’s notion of social capital emphasis the social relations to advance his/her interest such as a local support group organization and its conflicts and power function. Putnam’s concept has three components: moral obligations and norms, social values, and social networks which are major concepts for a new social organization such as a virtual community. Social capital according to
Putnam (2000, p. 19) refers to connections among individuals such as social networks and the norms of reciprocity and trustworthiness that arise from them”. Why is it one organization continuously revitalizing itself while others do not? “Our readiness to help others—is by some interpretations a central measure of social capital (Putnam, p. 116). According to Putnam, social movements and social capital are closely connected. Social networks are important for organization of movements. It is through this lived experience which a need to start a virtual community begins.

LITERATURE REVIEW

Meyer, Hyde, and Jenkins (2005) discuss the measurement limitations of social capital on the sense of community. Prior to their study few researchers have addressed community members through qualitative research and usually used scaled survey instruments to measure the sense of community (Meyer, Hyde, and Jenkins). Although Meyer, Hyde, and Jenkins conducted their research in poor communities and addressed the question of how residents of urban communities conceptualize the sense of community and what types of measurement instrument would be meaningful and useful to them; their study can be applied to other studies trying to measure the sense of community. Using an observation method rather than individual perceptions, Meyer, Hyde, and Jenkins explored the theoretical perspective of a community-driven methodology.

Social capital plays a central role in facilitating the mobilization of social movement organizations (SMOs) (Edwards & McCarthy, 2004, p. 621) which this study suggests is the same for virtual communities. The study by Edwards & McCarthy suggests five indicators to facilitate the emergence and mobilization of social movements: (a) strong leadership ties via family and friends; (b) weak leadership ties via civic engagement; (c) emerged from preexisting group/organization; (d) extent of weak ties in communities; and (e) access to patronage at founding.

Research on social capital and cancer support groups suggests the importance of psychological well being and social support for patients and their families (Butow et al., 2005; Price et al., 2006; Taylor et al., 2007; Ussher et al., 2006). What do cancer support groups provide that other support groups do not? According to McGrath (2000), cancer support groups provide identification with others in the same situation which leads to a sense of belonging and empathy. In fact, cancer support groups lead to “sensitivity which comes from having the same experience and the willingness to share it” (McGrath, p. 378).

As of April 2006, the Internet had reached 73% of all Americans (Madden, 2006). The New York Times (Barboza, 2008) reported on July 26, 2008, that China is ahead of the United States and has reached 253 million Internet users, a figure which represents 19% of China’s population. The Nielsen Company (n.d.) reported 220 million Americans are online. Increased access to the Internet and advances in technology have given users access to information which was not available a decade ago. Parents flock to the Internet to find information about childhood cancer diagnoses, treatment, trials and support. According to a survey by the Pew Internet Project (Fox, 2008), information gathering has become a habit for Americans. Parents are finding emotional support and a sense of community on the Internet (Ussher et al., 2006). The Internet provides a greater social connectedness (Putnam, 2000).

Putnam (2000) writes, “Participation in self-help and support groups has unquestionably grown in recent years” (p. 150). The increasing number of people searching the Internet for self-help groups has led to online social networking sites. Social networks connect people together. Some of the most popular social networking sites are MySpace, Facebook, Twitter, Live Space, and Live Journal. Since their introduction, social networking sites have attracted millions of users. Many users have integrated these sites into their daily lives. The beginning of 2009 marked a new advancement in social networking, as Facebook introduced a new mobile application for the iPhone to let people use their phones to interact with Facebook the same way they do from their desktop or laptop computer. Social networking allows people to form and sustain virtual communities.

