Use and value of information sources by parents of child psychiatric patients

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Abstract

Objective: With Web 2.0, the variety of information sources for parents of paediatric psychiatric patients has increased dramatically. Information use theory suggests newer sources supplement rather than supplant traditional sources of health information. This study sought to determine the use and value of traditional and emerging sources of information and whether the subjects had access to highly valued sources of information.

Methods: One hundred parents indicated the use and value of six sources of information on the child’s symptoms, diagnoses and treatment. The data were analyzed to determine if significant relationships existed between type of source and the use and value of the information sources.

Results: Ninety-four percent of the subjects had access to the Internet and almost half of those reported using the Social Web. Eighty-five percent had at least one high-value information source. The psychiatrist in the clinic, the Internet and the primary care physician were the most highly used and valued sources.

Conclusion: Use of digital information sources was greater than found in other studies of similar populations. This use appears to complement rather than supplant more traditional sources. Further studies are needed to see if the negative impact of lack of Internet access is replicated.

Keywords: children, consumer health information, doctors, general practitioners, information sources, librarians, parents, United States of America, Web 2.0, world wide web.

Key Messages

Implications for Practice

• Public libraries should enhance their mental health information resources and services, particularly targeting the use of Web 2.0 tools.
• Materials in the clinics as well as links on clinic website should be provided to assist parents of patients to locate and use high-quality mental health information.
• Mental health clinics should consider developing a significant Web 2.0 presence to guide and empower their patients.

Implications for Policy

• Efforts should continue and increase to ensure high-quality affordable access to the Internet.
• Organizations relating to mental health and librarianship should work together to provide continuing education on effective use of emerging information technologies

Introduction

There is evidence that psychiatric patients desire information about their illnesses,¹ we can assume
that parents and guardians of paediatric psychiatric patients also have a high desire for information regarding all aspects of their child’s illness. The number of available information sources has increased dramatically during the past decade and Web-based social networking tools make possible a virtually unlimited network of information providers. Unfortunately, there are limited research-based studies of information sources used by parents of child psychiatric patients and none that address the emerging Web-based social networking tools.

**Objectives**

The goal of this study was to explore the sources of information used by parents of patients at a child psychiatric outpatient clinic using patients from the State of Virginia in the United States. Specifically, this study sought to determine the frequency of use and perceived value of each source of information and whether the subjects had access to high value sources of information.

**Literature review**

**Information sources studied**

The selection of sources to be investigated was guided by previous studies of health information sources and by Dutta-Bergman’s Media Complementarity Theory. This theory posits that new sources, such as the Internet, are often used to complement, rather than replace traditional sources, such as family and friends. Mass media sources such as print and television were not included in an attempt to limit the length of the survey and also the limited availability of psychiatric information in these sources.

**Specialist in the clinic**

A number of studies have found that the specialist in the clinic is a highly valued source of health information but these studies also concluded that other sources were actually used more often. A significant reason for the apparent disconnect of use and value appears to be lack of time, perceived or real, available to spend with the specialist. This may be particularly true in mental health clinics where follow up visits can be very brief. Other reasons are the cost of healthcare and distance from healthcare provider.

**Primary care physician**

Khoo et al. reported that the general practitioner was highly trusted and also the most highly consulted source of health information. In a 2002 study of patients visiting ENT outpatient clinics, Rokade et al. found that general practitioners were highly valued and the main source of information for patients. They conclude, ‘In the twenty-first century, patients turn to their GP as the main source of health information.’

Other studies found that, while the primary care physician was a trusted source of health information, the Internet was more often used to access information. O’Day et al. concluded that, ‘psychiatric disability can create unique and serious barriers to obtaining good quality primary health-care.’ These barriers included:

- Difficulty in locating a primary care physician with the necessary empathic and communication skills
- Misunderstanding of the nature of psychiatric illnesses
- Lack of information of the side-effects of drugs.

**Family and friends**

In a study of health information-seeking behaviour of adolescents, Gray et al. found that family and trusted peers were the most utilised and valued sources. Lee et al. concluded that young Asian-Americans relied more on family and friends for mental health information than health professionals. Tanenbaum found that, while family and friends were reported as being a significant source of information, they were not highly regarded for understanding symptoms and diagnoses but were valued as guides to navigate the mental healthcare system.

