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Barber, SK, Lam, Y, Hodge, TM et al. (1 more author) (2018) Is social media the way to empower patients to share their experiences of dental care? The Journal of the American Dental Association, 149 (6). pp. 451-459. ISSN 0002-8177

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Social media is “an online environment established for the purpose of mass collaboration” and includes social networking sites (e.g. Facebook, LinkdIn), blogs, content communities (e.g. YouTube), collaborative projects (e.g. Wiki), microblogs (e.g. Twitter) and rating sites (e.g. Yelp).[1] In the last decade there has been a substantial increase in the use of social media in healthcare by providers for health communication to patients[1,2], inter-professional networking and information sharing,[3] and to encourage patient engagement with care providers.[4] Social media provides an opportunity for rapid dissemination of knowledge during health care crises, as demonstrated by the Zika outbreak where it was 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] A comprehensive study of social media use found patients use it 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; comparison of their condition and treatment with 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 healthcare professional and harmonious patient-professional relationships. However, negative effects were also evident, such as diminished subjective well-being, addiction to social media, loss of privacy, targeting for promotion and suboptimal interaction between the patient and healthcare professional.

In research social media has been used for recruiting participants and distributing surveys[7, 8] and testing the effectiveness of provision of patient information using new digital formats[9]. Acquisition and analysis of existing data has been used for a range of purposes: evaluation of the usefulness[10] and harms to health [11] 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, the current studies have used social media to explore patient experience of orthodontic treatment[16, 17], quality of life related to third molars[18] and bullying in relation to dentofacial features[19] using posts on Twitter. The opportunity provided by social media to gain first hand reports of patient experience throughout diagnosis and treatment offers valuable information for patient-centred care. Evidence-based dentistry requires that best evidence and clinical experience are combined with patient values and preferences; by better understanding patient experience dentists will be more equipped to discuss treatment options and how these might fit with individual preferences.

This study explores how dental patients use social media and suggests how this evidence can be used to improve information provision and patient experience. In this study we studied hypodontia but the methodology could be readily be transferred to other dental conditions. Hypodontia is a relatively common but complex condition, which can present those affected with difficult decision-making around care. The condition often requires long and burdensome treatment and better understanding of patient experience throughout the journey will potentially enhance outcomes through improved engagement, adherence and satisfaction with care.

The aim of this study was to examine social media use by people affected by hypodontia for communication about the condition and its associated dental treatment. The objectives were to: 1) Systematically search social media platforms for records relating to hypodontia and its treatment 2) Analyse the content of records arising from people affected by hypodontia 3) Summarise how social media is used by people with dental conditions and the significance of this for improving care

Methods

This study involved a systematic search of six social media online environments and qualitative analysis of the content using a phenomenological approach. The University of Leeds Dental Research Ethic Committee confirmed no ethical approval was required for the study due to use of data obtained only from publically available sources.

Search strategy was developed by identifying suitable social media online environments (Supplemental Table 1). Four were excluded; 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. Video-sharing platforms were excluded as it was beyond the scope of this study to analyse visual content and it was not feasible to transcribe audio content for analysis.

Six social media online environments were included (Facebook, Twitter, Instagram, Google+, Reddit, Tumblr). Key words relating to hypodontia and common treatment methods (Supplemental Table 2) were trialled in scoping searches to test the sensitivity and specificity of the key words. Non-specific 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 and consequently only these terms were included for the search.

Two authors (SB and YL) successively entered the search terms into the search function of each social media platform. Due to the volume of posts, restrictions were placed on the Twitter search to include posts within the last 42 months (posts from 1.1.2014 onwards) due to the high volume of hits. For all other social media online environments no restrictions were placed. Each individual post constituted a record and was indexed in Microsoft Excel. Duplicates were recorded and removed. Information recorded for each record included date of posting, information about the user where available (gender, location, affiliations), word content and a note of any other content e.g. link, photograph, video. Records were categorised using a coding system for user, type and theme of post and target audience. Two authors (SB and YL) performed the coding independently and disagreements were recorded and resolved by discussion. A defined inclusion criterion was used to select records suitable for content analysis (Table 1).

Two authors (SB and YL) performed the content analysis independently and in duplicate. The word content of records was extracted and given a data tag to enable anonymous reporting. Dialogue divided into meaningful units, which were then grouped into subthemes and themes to develop an initial framework. All authors contributed to refinement of the final thematic framework.

Results

Searches were conducted up to 6th June 2017, resulting in identification of 571 records. Instagram reported more hits than were accessible to view and Facebook returned a low number of posts than expected. This is attributed to privacy restrictions limiting access to personal posts. Records were only excluded if they were duplications, entirely irrelevant to hypodontia or in a language that could not be accurately translated into English. Following exclusions, 467 records were coded based on user, type of post and theme of post (Supplemental Table 3). The majority of records were captions associated with photographs on Instagram or ‘tweets’ from individuals or dental professionals on Twitter.

