

Internet discussion forums, an information and support resource for orthognathic patients

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Introduction: Orthognathic patients appear to be increasingly using the Internet to obtain information about their proposed treatment. The aim of this study was to investigate the information that orthognathic patients share and discuss with peers away from the clinical environment to improve the provision of information for orthognathic patients. **Methods:** Posts made by persons in a large publicly accessible online orthognathic discussion forum were analyzed; 1912 randomly selected forum posts were evaluated using a qualitative analysis technique known as “thematic analysis” that involves coding the posts and collating them into meaningful and distinct themes. **Results:** The main themes identified were (1) reasons for undergoing orthognathic treatment, (2) pre-surgery and postsurgery treatment stages including orthodontics, (3) surgery including postsurgical complications and difficulties, (4) expected and actual end of treatment changes, and (5) seeking and sharing information. **Conclusions:** This study demonstrates that orthognathic patients look to the Internet to supplement information regarding their proposed treatment. This may suggest a possible gap in the provision of information by health care professionals. However, it is clear that patients use Internet forums to seek additional information, support, and reassurance from peers undergoing similar treatment. Therefore, there is a need for clinicians to ensure that patients have access and are guided to appropriate and relevant Internet resources. (*Am J Orthod Dentofacial Orthop* 2015;147:89-96)

Provision of information to patients is an essential aspect of patient care in all clinical settings. Research has shown that orthognathic patients are more likely to be satisfied when they receive more information about discomfort and surgical risks¹ and when they were forewarned about negative events such as pain, numbness, and swelling.²⁻⁴

A review of the literature suggests that most previous studies in the field of orthognathic surgery have focused on information about the surgical aspects of the treatment pathway and not enough on the whole

orthognathic treatment pathway, especially the orthodontic phases before and after surgery.²⁻⁶

To increase posttreatment satisfaction, it is essential to understand what information patients want about the entire orthognathic treatment journey. Focusing on what information patients are seeking and discussing away from the clinical environment is a useful avenue to understand this. It is clear that with the increase in access to the Internet, patients are now using it to obtain health care-related information and also to discuss aspects of their treatment with peers. This is increasingly the case for orthognathic patients, who often tell clinicians that they have found some information about treatment on a Web site. For clinicians, this poses some important questions. What information do patients discuss with peers? Why do they choose to discuss this in Internet forums? What is the quality of information being shared on the Internet?

This issue of the validity of the information available on the Internet is a particular concern for many clinicians. In a study assessing the quality of information available to orthognathic patients on the Internet, Aldairy et al⁷ found that only 6 of the 25 Web sites in the United Kingdom provide medical information of such a quality that could be recommended to orthognathic patients. Internet discussion forums allow patients to interact with their peers and offer and seek advice, support, and

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information.⁸ However, the information shared is often subjective and may not be reliable.

To gain a greater understanding of what patients are discussing about orthognathic surgery, Sousa and Turrini⁵ and do Rego Barros et al⁶ analyzed comments from blogs and virtual communities in the Portuguese language. However, their analyses were limited to those relating to expectations or concerns regarding orthognathic surgery and did not include the entire orthognathic treatment journey. In addition, as acknowledged by do Rego Barros et al, the research only focused on virtual communities in the Portuguese language, and the authors recommended analyses of Internet users in other countries. Sousa and Turrini found that patients posted information that they considered to be essential but that professions considered too basic to be of concern. This is an important consideration; therefore, it is vital to understand what information patients require, rather than what health care professionals think they should know.

The use of qualitative research is increasing in health care and is a useful research method to gain an in-depth understanding of patients' thoughts and experiences. Analyzing discussion forums has been recommended as a qualitative research methodology because it can make the users' beliefs and concerns apparent in comparison with more closed-ended quantitative research methodologies. Since the researcher is not present during data collection and the conversations analyzed occur naturally, this prevents any bias by the researcher.⁹

There has been limited research published to date investigating patients' perceptions of their information needs concerning both the orthodontic and the surgical phases of orthognathic treatment. Analyzing the questions patients ask and the information they share will provide a valuable insight into what patients want to know so that clinicians can manage expectations and improve satisfaction. This research was conducted to address this gap in the literature. In our qualitative study, we aimed to gain insight into the topics discussed by orthognathic patients regarding the whole treatment process among fellow patients on an internationally used online orthognathic discussion forum to improve the provision of information for these patients throughout their treatment pathway.

MATERIAL AND METHODS

The Google Internet search engine was used to search for discussion forums with the terms "discussion forum," "orthognathic surgery," "surgical orthodontics," and "jaw surgery." An orthognathic discussion forum based in the United States was selected for analysis of posts

because it was identified as one of the most active forums in use. This was reflected by the number of messages posted (N = 18,846), and this forum is used by an international audience. The discussion forum creator and moderator consented to our analysis of the posts on the forum.

Since the discussion forum contained nearly 19,000 posted comments, posts selected for analysis were randomly chosen using a random number generator. This process was repeated until data saturation was obtained and no new themes were identified. Posts were analyzed with thematic analysis based on the guidelines of Braun and Clark.¹⁰ Thematic analysis involved reading all the posts repeatedly and marking ideas and notes in relation to orthognathic treatment. Posts were grouped together into topics and then reviewed and refined until meaningful and distinct main themes and subthemes were developed. A selection of quotes has been provided in the Results to illustrate the relevant themes.

Thematic analysis has been previously used to analyze comments on computer-mediated support groups by other fields in medicine, such as investigating social support online for people living with irritable bowel syndrome.^{11,12}

RESULTS

We analyzed 1912 randomly selected posts. Most of the people who posted on the forum either were considering treatment or were on the treatment pathway, sharing their concerns and experiences so far. Also, some who posted messages had completed treatment and were offering informational and emotional support to those who were considering or undergoing treatment. Five major themes, each with subthemes, were identified from the data and are discussed below.

Reasons for undergoing orthognathic treatment

A wide range of reasons have been identified to explain why persons chose to undergo orthognathic treatment. The 2 main reasons are considered below.

Difficulties with function was a reason that some mentioned; they were concerned with how their malocclusion affected them on a day-to-day basis. The most common difficulties referred to eating, speaking, and breathing. These can be key reasons for seeking advice or treatment.

"I was sick and tired of not being able to enjoy food properly."

"I'm constantly pushing my lower jaw forward in order to speak properly without my lower lip being caught under my upper teeth."

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