

# Lay public's use of a support group for general dental problems

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**Objective:** To categorize and tabulate layperson inquiries made to an Internet dental health support site to identify oral conditions and associated behaviors of concern. **Methods:** A retrospective tabulation of wall postings was made from an established dental health support website hosted by WebMD over a 2-year period (April 2013–April 2015). A mixed method approach of content and thematic analysis was used. Content analysis identified content of oral health concerns, while thematic analysis using grounded theory identified themes and beliefs concerning associated behaviors. **Results:** The presence of non-descript growths on the tongue and swelling and/or discoloration of the lips elicited the most inquiries. These were often self-diagnosed as oral candidiasis, a STD or a carcinoma, provoking high levels of self-concern. Unprotected sexual activity, excessive ingestion of soft and hard beverages, smoking and overexposure to the sun were the most frequently self-reported behaviors associated with their concerns. Many questions focused upon “normal” healing, including the amount of edema and discomfort that could occur following oral surgery or other dental procedures. Information concerning alternative treatments was often solicited, and many alluded that they had not been provided sufficient information to make informed decisions prior to dental treatment. **Conclusion:** Laypersons have many oral health concerns particularly in relationship to the development of undiagnosed pathologies in conjunction with a history of volitional behaviors. The dental community should monitor these sites to provide advice and links to information about common oral health concerns and their possible association with detrimental behaviors.

**Key words:** oral health, self-help groups, knowledge, health education, online, internet

## Introduction

Today, it is common for individuals to first seek health information online, especially if they are concerned that they or a loved one may have a new condition or if their access to care is limited (Bhandari *et al.*, 2014; Fox and Duggan, 2013; Oprescu *et al.*, 2013). An estimated 80% of Americans have sought health information online (Mo, 2012), and many perceive these searches to be as efficient and reliable as consulting a healthcare provider in person (Diaz *et al.*, 2002). A recent survey found less than 11% of adults first consult their provider, while roughly 50% initially use online searches (Diaz *et al.*, 2002; Hesse *et al.*, 2005). The most common reasons for seeking health information online are to identify medical facilities or providers; to research health conditions; and to form or access support networks specific to a health issue (Al-lukian, 2008; Cline and Haynes, 2001; US DHHS, 2000).

It is estimated that 25% of those performing online searches will join a support group. Many groups are sponsored by centralized health sources such as WebMD, Medline, and Yahoo! health (Cline and Haynes, 2001; Fox and Dugan, 2013). While some caution that there may be opportunities for self-promotion and potential compromise of treatment outcomes, proponents insist such sites offer benefits (Cline and Hayes, 2001; Bhandari *et al.*, 2014), including advice and emotional support from likeminded individuals (Nambisan, 2011). In a society where familial support may be lacking, such benefits may be important. There is evidence that support sites may

positively influence personal decision-making, resulting in more self-involvement in care (Cline and Haynes, 2001; Rollman *et al.*, 2014).

Many support groups for medical conditions exist, but WebMD is the only centralized public network for general dental/oral health issues despite oral diseases, especially caries, being prevalent in all ages (Selwitz *et al.*, 2007). Analyses of the postings to this site provide an opportunity to discern lay individuals' oral health concerns and possibly to gather why they choose to use an alternative health communication channel, whether in tandem or in lieu of communicating with a professional. Our goal was to tabulate and categorize individuals' posted oral health issues and any self-reported perceptions of associated volitional behaviors. The mechanisms used to communicate through the support group were also tabulated.

## Method

The top 15 health websites were identified and accessed (ebizMBA, 2013). On each site, “dental support group” and “oral support group” were entered to determine if a support group was available. Only WebMD had such a group. All wall posts initiated within the oral health support group were collected, tabulated and categorized over a two-year period (April, 2013– April 2015). Wall posts are comments made by individuals on a site to elicit possible responses from other group members (Greene and Choudry, 2001). Individuals were uniquely identified and each post was recorded.

A mixed method approach of content and thematic analysis was implemented. All wall posts were read and the authors reviewed and categorized each post according to the reason for posting (for self or another), whether the posting contained wording that indicated an associated volitional behavior (Y/N), access to oral healthcare (Y/N) and/or dental insurance (Y/N). If no mention was made, the category was defined as unsure (Uns). Additional content analyses were made concerning prior communications (professional, online, peer, or none), if a response to a query was given by another (Y/N), by whom (website administrator, private dental group, peer), and the type of response (poll to garner opinions, provision of information, suggestion to seek care). A random sample of 25% of the posts was examined by an independent evaluator to determine level of agreement.