Purpose of social media use

The proportion of records arising from dental professionals (42%) and people affected by hypodontia (39%) was similar. The purpose of dental professional posts was principally information sharing and advertising their services, compared to non-professionals posts, which were sharing experience, seeking information and less commonly, sharing information. Twitter and Facebook were most frequently used for information sharing, while Reddit appeared to be seen as a source for seeking information. Instagram was popular for sharing experience through photographs with descriptive captions, particularly with a few users who posted multiple times to document their journey through hypodontia care. Google+ records were predominantly links to other sites or articles.

One hundred and sixty seven records fulfilled the inclusion criteria for content analysis (Table 2). These included 80 unique authors, some who posted only once and others who posted multiple times.

Themes of social media posts

A comprehensive summary of the analytic framework is given in Figure 1 and supporting quotes are available in the supplemental files. Four main themes were identified:

1. Experience of hypodontia
2. Experience of treatment
3. Expectations and outcomes from treatment
4. Decision making around treatment

1. Experience of hypodontia

Understanding of hypodontia

Understanding of hypodontia was discussed in terms of features of the condition and adaptation to the condition. Diagnosis was one of the most commonly occurring topics and demonstrated the terminology used for hypodontia, often based on the aetiological basis, for example, “naturally missing teeth” [R10], “congenitally missing premolars” [R5] and “genetically missing teeth” [R16]. The explanation for the condition commonly related to failure of tooth development: “My body never made a full set of adult teeth” [T4] and “They're just not in my gums”. [Tw15]. There was evidence of the disparity in age range and experience related to diagnosis (Box 1).

Users widely understood the aetiological basis for hypodontia to be genetic or familial and this was generally reported factually without emotion. However, two users expressed negative sentiment, calling hypodontia "stupid genetically inherited hypodontia" [Tw4] and "the family curse!" [I8] and one user indicated previous blame or misunderstanding by others "It's not my fault that I have microdontia and hypodontia. Both genetic disorders run in my family and I can't help it" [Tw7]. One post from a frequent user who uses Instagram to document his journey through care added a somewhat confusing caption to a photograph of study models with missing teeth: "Remember kids, brush your teeth twice a day, or else this'll happen #hypodontia #microdontia" [I26]. This suggests either misunderstanding around the cause of hypodontia, or that he was likening the impact of poor dental health and subsequent tooth loss to his own experience of treatment for hypodontia.

The most commonly discussed consequence of hypodontia was retention of primary teeth. The eventual failure of primary teeth resulted in symptoms, such as mobility and pain, and "gaps" that lead to a perceived need for treatment (Box 2). An unexpected concern to be associated with hypodontia was an increased risk of cancer from American users on Reddit and Twitter (Box 3). Microdontia was the only other condition known by users to be associated with hypodontia.

Individual's response to coping and adapting to hypodontia was variable and there was evidence that parents may feel experience greater difficulties in coping than the affected child (Box 4). Other people showed a more positive response, suggesting adaptation to even severe forms of hypodontia is possible: "It is hard to adapt to oligodontia, but it can be done" [Tw37]. Users demonstrated acceptance of the condition, with one even planning to celebrate their condition with a tattoo, and there was a strong desire to support others through their journey. The positive role of popular culture figures in increasing the awareness of the condition was highlighted. Interestingly one character discussed, a young person called Dustin in a series called Stranger Things, actually has Cleidocranial Dysplasia not hypodontia.

Impact of untreated hypodontia

There were numerous posts pertaining to the overwhelmingly negative psychosocial effects of untreated hypodontia. These included impacts on behaviour, such as smiling, wellbeing and social interactions, and concerns about stigma, bullying and a lack of understanding by others (Box 5).

2. Experience of treatment

Types of hypodontia treatment

A number of treatment types were reported including restorative treatment (onlays, veneers and crowns), orthodontic treatment ("braces"), oral surgery (extractions, bone graft) and dental implants. The terminology used was often graphic and aggressive, particularly around removal of teeth and implant placement: "I had 8 teeth yanked, 8 holes drilled into my jaw..." [R11] and "Four titanium rods screwed into my jawbone" [I4]. Ambiguous terms such as "dental bonding" [R3] were used, which could mean placement of fixed appliances or a range of restorative treatments such as composite camouflage, veneers or adhesive fixed prosthesis.

Service delivery

Only two topics were discussed in relation to the delivery of care, treatment time and cost (Box 6). The posts emphasised that people receiving treatment often perceive it to be long and complex. Cost was the most commonly discussed barrier to care, particularly for users who were North America-based, and two links were identified on Twitter for people with oligodontia who were fundraising for their treatment. UK users highlighted previous lack of awareness or current uncertainty about the impact of hypodontia on eligibility for NHS treatment.

