
Internet and Parents with Children with Special Needs: A Meta-Analysis on PubMed Articles

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Abstract

Internet is becoming one of the major information sources for parents who have children with rare and difficult illness and special needs. The past few years have observed substantial efforts from the researchers to understand how these parents use Internet to access health information for their children. Based on their findings, the researchers also offered some recommendations to enhance the effectiveness of these resources. Unfortunately, a major part of the Internet resources targeted to these parents is still suffering from the problems identified by the researchers. Considering this, we have decided to summarize all the efforts and suggestions provided by the researchers. This paper presents our preliminary results of meta-analysis of all the literature available in PubMed database that deal with Internet use by parents who have children with special needs. In addition to systematic collection of the scholarly articles, we have provided our own recommendations based on our expertise in online social network and community healthcare domain.

Author Keywords

Children with Special Needs; Parents; Internet; PubMed

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

In 2008, Pew Research Center conducted a nationally representative telephone survey to understand how Americans use Internet for health purposes. They found that 61% of Americans use the Internet to find health information, and for 60% of them Internet had an impact in making health care decision.¹

Children with rare and difficult illness (e.g. a physical or an intellectual disability, autism, down syndrome, ADHD, cancer, etc.) or bad health conditions (e.g. obesity) need special care due to the uncertainty and emergency of their health conditions. According to US census, in 2010, 2.8 million (5.2%) school-aged children (aged 5 to 17) and 156 thousands (0.8%) small kids (aged below 5) had disability (here disability refers to having vision, hearing, cognitive, ambulatory, self-care, or independent living difficulty²). Parents who have children with special needs experience serious health concern for their children and invest their time, effort, money, and other resources, as much as they can do. For instance, De Rouck and Leys, after doing an extensive literature review in four electronic databases (Ovid Medline, PsycINFO, CINAHL and Sociological Abstracts), showed that parents of children admitted to a neonatal intensive care unit have high information need [1]. Internet is becoming a prominent source of information for parents with children with

¹ <http://www.pewinternet.org/Press-Releases/2009/The-Social-Life-of-Health-Information.aspx>

² <http://www.census.gov/prod/2011pubs/acsbr10-12.pdf>

special needs [2, 3]. Researchers also paid close attention to how these parents use the Internet (e.g. websites, online support communities, web 2.0, online social network, etc.) to access the information they need. For instance, Knapp et al., through a cross-sectional telephone survey, showed that, although three-quarters of the parents whose children have life-threatening illness consider the doctor as their primary source of information, 76% of them use Internet as an additional source [4].

Although the parents with children with special needs excessively use Internet now-a-days, the researchers found that, Internet resources are still suffering some fundamental issues [2, 3, 5-8] and most of the health-related websites are still not following the recommendations provided by the researchers. Observing this, we have decided to summarize all the scholarly findings and recommendations published to date in notable journals and conferences so that any future endeavor in this arena can be beneficial from our effort. We have also incorporated our own recommendations from our expertise in online social network and community health care area. In this paper, we are reporting our preliminary results mainly collected from scholarly articles available in PubMed database³.

Methods and Data Source

We performed a systematic keyword-based literature search in the PubMed database. We searched articles using the combination of keywords such as "Internet" "parent" "special care" and the different variations of these keywords (e.g. "eHealth", "rare disease",

³ <http://www.ncbi.nlm.nih.gov/pubmed>

"informal caregiver", "obesity", etc.). Our search considered all the articles published in the last 10 years in the "Humans" species domain. This keyword-based search resulted in 107 research articles. After going through all the abstracts, we have excluded a significant number of articles since those did not seem relevant to our search. We included any article which discussed the use of Internet by parents who have children with special needs. After filtering out the non-relevant articles, we also looked at other articles suggested by PubMed as similar to those articles. Finally, we have found 15 relevant articles. The findings reported in this paper are based on these 15 articles.

Results and Implications

After extensively analyzing all these relevant articles, we have identified some important findings and recommendations. Below we are pointing out the major findings and recommendations along with our own reflection.

Dominance of Women

Among parental Internet users, women are more likely to use Internet for their children as opposed to men, irrespective of whether their children has special needs [2-4] or not [9, 10]. For instance, Oprescu et al. showed that in an online support community where users are mainly parents of children of clubfoot disease, 86% of messages were posted by women and the rest 14% came from men [3].

Since men and women use Internet differently [11], we recommend that, an Internet resource for this type of parents should be designed keeping women's preference in mind. For instance, women have more trust on online communities as opposed to web portal

and social network as authenticate information provider [12]. Hence, we suggest that, more online communities should be created for these parents and those should be designed by giving priority of women's preference about Internet usage.