To develop empirically based definitions about the users' perceptions of and experiences with oral health problems and behaviors, the posts were evaluated again and an inductive thematic analysis was performed based upon grounded theory (Glaser and Strauss, 1967). Following grounded theory, a constant comparative methodology was employed, which permitted continuous comparison of newly collected data that had been coded. Open coding was developed with a pilot sample of responses and reviewed and agreed upon by the authors. The data were then categorized using selective coding, which permitted connections to be made between categories.

## Results

The 363 distinct wall posts were tabulated and categorized. Most were initiated as a result of a personal dental issue (89%), while 11% was initiated for others. Only 2% of the posts indicated limited access to care, while 35% indicated a visit to a professional prior to the posting. A small percentage lacked dental insurance (2%) at the time of posting. Percentage of agreement was 84% for these categories.

### Content themes

Three themes emerged and were categorized as: Pathoses, Procedures/Therapies and Miscellaneous. Table 1 summarizes the data. Selected quotes are provided to illustrate some of the themes. These have been edited and abbreviated to make them easier to read and to conserve space.

Pathoses were defined as conditions affecting the head and neck and were categorized as intraoral (tongue, teeth, periodontium, pharynx/tonsils, generalized) or extraoral (lips, temporomandibular joint). Conditions were categorized as being extraoral when no intraoral tissues were mentioned as being concurrently affected. Conditions included, but were not limited to, pain or discomfort, the presence of a growth or change in the appearance or texture of a structure. When no specific mention of the location of the condition was made, but the condition could affect multiple areas such as candidiasis and burning mouth syndrome, the location was categorized as unspecified generalized oral or extraoral (although there were no extraoral). Procedures/therapies were placed into subcategories of periodontal procedures, oral surgery, operative dentistry and prosthodontics, and

**Table 1:** Summary of content themes

Category	Subcategory	Frequency
I. Pathoses		245
	<i>Intraoral</i>	
	Tongue and Taste buds	86
	Dentition	64
	Periodontium	19
	Pharynx and tonsils	10
	Generalized intraoral location	25
	<i>Extra-oral</i>	
	Lips	39
	Temporomandibular joint	2
II. Procedure		105
	<i>Periodontal</i>	
	LANAP	8
	Periodontal/Endo	4
	Gingiva	2
	Bone Grafts	1
	<i>Oral Surgery</i>	
	Extractions	40
	Tonsillectomy or related	3
	Orthognathic	2
	Exostosis Removal	1
	<i>Operative and Prosthodontics</i>	
	Multi-unit Fixed Bridge and Single Crown	9
	Amalgam/Composite restorations	8
	Implants	5
	Complete Dentures	3
	<i>Endodontics</i>	15
	<i>Miscellaneous Procedures</i>	4
III. Miscellaneous		13
Total Unique Posts		363

endodontics. Queries concerning procedures that could not be placed in a single subcategory were listed as miscellaneous. For example, the timing of a child's first dental visit and the necessity of general anesthesia were categorized as miscellaneous procedural queries. The miscellaneous main category was used for queries that could not be categorized as either a pathosis or procedure. An example is the ingestion of various foods or beverages that could cause caries. Percentage of agreement was 80% for these categories.

*Pathoses (n=245).* The tongue and taste buds (N=86) and the lips (N=39) were the most identified intraoral and extraoral sites, respectively. Most queries concerning the tongue centered upon the presence of vaguely defined "lumps and bumps". For the lips, discolorations were the most common causes of concern. When finding these potential pathoses, many acknowledged not having yet sought a definitive diagnosis. Some included a picture with their query in the hopes that others might provide a diagnosis. Many posters with vague growths on the tongue were fearful of having contracted a sexually transmitted disease such as human papilloma virus (HPV). The possibility of a carcinoma of the tongue was also a common self-diagnosed concern.

