



## Exploring healthcare experiences among online interactive weight loss forum users



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### ARTICLE INFO

#### Article history:

Received 7 July 2015  
Received in revised form  
30 November 2015  
Accepted 18 December 2015  
Available online 31 December 2015

#### Keywords:

Health information-seeking  
Internet  
Weight management  
Obesity  
Patient-provider relationships  
Health care

### ABSTRACT

Internet use for health information is increasingly popular, especially among individuals who are embarrassed or feel stigmatized by personal health conditions such as obesity. Little is known about how healthcare experiences might be linked to using online interactive weight loss forums. We used qualitative methods to analyze forum users' discussions in three high traffic weight loss forums in order to explore characteristics of healthcare experiences (including patient-provider communication) and their influence on health information-seeking. We identified five major themes related to forum users' healthcare experiences that influenced where, when, and from whom health information was sought: (1) access to (and time spent with) providers; (2) providers not adequately managing weight-related shame and emotion; (3) lack of clarity of health information from providers; (4) lack of trust of health information from providers; and (5) rapport and personal relationships with providers. We conclude with recommendations and implications for future research and practice.

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### 1. Introduction

Internet use is prevalent in the U.S., with approximately 85% of the adult population having used the Internet as of May 2013 (Zickuhr & Smith, 2013). Use of the Internet as a source of health information is also common (Baker, Wagner, Singer, & Bundorf, 2003; Fox & Jones, 2009; Ybarra & Suman, 2006), with over half of all U.S. adults seeking health information from the Internet within the past 12 months (Koch-Weser, Bradshaw, Gualtieri, & Gallagher, 2010; Ybarra & Suman, 2006). Internet health information-seeking is more common among certain populations including individuals who are women, white, young, possess high levels of education, possess high levels of income, or have current health problems (Koch-Weser et al., 2010; Renahy, Parizot, & Chauvin, 2008; Ybarra & Suman, 2006).

The Internet is an appealing consumer health information source for several reasons. Despite geographical location or time of day, information can be accessed from online communities of individuals sharing common interests (Chung, 2013; Robinson & Turner, 2003; White & Dorman, 2001). The Internet also provides

the opportunity for individuals to easily find others who have similar health concerns, including those with mobility difficulties (Braithwaite, Waldron, & Finn, 1999) or rare diseases (Lasker, Sogolow, & Sharim, 2005). Health information from the Internet might be sought from various sources, including read-only websites and interactive websites where individuals can share and exchange information. Interactive, peer-to-peer websites have gained popularity over time (Brenner, 2012; Sarasohn-Kahn, 2008). They provide users with several benefits, including access to a wider social network and differing points of view (Tanis, 2008; Wright & Bell, 2003), higher levels of perceived social support (Ballantine & Stephenson, 2011; Hwang et al., 2010), and higher levels of perceived informational support (Ballantine & Stephenson, 2011).

The Internet also appeals to those who feel embarrassed about their health conditions or who prefer to remain anonymous (Gallagher & Doherty, 2009; Powell, McCarthy, & Eysenbach, 2003; Rains, 2014; Tanis, 2008), and it might provide a space where individuals avoid judgment based on physical appearance (McKenna & Bargh, 2000). For these reasons, the Internet could be an especially appealing source of health information for those who have stigmatizing characteristics or conditions, including overweight and obese individuals or those who are trying to lose weight.

Obesity is stigmatized in medical settings (Anderson & Wadden,

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2004; Puhl & Brownell, 2001; Puhl & Heuer, 2009), which might lead patients with overweight and obesity to seek weight loss assistance and information from sources other than their health-care providers. Studies have shown that negative encounters and lower quality relationships with providers are associated with Internet information-seeking (Anderson, 2004; Hou & Shim, 2010; Lewis et al., 2011; Rice, 2006; Tustin, 2010). A study of obese patients by Wadden et al. (2000) found that nearly half (45%) did not rely “at all” on their physicians for help with their weight, and an additional 30% reported that they relied on their physicians only a “slight amount.” In lieu of seeking information from providers, individuals trying to lose weight might preferentially turn to another source of health information such as the Internet. Despite this possible link between experiences in healthcare settings and the use of the Internet for weight loss information, however, few studies have examined relationships between these variables.

One available source of Internet-based weight loss information is online interactive forums. Limited research has examined these weight loss-related forums, but some studies have suggested that participation in these communities might result in greater weight loss (Johnson & Wardle, 2011; Neve, Morgan, & Collins, 2011). Even with these potential benefits, concerns have been raised about the quality of health information provided on forums. Interactive Internet forums might potentially provide access to some incorrect, misleading, or potentially harmful information (Esquivel, Meric-Bernstam, & Bernstam, 2006; Hoch, Norris, Lester, & Marcus, 1999; Hwang et al., 2007), although some of this incorrect information might be later corrected by other forum users (Esquivel et al., 2006; Hoch et al., 1999; Hwang et al., 2007; Mursch & Behnke-Mursch, 2003).

