Original Contributions

Is social media the way to empower patients to share their experiences of dental care?

Sophy K. Barber, MSc; Yung Lam, BDS; Trevor M. Hodge, MPhil; Susan Pavitt, PhD

Supplemental material is available online.

ABSTRACT

Background. Social media present opportunities to understand patient experience and information needs. In this study, the authors use hypodontia as an example to explore social media use by dental patients and how this provides for understanding patient experience.

Methods. The cross-sectional survey design involved systematic search of 6 social media online environments with hypodontia-related terms. The authors categorized records by using a coding system for user, type and theme of post, and target audience. The authors used a thematic framework approach to analyze qualitatively the word content of posts from people affected by hypodontia (nondentists).

Results. The authors searched and identified 571 records and included 467 of them in their study. The authors analyzed the content of records from people affected by hypodontia (n = 176). Themes emerged about the experience of untreated hypodontia, treatment experience and outcomes, and decision making. Content analysis provided evidence about peer-to-peer communication, areas of information need, and desire for peer support.

Conclusions. Social media communities have responded to the need for information exchange and peer support by the public. Analysis of communications helped identify a need for dissemination of understandable information to patients and improved dentist awareness of patient needs.

Practical Implications. Clinicians should reassess understanding and information needs actively throughout treatment and identify support needs. Clinicians should refer patients to quality information sources and peer support groups.

Key Words. Hypodontia; social media; experience; patient information; peer support.

Social media are "an online environment established for the purpose of mass collaboration" and include social networking sites (for example, Facebook, LinkedIn), blogs, content communities (for example, YouTube), collaborative projects (for example, wikis), microblogs (for example, Twitter [Tw]), and rating sites (for example, Yelp).[1] In the past decade, there has been a substantial increase in the use of social media in health care by providers for health communication with patients,[1,2] interprofessional networking and information sharing,[3] and encouraging patient engagement with care providers.[4] Social media provide an opportunity for rapid dissemination of knowledge during health care crises, as demonstrated by the Zika outbreak, when social media were used to spread information about transmission prevention, and for promoting widespread awareness of campaigns and programs.[1,5]

Increasingly, patients are turning to social media for information to support decisions about seeking a second opinion, coping with a chronic disease, choosing care providers, and treatment.[1] In a comprehensive study of social media use, investigators found that patients use social media for numerous reasons: psychosocial support for emotional well-being, improved self-esteem, finding information, building a support network, emotional expression without concern about the reaction of others, and comparison of their condition and treatment with those of other people.[6] These uses were associated with beneficial effects through improved self-management and control, enhanced psychological well-being, enhanced subjective well-being, more equal communication between the patient and health care professional, and harmonious patient-professional relationships. However,

negative effects also were evident, such as diminished subjective well-being, addiction to social media, loss of privacy, targeting for promotion, and suboptimal interaction between the patient and health care professional.

In research, investigators have used social media for recruiting participants and distributing surveys[7,8] and for testing the effectiveness of providing patient information by using new digital formats.[9] Investigators have used the acquisition and analysis of existing data for a range of purposes: evaluation of the benefits[10] and harms[11] to health posed by information sharing and product marketing by social media communities; understanding public communication about specific conditions, such as cardiovascular disease[12] and mammography experience[13]; and providing opportunities for drug safety surveillance.[14,15] In dentistry, study investigators have used posts on Tw to explore patient experiences of orthodontic treatment,[16,17] quality of life related to third molars,[18] and bullying in relation to dentofacial features.[19] The opportunity provided by social media to gain firsthand reports of patient experience throughout diagnosis and treatment offers valuable information for patient-centered care. Evidence-based dentistry (EBD) requires that best evidence and clinical experience are combined with patient values and preferences; by better understanding patient experiences, dentists will be more equipped to discuss treatment options and how these might fit with individual preferences.

In this study, we explore how dental patients use social media and suggest how this evidence can be used to improve information provision and patient experience. We studied hypodontia, but the methods could easily be transferred to other dental conditions. Hypodontia is a relatively common but complex condition, which can present those affected with difficult decisions to make about care. The condition often requires long and burdensome treatment, and better understanding of patient experience throughout the process potentially will enhance outcomes through improved engagement, adherence, and satisfaction with care.

Our aim in this study was to examine social media use by people affected by hypodontia for communication about the condition and its associated dental treatment. Our objectives were to search social media platforms systematically for records relating to hypodontia and its treatment, analyze the content of records from people affected by hypodontia, and summarize how people with dental conditions use social media and the importance of this use for improving care.

METHODS

This study involved a systematic search of 6 social media online environments and qualitative analysis of the content by using a phenomenological approach. The University of Leeds Dental Research Ethics Committee confirmed no ethical approval was required for the study because we used only data obtained from publicly available sources.

We developed the search strategy by identifying suitable social media online environments (eTable 1, available online at the end of this article). We excluded 4; YouTube and Vimeo share only video content, Snapchat is a mobile telephone application-based network, and LinkedIn is a business-to-business platform aimed at professional networking. We excluded video-sharing platforms because it was beyond the scope of this study to analyze visual content and it was not feasible to transcribe audio content for analysis.

We included 6 social media online environments: Facebook, Tw, Instagram (Ig), Google+, Reddit (R), and Tumblr (T). We trialed key words relating to hypodontia and common treatment methods (eTable 2, available online at the end of this article) in scoping searches to test the sensitivity and specificity of the key words. Nonspecific terms for hypodontia and all terms for treatment methods returned a high number of irrelevant posts. Hypodontia and oligodontia provided a satisfactory number of relevant posts, so we included only these terms for the search.

Two of the authors (S.K.B., Y.L.) successively entered the search terms into the search function of each social media platform. Because of the volume of posts, we placed restrictions on the Tw search to include posts within the past 42 months (posts from January 1, 2014 onward) because of the high volume of hits. We placed no restrictions for all other social media online environments. Each post constituted a record, and we indexed it in a spreadsheet (Excel, Microsoft). We recorded and removed duplicates. Information recorded for each record included date of posting, information about the user where available (sex, location, affiliations), word content, and a note of any other content (for example, link, photograph, video). We categorized records by using a coding system for user, type and theme of post, and target audience. Two of the authors (S.K.B., Y.L.) performed the

ABBREVIATION KEY

EBD: Evidence-based dentistry.
Ig: Instagram.
NA: Not available.
R: Reddit.
T: Tumblr.
Tw: Twitter.