**Table 2.** Communication theme examples and definitions

<i>Themes and Subthemes with examples</i>	<i>Frequency</i>
I. Communication patterns -- mention of communication prior to posting in the form of interpersonal (friends, relative, acquaintances, dentists and dental staff, and other healthcare providers) or media (literature, traditional and social media).	<b>128</b>
<i>Communication with dentist</i>	<i>119</i>
Post procedure about procedure itself. e.g. "My dentist is recommending Socket Grafting after the extraction of wisdom tooth in lower left jaw. Is this procedure necessary?"	19
Post procedure about ailments. e.g. "The root canal was performed and I was still having severe pain. I can not eat any solids because of the smallest piece of food gets near those teeth and I bite on it I go through the roof with pain. I have been in touch with my dentist and he tells me this is normal."	20
Pre-procedure. e.g. "If I go forward with Orthognathic Surgery, can I expect a major difference with respect to my facial profile?"	17
Miscellaneous ailments. e.g. "My dentist has ruled out linchen planus or any dental problems".	63
<i>Internet search</i> e.g. "After reading some of the possible causes of my problem as suggested by WebMD, I am now beginning to believe it is due to use of wrong toothbrush."	6
<i>Interpersonal/friend/family</i>	<i>3</i>
II. Response to queries and type of response-- count of who responded to participant questions (site administrators, lay members, private dental groups) and the type of response given (seek care from provider, give information, give opinion of cause of disorder, personal stories of similar accounts)	<b>159</b>
<i>Site Administrators</i>	<i>79</i>
Seek care plus information. e.g. "This article on crowns may have some information that may interest you. It says that temporary crowns are made of acrylic or stainless steel. You may want to speak with your dentist about this to see if it could be what is causing the green tint"	39
Seek care alone. e.g. "Have you been to the doctor or dentist about your symptoms?"	32
Information alone	6
Opinion/Recommendation. e.g. Persons suffering from tongue blisters should avoid eating food items rich in acid content like sugars, flours and so on. More quantities of fruits especially apples should be eaten as there is a proven record of lowering the occurrence of blisters."	2
<i>Lay members.</i> Personal stories and opinion. e.g. "I had this procedure done this morning. I would definitely recommend the Chao pinhole procedure."	<i>44</i>
<i>Private dental groups</i>	<i>19</i>
Opinion alone. e.g. "The hole in gum after tooth removal is normal; there is nothing to worry much about it. Those holes heal up naturally within 2-3 weeks."	8
Opinion and consult. e.g. "Don't be much worried about it though I can understand how annoying it would be. ...Go to a doctor or dermatologist to have it looked at though."	7
Miscellaneous queries	4
<i>Polls</i>	<i>17</i>

*"I have been experiencing severe tongue discomfort for over a month..., big red sores and indentations on the left side and underneath..., chronic metallic taste, pain, inability to eat, .... The symptoms are getting worse so I'm convinced it's tongue cancer."*

Extraoral concerns related to the lips (N=39) were primarily related to discoloration as well as inflammation and swelling and non-descriptive growths. In most cases, these were described as painless and of unknown etiology. Discolorations were typically described as being red or white, and posters often feared they could be cancerous.

Queries related to the dentition (N=64) often centered upon the development of or re-occurrence of a dental abscess. Again, few had communicated with a provider even when they had indicated they had access to care. Tooth mobility, undifferentiated dental pain and esthetic concerns, including discolorations of the dentition and malocclusion were also mentioned, although less often.

Many reported having tooth mobility and were unsure of the etiology. They theorized that aging, prolonged stress, and cardiac disease were possible causes. Postings about malocclusion were often made by parents, with most inquiring about when orthodontic treatment should be initiated.

*"My son started to lose his teeth at the age of 5. He almost lost his all baby teeth but he didn't get front teeth in proper number. In the upper jaw and lower jaw he has only 2 & 2 teeth instead of 4 & 4. He is now 8yrs. What is the cause and what is the solution?"*

Generalized intraoral conditions were a lesser, but still frequent concern (N=25). Within this category were concerns about oral candidiasis followed by burning mouth syndrome, although few had been definitively diagnosed. Many with this syndrome described the pain they were experiencing and how it was causing personal and familial distress.



### *Responses provided to queries*

There were 142 responses to posters' queries: 79 by the WebMD site administrators, 44 by lay members and 19 by private dental groups. Polls were also used (N=17) to garner support members' responses. Administrators most commonly provided information accompanied with a recommendation to seek care (N=39), followed by request to seek care alone (32). Only 2 responses were sole opinions as to what they believed the disorder to be (N=2), while private dental corporations were more likely to provide such an opinion alone (N=8). Almost all lay group members responded to queries with personal stories of similar experiences and a possible diagnosis.