The emergence of the Internet, and especially Web 2.0, as a source of health information has changed the role of family and friends as health information providers. Silence, et al. reported
that their subjects used conversations with family and friends as a method of integrating and validating information found on the Internet. Family and friends also pass along health information found on the Internet or conduct searches for those who are not able or willing to search on their own.13

Public library

The public library can be a source of health information through its analogue and digital collections but can also be a gateway to the Internet through its public access computer laboratories and WIFI networks. Borzekowski et al.14 found that the public library was the main access point to the Internet for their subjects, who were clinic outpatients with serious mental illness and were largely of a lower socioeconomic status. Kwon and Kim15 conducted a secondary analysis of the HINTS data to identify the characteristics of respondents going to a library for cancer information. They found that this group tended to be older, less affluent, and have less experience with the Internet.

Internet

Eight out of 10 Internet users have employed this technology to search for health information.16 Oh, Jorm and Wright7 found that Australian youth preferred the Internet in significantly higher numbers than other sources to access mental health information. Gray et al.8 found adolescents used the Internet to seek health information and that they had developed sophisticated skills for determining credibility of the information.

People seek health information on the Internet for many reasons. Among these are familiarity with the technology, easy access, anonymity, the occurrence of a health need such as a chronic illness, new diagnosis, or having a new medication prescribed.7,17–19 The Internet is often used in conjunction with other health information sources such as a healthcare provider.18 Gray et al.8 found that online information was used most often as a complementary source and reported ‘an interplay among Internet and personal sources’ (p. 1474). Furthermore, they found that online information was also used to enhance, or perhaps avoid, a visit to a health professional.

There are a variety of barriers to accessing health information on the Internet including:
- Perception of expense
- Lack of computer access
- Difficulties with typing and reading14
- Not being able to recall or spell a diagnostic term
- Being overwhelmed by the large number of search results
- Difficulty understanding the information retrieved.12

Lack of awareness of online sites with quality vetted information can also be a barrier. While there is an increasing number of such sites, Khoo et al.4 and Oh, Jorm and Wright7 found that many of their subjects were not familiar with them.

Web-based social networks

Many patients desire to share as well as seek information and health experiences with others.18,20 The first-generation Internet provided many tools to access health information, but often did not provide the information sharing capability desired. Those seeking health information online frequently ended up speaking to a friend or family member about the information they had located online.21 This barrier to sharing in the digital environment has been reduced in the past few years. The transition of use of the Internet from primarily information receiving to information generating has been characterised as significant enough to warrant its own nomenclature, ‘Web 2.0’. Web 2.0 tools are seen by some as a revolutionary leap in the ability to manage, remix, and transform health information.22

In the mental health area, examples of a high-impact Web 2.0 tool include WebMD® Communities, National Institute of Mental Health (Facebook®), and the teen mental health blog delivered by Dr Stan Kutcher and David Venn.23 Dr Kutcher has also created an iPhone app for the Sad Scale, a depression screening tool.

Despite the evident potential of Web 2.0 tools to empower and inform patients and their families, the dissemination of this innovation is still in the formative stages. Chou et al.24 found that approximately one-quarter of those who accessed the Internet reported using social media in the past.
year to access and exchange health information. In a study of outpatient psychiatric patients, Borzekowski et al. \(^14\) found that only 20% of those who had accessed the Internet participated in a social network.

Health information seeking by parents

Studies investigating health information-seeking behaviour by parents yielded results very similar to those in which the adults were seeking information about their own medical situation. Parents trusted the physician, \(^4\) but the majority of parents used the Internet to find information about their child’s diagnosis. \(^12,25\) Use of social networking tools by parents to find and share health information also seems to be in the early phase with several studies describing experimental Web 2.0 systems. \(^26,27\)

Summary of literature review

From this review, it is clear that the digital revolution has impacted the behaviour and preferences of health information seekers, but as predicted by Dutta-Bergman, \(^2\) newer communication vehicles do not necessarily replace existing ones but are often used to complement the information found in more traditional sources. As a result, it can be expected that those seeking health information will often utilise multiple sources.

Another ongoing theme found in the literature is the tension between use and value of health information sources. While the Internet is the primary source of health information in the majority of recent studies, the specialist and primary care physician are often valued more highly.

Methods

Study participants

Subjects in this study were parents or guardians accompanying patients at a child psychiatric outpatient clinic who visited the clinic during the summer of 2009. The child and family outpatient clinic is a part of the University of Virginia Health System Department of Psychiatry and Neurobehavioral Sciences and primarily serves the rural and suburban areas of central and southern Virginia. Approximately 60% of the patients use Medicaid as their insurance. Medicaid is a state-administered medical assistance program for patients with incomes <80% of the Federal Poverty Level ($8664 at the time of this study).