Understanding of healthcare-related influences on using online interactive weight loss forums is limited. The purpose of this study, therefore, was to explore characteristics of healthcare experiences (e.g., various aspects of patient-provider communication) and their influence on health information-seeking behaviors as discussed by users of online weight loss forums. Our goal was to improve understanding of potentially modifiable healthcare experiences that could be targeted to promote open patient-provider communication about health information sought online and to inform the design of interventions to facilitate appropriate and beneficial use of the Internet for weight loss information.

## 2. Methods

Because little is known about how healthcare experiences might influence weight loss information-seeking from online interactive forums, we utilized qualitative methods to explore discussions of healthcare experiences that occurred on such forums. Generally speaking, Internet forums are interactive online spaces where forum users can post a topic to which other forum users can respond (known as a “thread”). The number of peer responses in a single thread could vary from zero to several hundred, and the “original poster” or “OP” can also respond or ask additional questions of his or her peers. In many Internet forums, usernames are linked to individual profiles where forum users might or might not disclose self-reported demographic information. Utilizing forum posts as a data source allows for an unobtrusive examination of forum users’ thoughts, opinions, and sentiment related to the influence of healthcare experiences on their health information-seeking behaviors.

### 2.1. Selection of websites

To obtain data from a variety of individuals participating in weight loss forums, we collected data from three websites that

were publicly-available, consumer-directed, and weight loss-related. These three websites were selected based on several criteria. First, to obtain the most information-rich websites (Patton, 1990), we used website traffic rankings to select relevant websites with the highest number of page visits and the highest number of unique visitors. Specifically, we used “Alexa Rankings,” which combine page views and unique site users to determine website traffic (Alexa Internet, Inc., 2013). Alexa Rankings allow for examination of top-ranked websites in the U.S. in specific categories. We examined top-ranked websites in the “health” category in the U.S. to identify the top three weight loss-related websites that included peer-to-peer forums. In addition to the Alexa Rankings for website traffic, we used the following criteria for inclusion: (1) forums were accessible at no monetary cost; (2) forum posts were linked to usernames; and (3) a forum search function was available to allow for directed searching of posts.

Based on these criteria, we selected three high-traffic websites (“Website A,” “Website B,” and “Website C”). For all three selected sites, a higher proportion of women than men visit the website; additionally, the majority of visitors to all three sites are from the U.S. (Alexa Internet, Inc., 2013). All three websites contain several forums addressing various aspects of weight, diet, and physical activity, and all three websites allow users to self-report demographic information including location, age, and sex.

### 2.2. Data collection and management

We collected data from the three selected websites in two ways: (1) using a random selection of forum threads to provide an unbiased collection of threads; and (2) using forum keyword searches to yield data relevant to healthcare experiences. Both random sampling of threads (Cousineau, Rancourt, & Green, 2006; Hwang et al., 2010; Mo & Coulson, 2008) and directed searches of relevant threads (Hoffman-Goetz, Donelle, & Thomson, 2009; Macias, Lewis, & Smith, 2005) have been used in previous studies analyzing health-related web forums. Although some studies have analyzed all posts from within a single forum (e.g., Coulson, Buchanan, & Aubeeluck, 2007; Esquivel et al., 2006; Hwang et al., 2007), those studies have limited the collection of forum posts to short time periods, or they examined forums that were smaller and had lower levels of traffic. Using our two-pronged approach to sampling of threads allowed us to achieve both breadth of forum threads (by collecting data using a random sample of threads) and depth of forum threads (by collecting data specifically related to our topics of interest).

Our sample included 300 total threads that ended (with the final posted response) between October 1, 2013 and February 28, 2014. We selected half (150) randomly and half (150) using relevant keyword searches. Although unnecessary, in the event that the number of threads had been insufficient to explore our research questions of interest, we would have sampled additional threads until we reached saturation of our themes.

Random sampling proceeded as follows for each website. First, we randomly selected five dates from within the five month period. Next, we randomly selected ten threads on each of these five dates by first randomly selecting one forum from the multiple forums listed on each website, then by randomly selecting a thread from that forum on the selected date. We repeated this process to yield a total of 150 randomly-selected forum threads (50 per website).

For keyword searches, we used each forum’s search function to search for the following keywords to identify threads relevant to healthcare providers or healthcare experiences: *doctor, dietitian, dietician, nutritionist, healthcare, health care, clinic, hospital, medical, primary care, ER, physician, doc, and dr.* For each website, we collected the 50 threads with the most recent end date (i.e., up to

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