RESEARCH METHODOLOGY

The purpose of this qualitative study is to gain insight into the lived experiences of grandmother who have grandchildren diagnosed with cancer through the use of virtual communities. The greatest strength of qualitative research lies within its ability to explore and understand human phenomena and lived experiences. A pioneer of quantum mechanics and theory of relativity, Einstein was far ahead of his time when he said, “Not everything that can be counted counts, and not everything that counts can be counted” (as cited in Harris, 1995). The theoretical underpinning of this study is phenomenological in nature. The theoretical perspective of phenomenology guided this study as a basis for explaining social reality of the lived experiences of grandmothers who have grandchildren diagnosed with cancer and their use of virtual communities. Phenomenology roots are derived from the German mathematician, Edmund Husserl, who is the father of the phenomenology movement. Phenomenology explores the understanding of human phenomena and can be used to describe the everyday experience of life (Munhall & Oiler, 1986).
Methods
A comparative case study design was used in this study. According to Stake (1995), case studies involve a specific instance of a phenomena bounded in time that centers on a specific community, event, or person. The case became center stage according to Schwandt (2001). A case study approach was used to understand the complex social phenomena of these women (Munhall, 2007). According to Yin (1994), a case study is appropriate when there is “no clear, single set of outcomes” such as lived experiences of grandmothers (p. 15). I utilized a multiple case study, where each grandmother represented a case to provide a holistic view and insight into the real life setting of childhood cancer.

Participants were selected using a purposeful sampling strategy so they would reveal the phenomenon of childhood cancer experiences for grandmothers who have grandchildren diagnosed with cancer. The strength of purposive strategy lies in its information-rich cases which lead to insights and in-depth understanding (Patton, 2002). In order to solicit participants, a flyer, web site, and questionnaire for initial selection of participants were used. The flyer briefly described the study, eligibility requirements, web site information with instructions for signing up, and contact information. Once the flyer, website, and questionnaire were complete, the Association of Cancer Online Resources (ACOR) Pediatric Oncology listserv administrator was requested to advertise the study. Participants who met the eligibility requirements were contacted for interviews.

Data Collection
Data was collected by the author using a combination of a series of interviews, emails, blogs and information collected from the questionnaire. The information conversational interview allowed the author to enter the person’s perspective (Patton, 2002). According to Patton, the informal conversational interview is the most open-ended perspective to interviewing. Using a hermeneutic phenomenological perspective to elicit narrative data, the interviewer aimed to enter a partnership of trust by using a technique of informal conversation (Cohen et al., 2000). The basic presupposition of the hermeneutic phenomenological is that a “driving force of human consciousness is to make sense of experience” (Cohen et al., p. 59). This approach provided for spontaneity. It further deepended the communication with the person being interviewed to develop a richer understanding of the lived experience. By letting the interviews take shape from the participant’s perspective, the interviewer attempted to capture the lived experience of childhood cancer through qualitative interviews, while narrating their experience from a grandmother’s perspective (Frank, 1997; Kleinman, 1988; Schutz, 1967). Using Seidman’s (2006) phenomenological interviewing approach, the interviewer followed the concept of three separate communications with each participant.

Narrative analysis guided the study by generating and analyzing stories of life experiences of the participants’ (Schwandt, 2007). By using narratives, the interviewer sought to “make sense of commonsense knowledge of everyday life and give meaning to the life-world. Using a technique called hermeneutic photography along with narrative analysis as “an aesthetic technique” was used to “elicit participants’ stories and illustrate themes of experience” (Hagedom, 1994, p. 44). Photo elicitation interview was first introduced by Collier, an anthropologist, in 1967 (Clark-Ibanez, 2004). Social scientists believe that photo elicitation interview can “trigger memory, lead to new perspectives, and assist with building trust and rapport” (Epstein, Stevens, McKeever, & Baruchel, 2006). Prosser and Schwartz (2004) suggest the researcher look at their underlying assumptions when using photographs in the sociological research process. By collecting pictures during the interview phase of the study, the interviewer was able listen and find the silent voice behind the photographs and narratives (Schratz, 1993).

Data Analysis
Analysis of data began with the first interview and field notes. The first 24 hours after an interview is critical to the rigor and validity of the data (Patton, 2002). Every attempt was made to transcribe interview data within 24 to 48 hours. All data were transcribed verbatim. Second and third interviews and email communication was conducted to confirm the findings. Next data reduction, or more commonly known as coding, was conducted (Cohen et al., 2000; Creswell, 2005; Patton, 2002; Schwandt, 2007). Coding requires constantly comparing and contrasting data while categorizing the data into themes. Once themes were developed, the interview used thematic analysis and underlined and highlighted text, writing in margins and examining all text line by line for tentative concepts for latter chapters, keeping in mind an emergent design (Cohen et al.). A constant comparison of grandmothers’ stories through thematic analysis was conducted by using “extensive quotes and rich details to support the themes” (Creswell, p. 266).
Using the theoretical lens of illness experience and narrative ethics of Frank (1997), the researcher began to develop a framework for seeking to understand the meaning of the grandmothers’ stories. Using a combination of elements from Goffman’s (1959) dramaturgical framework, Noddings’ (1986) care theory, a feminist perspective, with several other elements the author began to create themes and a collective conscious framework centered on shared meanings (Figure 2).