Research questions

The following research questions were addressed in the study:

1. What percentage of subjects had access to the Internet at home or work?
2. How many information sources are used by each subject?
3. Is there a relationship between type of source and the number of times the source is used?
4. Is there a relationship between type of source and value of the source?
5. Do subjects have at least one highly valued information source?
6. If the physician in the clinic is not a highly valued information source, is there an alternative?
7. Is there a relationship between the number of visits to the mental health clinic and the use/value of the psychiatrist in the clinic as a health information source?

Questions 3, 4 and 7 generated null hypotheses that were tested.

Data collection

The study used a parent-report, anonymous, voluntary paper questionnaire which explained the purposes of the survey and provided assurances of confidentiality. The survey collected information on the patient’s age, number of previous visits the patient had made to a mental health professional, and whether the parent/guardian had access to the Internet.

Subjects were requested to indicate which of six information sources were used to become informed about the symptoms, diagnoses, or treatment of the patient. They were also requested to indicate the value of each source used (low, medium or high). The sources were, physician in this clinic (psychiatrist), other physician (e.g., family practitioner), family/friends, public library, Web medical
information sources (e.g., WebMD®) and Web Social Networks (Web 2.0). Subjects were requested to provide examples of the Web 2.0 sites that they used.

The survey was given to the subjects by the clinic staff during the check in process. There were 551 patients visits during the study time period with a number of patients visiting more than once. The front desk staff handed out the surveys, and no one filled out a survey more than once. To be useable, a survey had to be fully completed while the guardian was in the waiting room and then placed in the survey box. One hundred surveys were completed and usable.

**Results**

Demographics and number of previous visits

Patient ages ranged from 2 to 18 with a mean of 11.37, a mode of 9, and a standard deviation of 4.02. The majority (63 of 100) of the patients had made more than 10 previous visits to a mental health professional with the remaining 37 subjects almost evenly divided between 6 to 10 (18) and 1 to 5 (19) previous visits.

Questions one and two

Ninety-four of the 100 subjects reported having Internet access at home or at work. Due to the overwhelming number of subjects having access to the Internet, comparisons of use and value of information sources was limited in some of the analyses to those with Internet access. Each of the six sources of information was indicated as used by at least 48% of the subjects with Internet access. The mean number of information sources used by the 94 subjects with Internet access was 4.26 with a standard deviation of 1.53 and a mode of 6. 84 or 89% of the subjects indicated that the physician was the most frequently indicated source of information in the clinic. The Social Web and public libraries were the least frequently indicated as information sources but were still reported as used by close to 50% of the subjects (see Fig. 1).

Of the 45 subjects indicating that a Web 2.0 site was of value to them, 43 provided at least one example of a site used. WebMD® Communities was by far the most common example. Others listed include Yahoo!® Health, National Institute of Mental Health (Facebook®), National Autism Association (Twitter®), PsychologyToday.com (blogs), iVillage (blogs), MayoClinic.com (Facebook® and Twitter®) and Univision.com (chats).

Question 3

A chi-squared test of independence was conducted to test the null hypothesis, ‘There is no relationship between type of source and the number of times the source is used.’ This hypothesis was rejected, \( \chi^2 = 79.26, \text{df} = 5, P < 0.001 \). There is a highly significant relationship between type of psychiatric health information source and frequency of use.

Question 4

In addition to being the most highly reported source of information by subjects with Internet access, the physician in the clinic also received the highest percentage of high value (60 of 84 subjects, or 71.4%) of any source. The next highest percentage of high value (39 of 78 subjects, or 50%) was the Internet, followed by the other physician source with 37 of 81 subjects, or 45.6%. The public library as a source had the greatest percentage of low value rating (21 of 46 subjects, or 45.7%), as contrasted with only five subjects (6%) assigning a low value to the physician in the clinic (Fig. 2).

A chi-squared test of independence was conducted to test the null hypothesis, ‘There is no relationship between type of information source.
and value of the source.' This hypothesis was rejected, $\chi^2 = 72.08$, $df = 10$, $P < .001$.

Question 5

Of the 100 subjects in the study, 85 reported at least one source of information of high value. Of the 94 subjects with Internet access, 82 or 87% reported at least one high value source. For the six subjects without access, 3, or 50%, reported having a high quality source of information. The difference in percentages between those with and without Internet access was close to significance, $\chi^2 = 3.56$, $df = 1$, $P = 0.06$.

