Information Behavior and Everyday Life Information Seeking of Parents of Children with Special Needs in Internet Forums

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Abstract:

In the last decade, home use of the internet has increased tremendously.
This increase has led to a greater demand for more interactive channels of communication, which facilitate formation of group and personal interactions. Internet forums are one of the most popular interactive channels of communication. They enable multi-discussions (between many participants) not dependant of time and place. A public of million Israelis: parents, brothers and grandparents are related to children with special needs.
(There are an estimated 195,000 children whose daily life is highly effected by their special needs). Life long coping or caretaking with the children's special needs may cause their relatives both physical and emotional difficulties. In addition to difficulties directly associated with special needs, other difficulties will result from being alienated from the larger society: lack of information, lack of social interaction and lack of employment. Resources for help and support exist in the community (mostly in big towns): mutual aid support groups and self-help groups. Unfortunately different barriers prevent this large population of seeking help, take part and be assisted by these resources. Internet forums combine the advantages of self-help groups and the accessibility of computer mediated communication.
There is very limited research about the contents of information shared among participants and types of help offered on Internet forums for parents of children with special needs.

Therefore, the objective of the present study was to analyze the meaning and contribution of participation in internet forums for parents and families of children with special needs. (ADHD-Attention Deficit and Hyperactivity Disorder on one forum and Mental Retardation on the other).

The study focused on both information behavior and everyday life information seeking behavior of participants. Online information interactions were perceived as "neural networks" of forums.

3 major themes were checked:

1. Participants in forums, theirs and their children's personal data.
2. Traces that participants left on forums: the messages they sent, reflecting the context of their everyday life and information seeking behavior.
3. Communities, created in forums as a result of participants response and interpretation of their peers' messages.

six big questions formed the study:

1. How are participants' everyday life context and experiences reflected in their messages?
2. Who are the participants of the forums? Are they parents of children with special need? Family relatives or friends writing on behalf of parents? People who are diagnosed with the disorder? Or professionals? What are their and their children's personal data?
3. How do participants relate to information issues as exposed in their messages? Who gives the information? What is the quality of information? Who is considered an information source or authority? Could information behavior of parents of children with special needs be identified in forums? What are the characteristics of their information behavior?
4. What is the general atmosphere or dynamics of forums? What are the self-exposure levels and response speed of forum moderators and participants? What language do participants use? How is information documentation treated in forums?
5. What exchange relations take place amongst participants? Is it mainly emotional support? Informational support? Physical support? Appraisal? Are there any other resources exchanged by participants?

6. Do participation in forums and the exchange of resources create a community feeling amongst participants? What kind of community is created? Is the community created a real community? Only a virtual one? What need of the participants does the community fulfill? Belonging to a social group? A support group? A self-help group or a group of professionals?

Research population:

This study is centered on two internet forums, their participants, moderators and texts-messages posted to forums. The forums are maintained on an Israeli portal-Tapuz. Tapuz is the house of many forums, chat rooms and blogs. Recently, it celebrated a decade of virtual communities' activity.

Parents and families of children with special needs are the target population of these two forums. During the observation period, the two forums were moderated by volunteers. 453 people participated in the forums and sent 3371 messages. Forum ADHD with 347 participants: (76.7% of research population) who sent 2226 message. Forum "families of people with mental retardation" with 106 participants (23.3% of research population) who sent 1145 messages.

Data collection:

Data was collected through passive observation of online messages posted by the participants. Participants' profiles were created from participants' own words and the data was analyzed for emergent themes. These included demographics and experiences of parents or relatives of children with special needs.

Passive observation taught me the meaning of participating in forums and minimized intrusion to participants' privacy or intimacy.

I observed the two forums in 2 time periods: between 01/ 09/2005-28/09/2005 and between 01/01/2006-14/01/2006 (42 days of observation).

Research Method:

A qualitative research methodology was used, though data collection and analysis were quantitative. Content analysis was the research method chosen to analyze online messages posted by the participants in the duration of research time. The single message was the unit of analysis. Though the context of whole thread was taken into account. Every message was classified according to one main theme. Many themes emerged as a result of researcher's closer acquaintance with the forums; therefore a very detailed coding system was developed, based on Burnett's typology on information exchange in virtual communities (Burnett, 2000, 2004).

Researchers still argue whether content analysis requires quantification or not. It was chosen to quantify findings and reach "truth" of forums by having many categories for analysis of messages' content. (76 categories only for sorting message's theme). The sensitive coding system assisted in answering most of research questions. A need to answer all questions, forced grouping of these categories into 12 major categories.

Ethnics Issues:

The researcher did not ask for participants' informed consent. Technically, their great number did not enable it.

