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ISS 210 Honors Option

A Study of Virtual Communities

Use of Cyberspace for the Disabled

Both Drs. Gerald Gold and Donna Avery bring unique perspectives to the idea and study of the effects and results virtual communities and the Internet have on the disabled and their families, caregivers and loved ones. While many points of their research reach the same conclusion, they come from different places of study, Dr. Gold being disabled himself and conducting his fieldwork in 2012-2014, and Dr. Avery being the parent of a disabled child, publishing her research in 1998. Both professors discuss the Internet and technology's benefits socially and medically to those affected, and their families, as well as the drawbacks and warnings to future virtual community members.

Obvious advantages that both professors point out in their work are the physical advantages of technology advancement in getting in contact with others leading similar lives in relation to living with a disability or a loved one with a disability. Dr. Gold makes a point of addressing how virtual communities are no longer limited by scheduled meeting times or fixed gathering places such as more traditional support groups. While the latter work of Dr. Gold considers the world of Cyberspace as a physical "place" in itself for anthropological research to be conducted, both authors can attest to the helpfulness of virtual communities connecting people across countries, not only allowing for constant and 24/7 response time on any posts or threads, but the ability to stay in ones home and use

their computer is invaluable to anyone with hindered mobility due to their disability. Dr. Avery describes “dialogue-with-distance”, also quoting (Coleman 1997) in how the use of a computer or the Internet is beloved by the disability community because many members of virtual communities have been “‘socially quarantined’ and excluded from active participation in society.” This ‘negative gaze’ as Gold describes it, is completely obsolete when corresponding electronically with other community members because the Internet creates a type of ‘level playing field’ where participants can’t be judged by anything such as their appearance, disability in question, race or background which creates a welcoming environment in itself that most members would not experience in normal day to day society. In his section of study comparing virtual support groups to traditional groups, Gold describes a concept he calls “Experiential Authority” which allows the disabled and their caregivers to speak freely about any and all treatments or other conditions/obstacles they have undergone, avoiding the sometimes hostile or patronizing response from a doctor, in what seems to be a much more welcoming and less intimidating environment than your traditional doctors office.

Virtual Support and the Cyber Culture of Disability

One of the most interesting aspects of reading through each anthropologist’s research was the way in which they described the cyber culture relating to disabilities. Gold more specifically specified his work on a virtual community he had been a member of called MSN-L, designed as a support community for those living with Multiple Sclerosis. His research was relatively informal as he addresses the fact that he was foremost an active participant in the community, but that he was

secondarily an observer in his studying the interactions through out the entire site. Several members of this community were also involved in other virtual communities with similar topics and support groups, but this didn't prevent the high traffic in both public threads and private messaging/correspondence. As gold describes, "cruising" through messages was necessary to search for relevant topics, or else the community member could spend hours reading through every thread. Dr. Avery approaches the culture of virtual communities in a slightly more general way, however, she raises many of the same observations as Dr. Gold despite the fact that the internet was far less popular than it is today. In 1998 when writing her research she noted that there were 156 million conversations taking place in cyberspace and today this number and traffic has exponentially increased. Nonetheless, Avery describes her experiences in virtual communities as likened to a "modern day Enlightenment's salon". With the social solitude of being disabled is resolved on the internet, it is invaluable to parents and the disabled themselves to relate and have a measure of self expression in relating to one another's troubles regarding the social stigma that comes with the idea of "disabled" and also their reactions to what she calls 'The Stare' coming from other parents that view the disability of her son as a tragedy and imperfection in society.

Topics of Discussion

The topics of discussion across the different communities described by both professors was varied, this being most likely due to the difference of time and types of communities they explored. Dr. Gold laid out that the MSN-L network usually centered around new drugs, pioneering physicians in their field, means of dealing

with symptoms (often leading to controversial discussion), and narratives of the personal lives of members and their own day to day struggles or issues.

Commentators on medical issues or medical symptoms are rarely other medical professional, yet many members directly rely on these types of narratives in dealing with their own symptoms. Gold also describes an initiation-type process where new members all usually submit publicly what he calls a “narrative of eligibility” which includes things like who they are and essentially why they are qualified to take part in discussions and the community as a whole. These narratives are often the subjects of private or public discussion. Other topics on MSN-L usually go through phases or waves such as the discussion of marijuana or any new drugs as a relief of symptoms. However, no main point maintains center stage on the group for more than a couple weeks despite the ever-present discussions of effects on various newly developing medications. Dr. Avery being the parent of a disabled child included different types of topics discussed on support groups, mentioning the need parents of disabled children have for emotional support rather than seeking constant or immediate medical support. Avery writes, “To know that such an empathetic audience is always available--for the virtual support-group won't even close for the holidays; and someone will be awake and ready to talk at any time of day or night, because members are located all around the globe--is reassuring beyond measure.” While Gold and Avery both have different uses and intentions for their virtual communities, Avery describes how over time, her return to the virtual community “Our-Kids” had evolved into much more of a medically centered organization with additional emphasis put on the grief and depression of the

parents, rather than the social updates and interaction she had previously known, much more similar to Gold's description of MSN-L.