### **Discussion**

This paper provided unique insight into the use of an oral health support website by lay individuals seeking dental information. Despite the fact that oral diseases, especially dental caries, are almost universal, this is the only general oral health support group that we were able to identify on the most popular centralized health websites. Possible explanations for the paucity are beyond the scope of this paper but beg further research.

During the course of the two-year observation period, 363 unique wall posts were identified. In most cases, those using the support group were there for the same reasons that persons utilize medical health support sites: to seek opinions concerning the need for treatment, alternative therapies and the possible sequelae of treatment (Diaz *et al.* 2002)

While online health support groups can positively influence medical decision-making and help patients self-manage their care (Rollman *et al.*, 2014), a few drawbacks are known, including the potential for self-diagnosis, self-medication and advertising (Cline and Haynes, 2001). In this sample, little or no advertising was noted. In terms of information, the website administrators were more likely to provide an opinion and supportive information and advise the poster to seek professional care as compared to private dental companies who were more likely to provide only an opinion. Laypersons were likely to relay their experiences without a clear understanding of the circumstances or associated history of the poster, and this has been evidenced by others (Sudau *et al.*, 2014). It is notable that members were not very integrated, overall, as a social network support system. Although research shows that those viewing without posting as well as posters can receive emotional and informational support gratifications from social networks systems, the benefits that come with the ability to discuss sensitive topics anonymously are best established through openness and a willingness to share stories (Setoyama *et al.*, 2011).

Individuals seek opinions and advice from other lay persons as opposed to their health care professionals for many reasons, including the ease and immediacy of contact, a feeling of sharing a common adversity and the ability to remain anonymous (Hu *et al.*, 2012, Kang *et al.*, 2013; Rollman *et al.*, 2014; Tanis, 2008). Anonymity is very important to those who are concerned that a personal behavior or habit may have initiated or exacerbated the condition such as the use of tobacco, among others (Shahab *et al.*, 2014). Additionally, patients may be reluctant to share with their

provider that they are performing online searches because of the possibility of negatively affecting their relationship with their provider (Diaz *et al.*, 2002).

Oral health professionals should acknowledge online communities as important repositories of information and seek to develop these sites to better educate the public concerning public health issues (White and Dorman, 2001). In this investigation, the identification of nondescript growths both intra-orally and extra-orally was of primary concern, with individuals fearing them to be HPV, HIV or a carcinoma. The use of tobacco was frequently mentioned as an associated behavior in the development of "lumps and bumps". In addition, excessive sun exposure and soft drink consumption were frequently mentioned behaviors, but it was obvious that many posters did not understand the association of the behavior with the development of either skin carcinomas or dental caries. Links to timely and accurate information from oral health websites could educate and allay potential fears.

It was evident that posters felt unclear as to the rationale for treatment, the possible advantages and disadvantages and the financial obligations that might be incurred. Many seemed unclear if they should contact their provider after adverse sequela developed. Similar post-procedural questions are frequently observed in support groups for breast cancer and rare diseases (Walker, 2014) and emphasize a communication issue to be addressed. Even when adequate communication occurs, 40-80% of the health information provided by practitioners is quickly forgotten (Kessels, 2003).

The dental community would be well served to monitor support sites to gauge the oral health concerns of lay individuals, especially in regard to volitional behaviors, and to develop tools and materials in response to these concerns (Liang and Scammon, 2013; Harorli and Harorli, 2014). Pre-written materials for common questions and guides to reliable oral health websites are useful tools for helping dentists communicate with today's health information-seeking consumers (Walker, 2015).

The conclusions that can be drawn from this investigation are limited, as we had no means to consistently identify demographic characteristics of the posters nor a means to verify truthfulness of the posting content (all self-reported). Research indicates white Caucasians, adults, females and those who are more health-oriented are the primary online health information seekers for medical information (Cline and Haynes, 2001; Dutta-Bergman, 2004; Fox and Dugan, 2013). While not investigated in this study, there is evidence that both groups with high socioeconomic status with access to care and the least affluent with less access are equally likely to seek information online (Bhandari *et al.* 2014; Nolke *et al.*, 2015). Future studies should investigate gender and race for possible significant differences in content and behavioral categories. In addition, because there are little data available regarding the frequency and presentation of symptoms and subsequent healthcare seeking behavior in the general population, these relationships need explored (Elnegaard *et al.*, 2015). Despite limitations, this is a first study of the only offered general dental/oral health support group on a popular centralized US network. Future study of the public's needs for dental information might better inform educational outreach and communications to help people better manage their oral healthcare.

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