Inaccurate, Incomplete, and Unclear Information

People suffer from illness-related uncertainty as many health-related websites provide unclear, inaccurate, and incomplete information [13, 14]. Parents with children with special needs also experience the same problem [3, 6]. In addition, the parents, in several cases, are unable to distinguish between high quality and low quality information [2, 4, 6] and become perplexed to follow a particular health-related information.

To address this problem, we recommend that, health-related information should be written in plain, simple, and easy language so that even a layperson can comprehend the meaning very easily and act accordingly. Moreover, for the sensitive information, a trusted source (e.g. a specialized doctor, a reputed scholar in that domain, a well-known medical institute, etc.) must accompany the information. For example, sensitive health-information such as list of medications should be approved by specialized doctors to highlight the authenticity of the information. In case of non-sensitive information, a rating system by the existing user would be appropriate to differentiate between high and low quality information.

Experience-based Information

Researchers showed that parents prefer to learn the experience of other parents in similar situation [5]. However, it is non-trivial to encourage parents to share

their experience in the public domain. We recommend that, a reward-based system can be helpful in encouraging more parents to share their experience. For instance, a parent will be announced as parent of the month if their experience is “found helpful” or “liked” by a significant number of other parents. A model similar to yahoo answers and Facebook-like social network can be generalized in this regard.

Trusted Source of Information

Mackert et al. showed that parents with obese children usually do not trust the government as the health-related information provider [15]. On the contrary, university researchers are considered as the trusted source of information.

Considering this, we recommend that, the government should be very precise and accurate about the information they provide in Internet and their provided information should be endorsed by the reliable medical doctors or reputed and expert researchers.

Community-based Computer Center for Underserved Parents

Knapp et al. showed that older parents, less-educated and non-English speaking parents are unenthusiastic Internet users [2], sometimes due to lack of access to the computer and Internet. Hence the researchers gave importance on interventions to improve their computer and Internet literacy by designing community-based computer center [2, 16].

Based on our expertise on community informatics and community-based computer center, we also believe that, such interventions would be really helpful for the parents who have children with special needs.

Information Representation

Mackert et al. conducted a study on low health-literate, culturally diverse parents and showed that visual content, as opposed to simple text, could be helpful for the parents to grasp the important information for their obese children [12]. Richness in content is necessary but not sufficient; the presentation style is very important as well [4, 12].

Merely designing a website with proper content and fancy design might not be useful for the actual users if their need, preferences, and context are not considered. Hastings showed that, if we want to design an integrated child health information system, our central focus should be on the parents [17]. We believe that, the same finding is also applicable for designing a health related website for providing informal care. Since it is non-trivial to measure the right balance between text and audio-visual content, we recommend that, each health sites, before launching their final version on Internet, should perform an extensive user study involving the parents and refine the site design accordingly.

Publicly Available Search Engine for Diagnosis

Bouwman et al. discussed two cases which showed the necessity of publicly available Internet search engines as an effective diagnostic strategy in identifying rare diseases [18]. They also designed such a search engine dubbed as “Doctor’s Google.”

Although this is an excellent initiative if the parents can diagnose the rare disease using the search engine, we recommend that, the information should be used in a careful manner and parents should consult the doctor before taking an action.

Conclusions and Future Work

In this paper, we have reported the results of a meta-analysis on the literature systematically collected from PubMed database. In this ongoing research, our goal is to synthesize the contributions of the researchers who performed extensive research on how parents with children with special needs use the Internet. We also recommend some guidelines to make Internet more useful for these parents. These guidelines are as follows: (a) Online community for these parents should be more women-focused; (b) Avoid complex medical terms and use plain, simple and easy language to describe medical information; also the information should be endorsed by authenticate sources such as a specialized doctor, a reputed scholar in that domain, or a well-known medical institute; (c) Encourage the parents to share their experience with other parents on similar situation; sites might introduce a reward-based system for the parents; (d) The health-related information provided by the government should be endorsed by the reliable medical doctors or reputed and expert university researchers to gain more trust from the parents; (e) More interventions are required to the underserved parents to use Internet; community-based computer center can be an example in this regard; (f) Information provided in the web should have a right balance between text content and audio-visual content; and (g) although publicly available search engine can be an excellent effort for diagnosis of diseases, parents should consult the doctor before taking an action based on the recommendation from that search engine.

In future, we want to explore some other relevant database such as ERIC, Ovid Medline, PsycINFO, CINAHL, Sociological Abstracts, and Social Services Abstracts. We also want to extend the domain for other

informal caregivers (e.g. children, friends) and patients (e.g. regular senior citizens, older adults with serious illness, etc.).

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