The following measures were taken: names of forums, name of portal hosting the forums and their URL were mentioned. Participants' numbers as given by database were mentioned while quoting their messages, not their names. Titles of messages were omitted in order to avoid retrieval by search engines.

Reliability:

The researcher was the central mean of inquiry in this study as is common in studies deriving from qualitative methods. The usual means were taken in order to certify the study's reliability.

1. Coding and sorting system of online messages was passed through interjudges check. Two judges judged that coding system in the early phase of research. Both of them are teachers, in their late forties. One of theme is an Information Science MA student as well. They judged 344 (10.2%) of participants' messages. The level of agreement between us was above 80%.

Further measures were taken, including:

2. A computerized database on MS-ACCESS was created.
3. Saving and presenting analysis documents in the "Quantitative Results" part of research.
4. Quoting participations' messages in the "Discussion" part of research.

Results:

Results are brought in relation to 3 major themes of interest that were checked in research.

Participants:

Many participants in both forums preferred anonymity, albeit multiple possibilities they had for presenting themselves. Percentage of anonymity varied in relation to each variable and between forums. It was found amongst these who revealed their personal data that the majority of participants were female, mother and married in the age group of 30-60. Participants' gender: forum ADHD-232 females (66.8%), 72 males (20.7%), 43 participants did not mention their gender (12.40%).

Forum "families of people with mental retardation" – 64 females (60.3%), 30 males (28.3%), 12 participants did not mention their gender (11.40%).

Heterogeneity characterized participants' relation to forums, mostly participants of "ADHD forum". Most participants were parents of children with ADHD or to be diagnosed with ADHD. The second group identified amongst participants, were young adults suspected of being or diagnosed with ADHD. The third group were professionals.

Messages:

Maximal content analysis of online participants' interactions revealed the similarities and differences in forums activities and exchange relations. It also exposed the contribution of participation in forums.

The two forums were aimed for parents and families of children with special needs. These special needs relate to medicine/ disability. Differences were found in participants' themes of interest, frequencies of interest in certain themes, time of messages posting and type of exchange relations. The differences maintained in two time periods of observation. First observation period of September 2005 was more intensive in both forums, in terms of bigger amount of messages and richness of contents, (multiple themes of messages). Themes reflected in participants messages were connected to a very unique part of their everyday life: their child's disorder and life span coping with it. Participants of "ADHD forum" showed greater interest in health information issues. That interest derived from the disorder's nature and its consequences on the child's development. Early diagnosis and right medication therapy would make child's development normative. Participants of "families of people with mental retardation" expressed a greater interest in emotional coping with their children's disability. Their opportunities to influence child's development were more limited. A check of messages' posting time reinforced the difference between the two forums. The majority of messages from "ADHD forum" were sent in the day time. Probably because they dealt with information seeking. Most messages of "families of people with mental retardation" were sent at night. Participants were free of there daily tasks then and asked for their peers' emotional support. "ADHD forum" appeared to be information oriented while "families of people with mental retardation" forum was emotional support oriented.

Similarities were found in participants' information behavior, general atmosphere and kind of communities emerging in forums.

Information behavior of participants in both forums was collective, collaborative and positive. Intensive exchange transactions were maintained in both forums, mostly by answering participants' questions. The give and take relations were for the public good as information was given and received free of charge. Though it had economical implications. Accurate information or recommendation of a doctor specializing in ADHD, a good diagnosis or treatment services could save parents a lot of money, time and frustration. The larger amount of answers compared to questions in both forums, showed that the spirit of kindness and generosity governed. That spirit created dialogue between participants. Only a small group of participants in both forums created contents. The effort of content creation was not egalitarian but there were no complaints about it. Every participant gave as he could and took according to his needs. It is a common understanding that the process is dynamic and beneficial for all.

Communities:

Finding made clear these participants did not seek information alone and "did not surf alone". They also benefit from their participation (benefits connected to public good). Participants were members of well functioning and effective communities- online self-help communities. "ADHD forum" was functioning as a virtual community. "Families of people with mental retardation" forum was functioning as both a real and a virtual community.

Conclusion:

Participation in these two forums specifically and in health-related virtual communities in general has a very important contribution for participants. They helped and were helped by their peers. They exchanged benefits connected to public good like informational or emotional support. Weak ties with strangers became (very rapidly) meaningful relations between participants who share the similar experiences.

Participants teach professionals the meaning of a special experience: parenthood of children with special needs or living with special need. They present the problems and needs arising from this experience. Given the accurate information and feedback, professionals get a real opportunity to ameliorate services they give to both children and parents. A winning combination of experiential knowledge (of parents) and expertise (of professionals) is achieved.