Virtual Families and Community Roles

Both virtual communities that are more deeply discussed, including "Our-Kids" and MSN-L, are described as having very unique and specific community roles and an ever-changing dynamic. Avery quotes (Jones 1997) to say that virtual communities are more than just people with similar lifestyles, but are "parallel groupings of people headed in the same direction for a time". Despite members constantly coming and going, subjects of sites such as "Our-Kids" which is designed not only for emotional support but for the advancement of children and the disabled in society which creates actual 'families' through these added bonds. Gold surprisingly talks about what could be taken as the exclusivity of the community, by explaining that not every new member receives a very warm welcome or much response from their initial postings and will then most often leave the group. He emphasizes that MSN-L is a very specific type of community that is appropriate for every person with MS, saying, ""new members are expected to contribute in a compatible way to existing message threads and there are many who do not find the support they are seeking" (Gold). In MSN-L, there is an informal moderator that contributes to frequent opinions, narratives and private messages. A distinct role in the community is the "resident medical expert" which was originally held by a man named Soloman, however as members join and leave the community, the position is usually refilled by another member having some form of medical credentials.

Private Posting and Communal Scrutiny/Backlash

Private posts are seen as 'deeply personal' and are not the type of thing any member would want public scrutiny for. Gold explains that aspects of most private messages could be public, however once they mention any of the names of other community members, the messages need to remain for personal use out of respect. Following the discussion of two personal experiences, Gold distinguishes that in a community like MSN-L, it is much easier to mobilize the site over something like a personal attack, rather than come to the aid or support of even a notable community member/poster in need. Site mobilization and privacy issues can also result in what Gold titles 'the conflict of public and private' relating to things like a community member's discussion of sexuality or sexual frustration which is largely contained to private messaging, accidentally being sent to a public thread. It is also quite common for people to create a public persona of themselves that they are largely unaffected by symptoms, etc. where only on private messages will they detail their own personal struggles. In Dr. Avery's view, following an attempt to rejoin one of her former communities in an effort to collect research, she notes that a type of tribalism is promoted by close-knit and very active communities that becomes an 'us-versus-them' mentality. She writes, "When it was this 'old friend,' then, who instigated the flaming, I was surprised; but when he kept reigniting the embers until there were 58 angry postings to the list and a couple dozen to my personal Email address, all within the space of a week, I was bewildered. He did nothing to correct the group consensus that I was a mercenary researcher who had raped the archives and had published everyone's secrets, without asking for permission" (Avery). The concept of

anonymity allows for verbal violence just as easily as it allows a safe haven for its members.

Reflection

Overall this process has been very different from any research project I've ever taken part in. I have always been good at doing historical research, but reading through the work of two anthropologists has become quite another animal as even when something has been written 15 years ago, it is still applicable in present day. Dr. Avery's studies on disabled virtual communities was written when I was about three years old and the Internet was still a very new concept. Today society in the United States has gone rampant with technology and the Internet has connected people across countries more than was probably ever anticipated. Physical space, as Dr. Gold points out is no longer an issue for a disabled person in need of support, and virtual communities have taken on a sort of physical place of their own. In all I have learned a lot from both the work of Dr. Avery and Dr. Gold and in all honesty I had never previously really considered web accessibility from the eyes of a caregiver or someone with a severe disability or disease. Because of this, this entire process and thinking/looking at sites like MSN-L and "Our-Kids" has been an eye opening experience and something I will definitely keep in mind as I grow in the User Experience field and begin to focus more on web accessibility as an Experience Architect. The chance to ask Dr. Gold questions personally was also a unique take on research for me as I have grown much more accustomed to reading sources and making inferences or analysis on the work presented rather than directly contacting the author.

Works Cited

Avery, Dona M. "CMC Magazine: Electronic Parenting Or, It Takes a (Listserv) Village to Raise Families with Disabilities." *CMC Magazine: Electronic Parenting Or, It Takes a (Listserv) Village to Raise Families with Disabilities*. N.p., n.d. Web. 01 May 2015.

Gold, Gerald. "Faculty of Arts | York University." *Faculty of Arts | York University*. N.p., n.d. Web. 01 May 2015.