Finding the other 5%: Understanding the role of social networking technologies in building personal networks for young adults with cancer

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Abstract: In this paper we explore the ways in which young adults with cancer (aged 17-24) build support networks through computer mediated personal networks. The support networks are influenced by technological affordances and the ongoing experiences of living with the illness and treatment regimes. We report a single, in-depth case study of one young adult with cancer and her use of mobile telephony and web based social networking sites in building support networks. Three important themes emerge from this case. First, in this context computer mediated communications (CMC) are not exclusive to the maintenance of online relationships, but mediate networks of “core”, “significant,” and new ties (primarily online) over time. Second, the social engagement between the subject and members of their social networks is dynamic with different modes of communication predominant at different points in time and different relationships significant at different points in time depending on state of illness, treatment and context. Finally, the interplay between CMC and different ties influence the characteristics of the networks, which is characterized by bridging and segmenting networks.

Introduction

Current literature suggests that people are utilizing communication tools such as the internet to find specialized information and support with people whom they share similar experiences and stories of illness (Burrows et al., 2000; Hardey,
Against this background, we find that young adults with serious or chronic illnesses are going online to find information as well as accessing existing and new social relationships through online tools (chatrooms, blogs, forums, social network sites such as Facebook and Myspace). Evidence shows, these technologies are potentially connecting young adults to both existing networks of relationships as well as those based on specialized interests or experiences. In a study of online self-help groups for breast cancer, Høybye et al (2005, p.216) found that sharing personal accounts of illness (stories) led to transformation and empowerment by offering a mode of action—“Internet based support offer a space for recognition, a social level for sharing knowledge and experience and an individual level for finding ways to live with breast cancer.” Again, Bowker (2008) highlighted in a study of people with disability that the lack of visual and social cues allowed them to meet strangers and converse based on common interests rather than physical, mental or social signifiers. However, the study of people with either a serious or chronic illness has primarily focused on online groups (e.g. www.grouploop.org an online support community for young adults and adolescents living with cancer) who share goals and interests, and promote active participation (Preece & Maloney-Krichmar, 2003).

On the other hand, authors such as Boase et al (2006) argue that the use of communication technologies by these users varies according to the changing situation of their condition and health needs although, they are interacting with a circle of core and significant ties that predate their diagnosis and subsequent illness. The author’s define core ties as people with whom the individual has frequent contact, emotional intimacy and availability of network capital. Wellman (2001, p.233) refers to network capital as the availability of resources through ones interpersonal ties that are “widely available, usually specialised, and unevenly distributed among people, ties, and networks.” Significant ties on the other hand, refer to people outside the individual’s core ties. They usually have less frequent contact and are not as closely affiliated and, whilst they are not strangers, their interpersonal importance can fluctuate over time as people access these networks to get help or advice. On a day-to-day basis, the individual may have contact with a variety of core and significant ties through different social networks both face-to-face and computer-mediated.

As such, how people in this situation use communication technologies to access support through different networks and social ties is articulated through their personal networks. Personal networks can be described as networks of ties derived from a sample of individuals that enumerates the local social networks (Marsden, 1990), kinds of relationships they contain, and the kinds of resources that flow through different kinds of networks (Wellman, 2007) that shape individual and group action. However, through our research, we also observed that the communication medium itself constrained and influenced the action and social relations between the people and their personal networks (Rice, 1994).