Utilizing Social Networks to Analyze Needs of Caregivers of Autistic Individuals

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Abstract

With an increasing number of Individuals with Intellectual Disorders (IID), there is a building concern about the amount of resources available for the families affected. The focus of this research is on Autism Spectrum Disorder (ASD). According to the Center for Disease Control, the prevalence rates have nearly doubled within the last century. This study aims to study what trends are prevalent among caregivers of autistic individuals in terms of why they resort to social networks. This study was conducted by observing an online forum through the social network, Facebook, and collecting a set of one-hundred randomized posts over a time span of thirty-days. Results concluded that families, especially parents, faced risk of psychological distress resulting from isolation and confusion. This has the potential to become a primary avenue for communication within health care industries and families with IID. Future implications of this study regards the importance of social networks in communicating with patients with future research needed in the area of mobile health networks.

1   Introduction

Social networking and social networks sites are currently becoming the most popular avenue for communication (Hawn, 2009). The utilization of social networks are growing and are being implemented as the primary form of communication between health industries and patients for easier accessibility of health related services and information (Boehmer, Fewins-Bliss, Lauckner, Li & Oh, 2013). With easier access to social networks through the Internet, communication goes from one-to-one conversations to reaching thousands to millions of people with the click of a button (Hawn, 2009).

Communication of information about health care has transitioned to virtual networks and informative websites that can be used by patients from any location where many patients visit online health communities to receive support (Huh, Pratt, 2013). There is a general consensus among scholars that online forums and informative websites are highly used in order to meet health care needs (Aase, Timimi, 2013). In societies where the advancement of technology is rapidly growing, virtual networks are addressing concerns and needs lessening the need for in-person visits. Research has found that online forums and health care have been addressing needs and concerns that has lightened the work load of hospitals and clinics in terms of reflecting "the consumer's response to the impact of time constraints in clinical practice and the impact on direct patient-care interactions (Aase, 2013, 473)." But the question of whether all types of populations are represented is a concern. Although there is information about health care services generally on social networks, there isn't enough access or information about health care services for IID and their caregivers. Although there are more data and research about the utilization of general health concerns and issues via online networks, the target of this paper is what type of health concerns are being frequently addressed within social networks by families of autistic individuals instead of the general public.

This study focuses on why caregivers of autistic individuals resort to social networks and what they discuss. The purpose of this study is to determine what type of health information and concerns do communities of families of Autism commonly seek through social networks.

Research Questions
1. What type of information do communities of caregivers and autistic individuals seek on social networks?

2. How can hospitals and health care systems better use social networks to better meet the needs of families of individuals with intellectual disabilities?
3. How can social networks sites help to understand their health care concerns and issues?

Significance of Study

This study addresses frequented concerns and issues representative of families of autistic individuals via social networks. This study intends to benefit families of Autism on understanding their needs and concerns. This study will be beneficial towards families and health care industries that lack understanding about the needs of autistic individuals and their families. By understanding the needs of communities with Autism, health care industries can develop services and plans that will help ensure proper treatment and care of these communities.

Methodology

This research utilizes a method called Descriptive Research. Through this research study, purposive sampling was used. Data was collected using online forums and social networks while keeping users confidential. Every individuals' responses were recorded into an excel spreadsheet over the course of 7 days and each post was assigned a number based on the order of each post. Responses were collected every day to keep consistency. 10 posts were collected everyday over a period of 30 days totaling 300 posts. Out of the 300 posts collected, 100 were chosen using an online random number generator and these 100 posts were analyzed and categorized into 6 different categories based on the purpose of the post. These categorizes included "Encouragement", "Seeking Help/Advice for the Caregiver", "Seeking Help/Advice for the Autistic Individual", "Advocacy/Awareness", "Lack of Services", or Miscellaneous.

2   Conclusion

This research study was conducted entirely online and the forum had open access to all Facebook users. Individuals created virtual profiles from the comfort of their home or preferred setting. The privacy of having an online profile and being able to limit the amount of information to which the public eye can access, provided a sense of security and feeling of freedom. This allowed individuals whom were seeking health information and support report a higher level of self-efficacy (Boehmer, Fewins-Bliss, Lauckner, Li & Oh, 2013).

As a result, the majority coming out to fifty-two percent of the collected posts revolved around encouraging other caregivers to accept their child and to keep going when times were frustrating. Many caregivers within the group have used this group as an outlet and safe area to vent their hidden frustrations and concerns with knowledge that other caregivers within the group understand their feelings. Over half of the posts that were categorized into "Seeking Help for the Caregiver for the Individual and Caregiver" were concerning treatments and medications available for the autistic individual. Examples of posts include whether taking Zoloft or XR would help with the individual's anger management. The question of whether the medication is safe or effective for the individual is uncertain and needs to be made more aware in the community to prevent overdoses or improper use.

An unexpected finding was the amount of psychological distress caring for an autistic individual could have on the caregiver. Multiple posts indicated isolation from the physical world caused by the amount of care and attention some autistic individuals require. While there are services and care for autistic individuals in the world, the psychological state of caregivers are often neglected or overlooked. Psychological distress can stem from multiple factors such as sudden disruption in a caregivers' life, isolation from peers and colleagues, inability to work, or distress in the caregivers' relationship. These factors have been voiced within the Facebook group as caregivers expressed sudden life disruptions and their frustrations, while experiencing meltdowns or periods of anxiety.

The psychological distress that is placed on these caregivers have serious implications as the distress could lead to severe consequences. The signs of the psychological distress is not present or obvious to health care industries due to the focus being on the autistic individual but health care industries and policies need to take into consideration the caregivers and their needs as well. Caregivers within the Facebook forum have voiced their lack of understanding of the disorder and support resulting in their feelings of isolation and depression. Last checked on May 20, 2014, there were 42,310 members that joined the Facebook group for some type of need or interest.

Future Research

In the future, more research is needed in the field of information sciences and how technology can improve the communication gap between hospital professionals and patients. An important aspect that needs to be researched is the unexpected finding of caregivers experiencing severe psychological distress while caring for an autistic individual and what types of resources are available that can aide caregivers.

Through this study, social networks like Facebook, has allowed participants to express concerns and needs to a virtual community with other caregivers that could relate to one another's experiences. Although the most popular method of information dissemination has been through physical consultations between physicians and patients, there are limitations within different communities that prevent frequent physical visits resulting in a higher need for awareness and information to be through social networks. Social networks can provide hospitals guidance and more of a personal connection between physicians and patients in order to ensure that needs are properly addressed. Collecting information from social forums can result in building better health systems that cater to the needs and availability of families with individuals with intellectual disabilities.

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Table of Figures

Categorization of Facebook Posts

- Encouragement — 52%
- Seeking Support/Help for Autistic Individual — 20%
- Seeking Support/Help for Caregiver — 15%
- Advocacy/Awareness — 5%
- Misc — 5%
- Lack of Services — 3%