**Figure 2.** Theoretical framework: This diagram illustrates the relationships central to the shared meanings of my collective conscious framework.

**RESULTS**

It is difficult to summarize the participants’ stories in one or two paragraphs, so a visual aid is presented to describe the common themes of the lived experiences of the participants as they searched for social support through virtual communities (Figure 4). The participants’ interviews along with their blogs, tell a story of constant fear, how no one understands, and how these women were affected by a double dose by watching their own child and grandchild suffer. The four themes surfaced throughout the many interviews, questionnaire, emails, blogs and photo elicitation. The four key areas which echoed throughout their narratives which make up the lived experiences model are: (a) fear of death, (b) social interaction, (c) double dose, and (d) they don’t get it.

**Figure 4.** Lived experiences model: This diagram illustrates the common themes among grandmothers who have grandchildren diagnosed with cancer.

The fear of death was the first common theme which echoed all the participants. One participant discussed her vivid memories of a dream where her grandchild was lying in her casket and how she found support through her online virtual community. The second theme that emerged was a need of everyday social interaction. Social support helps relieve stress and manage coping and participants found a sense of community through an online listserv virtual community. The theme “they just don’t get it” surfaced during interviews when participants explained how they could not find support in their local community, church, or school, but found support online. All participants felt they were given a “double dose” by not only watching their grandchild suffer, but also their own child. Again, without an online virtual community, the participants felt isolated.

**DISCUSSION AND LIMITATIONS**

This present study has some limitations that should be considered when reading the findings. The first limitation is the number of participants. While four may be considered an adequate number of participants for a qualitative research study, it may limit the extent to which one can generalize the results (Schwandt, 2007). In a similar matter, because of the purposeful
sampling of this phenomenological study, the participants are made up of a relatively homogeneous group. All participants were White grandmothers of similar ages. Further demographic information was not obtained in regard to race, marital status, education level, employment, or household income. Since the focus of the research was on grandmothers, grandfathers were never considered. While interviewing one participant, it became clear that her husband also had a story to share. Future research can extend to include grandfathers and other family members outside the immediate family. So often today, we find it takes more than a mother and father to raise a family. In addition, we find children taking on increased responsibility as both parents work to provide the basic financial needs of a family. Another area for possible research could focus on the diagnosis day in more depth for grandparents and children.

During the period the questionnaire was available several women inform me of a mother, sister, or friend who they wanted to participate in my study. A close friend of mine who is an identical twin, wanted her sister to participate. Each time she spoke to her twin sister about the study, she would say, “I don’t have anything to say.” A coworker, whose niece died of a rare cancer, wanted her sister to participate, but she refused to talk to her about the study or participate. Another friend whose niece had cancer, wanted her sister to tell her story, but her sister confided in her that “it was just too painful.” In each case, the potential participant was given my e-mail address, a link to the Web page describing the study, and a link to the questionnaire, but I never received a response from them. Further research in this area is needed.

As more grandparents become primary caregivers for their children, researchers may want to focus on how raising grandchildren with cancer affects their lives and those around them. Another area for research may be from the socioeconomically disadvantaged perspective and how grandparents cope when travel is financially impossible. Finally, researchers may want to focus on future qualitative and quantitative inquiry on the long term effects of grandparents’ health and mental well-being and how virtual communities play a role in that area.

CONCLUSION

For all grandmothers, virtual communities such as ACOR, Facebook, and other social networking sites played a major role in building a sense of community, and removing the isolation they felt. For researchers, The Lived Experience Model, Theoretical Framework, and Collect Conscious Framework provided in this study may help other researchers to conduct further research in the area of virtual communities, social support, and social theory in an ever changing information systems world.

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