Question 6

There were 36 of the 100 subjects who did not indicate the physician in the clinic as a high value source of information. Nineteen of these subjects did report other high value sources, nine had one high-value source, eight had two high-value sources, and two subjects had three high-value sources. When the physician in the clinic was not selected as a high-value source of information, the other physician and the Internet were the most frequently cited high-value choices. Seventeen of the 36 subjects that did not indicate the physician in the clinic as a high-value source did not indicate any source of information of high value (Fig. 3). Interestingly, none of the subjects without Internet access indicated the psychiatrist in the clinic as a high-value information source.

Discussion

Given the likely socioeconomic status of the subjects in this study, the fact that 94% reported having Internet access is surprising, and is contrary to the findings of studies such as Borzekowski.
The reported use of Web 2.0 tools also exceeds that of previous studies. The subjects were clearly interested in obtaining mental health information and often used both traditional and digital resources.

As in previous studies, the specialist and the primary care physician were valued providers of information, but, contrary to many previous studies, Internet information was equally of value as the primary care physician. Perhaps psychiatric patients present a special challenge when it comes to accessing the primary care physician for health information, or it could be that the sophistication of Internet users has increased confidence in the information retrieved.

Parents or guardians of patients at public psychiatric clinics often wait months to see the psychiatrist and appointments can be very brief, so the finding that 63 of the 100 subjects indicated that the psychiatrist in the clinic was a high-value source of information is somewhat surprising, although in line with the results of other studies that investigated the perceived value of specialists as information sources. This study found that the increased familiarity with the psychiatrist in the clinic through multiple visits would logically lead to increased reliance on the psychiatrist for information.

It is reassuring that 85 of the 100 subjects reported having at least one high-value source of information to be informed about the symptoms, diagnoses, or treatment. For the 36 subjects who did not perceive the psychiatrist as a high-value information source, most of them indicated that they had other, and often multiple, high value sources. Again, the results from the small portion of the sample that did not have Internet access should serve as a caution since, for these subjects, either the psychiatrist in the clinic was a high-value source or no high-value source was reported. To what extent can the results of this study by generalised, i.e., how unique was this subject grouping and the information sources used? The information source choices in the survey were purposely selected as both commonly available and utilised in many previous studies. The clinic studied served a widely distributed population and is similar to public health clinics throughout the United States. This study did target patients with psychiatric conditions and, perhaps, parents of children with conditions that require less specialised knowledge might use and value information sources differently.

Limitations

This study had a number of limitations. The subjects were the parents or guardians of the patient and so their experience was one step removed from the actual symptoms. The wait time for patients in the clinic was 5–10 minutes, this might have impacted the number of patients that completed the survey. There was no control for race, ethnicity, or socioeconomic status, even though some studies have found these to be a factor. Also, this study chose the term ‘value’ rather than ‘trust’ though both terms have been used in previous studies. Furthermore, the study did not capture information on why the subjects valued a particular information source.

Conclusions

Further studies should be carried out to determine if the high degree of access to the Internet found in this study can be replicated in other samples of this population. These studies should attempt to locate and include subjects who do not have access to see if the negative relationship between access to the Internet and access to high-value information sources can be replicated. Mental health clinics might consider working with public libraries and public library professional associations to provide patients with information on mental health information sources and to public access Internet.

Previous studies have concluded that parents of patients are seeking assistance in finding health information on the Internet and, since it appears that parents of child psychiatric patients use and value the Internet as a source of mental health information, mental health clinics may want to consider providing descriptions of and links to high-quality information sources on the Internet.

The use of the Social Web as a source of mental health information in this study sends a clear signal to mental healthcare providers that parents want to interact and exchange information with each other and with trusted providers. It is critical
to determine the most effective way to utilise these emerging tools so that mental healthcare providers can enable and enhance this interaction and exchange. Since the use/value gap was greatest for both the public library and Web 2.0 tools, there is an opportunity for public libraries to develop programs and services to offer access and training for effective use of this emerging technology.

Child psychiatry clinics, particularly those serving a lower socioeconomic patient group, face significant challenges in ensuring that the parents and guardians of their patients have access to high-value information on the symptoms, diagnoses and treatment of their children. As Maged, Boulos and Wheeler point out, it is very important to consider the relationship of emerging information technologies with more traditional sources of health information. Even though the mental healthcare providers in the clinic remain a frequent and valued source for information, they need to consider effective and sustainable ways to incorporate and amplify the impact of their expertise in a rapidly changing digital world.

References


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