Impact of treatment

Receiving hypodontia treatment was reported to have positive and negative psychological impacts. People expressed excitement at treatment progress: "I get my teeth put on in a week or two!! I'm so excited" [R16], "Can't wait to get my dentures" [T13] and "Getting surgery next month....I'm pretty hype" [I13], but others expressed negative experience at their treatment stage: "Can't wait to throw this denture in the bin" [I25]. There was evidence that treatment could evoke an emotional response "Appointment number 2 at the dental hospital today – at least I didn't cry in the ladies room this time! #oligodontia" [Tw38] and others used humour to explain their experiences: "Was taunted with sweet metal teeth, which were soon after ripped away from me with the promise of boring normal coloured teeth later. I was not pleased" [I5] and "Just got these badass braces, I feel shhhuper shhhexy ngl" [I34].

The social impacts of treatment included missing out on social events, feeling selfconscious in front of people and experiencing negative reactions from others, often as a consequence of physical effects such as lisping, post-operative complications and discomfort (Box 7). People expressed hopes about the treatment process: “Hopefully it will be a smooth process” [T6] and “Really excited, but nervous at the same time!...Hopefully all goes well!” [I7]. Coping strategies included self-reward “So I treated myself...earrings... because this past week has sucked” [T18], support from colleagues “First of all I love my boss. Having someone be so supportive and kind is so important” [T17], family “My family was very supportive of me from a young age and found the best possible solution to give me a smile I would be proud of” [I40] and strangers “Also someone on Instagram drew me? They used one of my selfies as a reference and actually drew me? That’s f**king awesome???!!!” [T17], and sharing their experience with others “With this account, I want to give the world a glimpse into my daily life as a young adult with false teeth” [I40].

3. Outcomes from treatment

Outcomes from treatment were framed as expectations or actual effects. The expected outcomes included physical effects of treatment “expand my teeth....raise my molars up...prop up my jaw...correct my deep bite... adjust the misaligned teeth...” [R8] and the benefits that these effects would bring: “keep my child smiling and eating properly” [R14] and “smile properly and confidently again!!!” [I11]. Others had very high expectations of the impact of treatment “life changing once completed” [I14] and “Massive #thankyou to everyone who's involved, you are literally going to change my life!!” [I17] or simply a desire to be ‘normal’ “Four to five years of various dental procedures, and I'll have a mouth that resembles that of a person” [I24].

The actual outcomes were overwhelmingly positive and related to perceived health benefits and improved psychological wellbeing (Box 8). Negative comments included the lack of permanence of treatment and need for more treatment “I thought my dental bonding to fix this embarrassing problem would be the end of my troubles, but I guess not” [R3], biological complications “The gum around and underneath one of my fake teeth is all nasty as infected and is receding, great probably gum disease yay for hypodontia” [Tw34] and technical complications “When your tooth falls out the day before a public reading and the implant post is exposed. #oligodontia” [Tw36].

4. Decision-making around treatment

The final theme to emerge related to decision-making, namely seeking advice about treatment need and the decision to have treatment. There was evidence that people felt uninformed about the need for treatment, options for treatment and the 'best' treatment (Box 9). The choice to have treatment was portrayed as a necessity to be normal "So, to compete as a human being in American society...." [R11] while others appeared active participants in the choice "Now, there are a lot of options one can take in this situation, but I chose the hardest one with the best payoff: to pull the baby teeth, get implants, and then crowns." [T4] and "I can't believe I decided to change my teeth. I'll miss you, my special, unique spaces. (ha. not really tho.)" [T5]. A common topic was delay in decision-making due to fear: "I delayed progressing with treatment because of the shock of that information" [R17] and "Not you're average Friday afternoon.....today I had something done that I've put off for years" [I4].

Discussion

Evidence-based dentistry (EBD) aims to combine high quality evidence with understanding around patient needs and values to deliver optimal care. This study used modern communication methods to obtain information about patient experience, values and needs for integration into EBD. In accordance with previous work[1, 2], this study found social media appears to fulfil two key functions for patients and their families; to address information needs and provide peer support. All too often research dissemination involves creation of a webpage, however, this study reveals a much wider opportunity for using online communication methods.

Information needs included uncertainty around the condition and its treatment in terms of treatment options, impact and effect. The reaction of users in relation to the unpredictable longevity and eventual failure of retained primary teeth and the unexpected impact from treatment suggests an inadequacy in preparing patients for the effects of hypodontia. Concern around the association between hypodontia and cancer highlights both the difficulties in disseminating complex research to those affected and the 'echo chamber' effect[20] that can rapidly build up in online communities. Online environments enable rapid and far-reaching dissemination of information with active patient involvement, however, this opportunity can become a threat if the quality and accuracy of shared information is poor and undue credibility is given to individuals who post medical advice and tips.[21]

Across all themes the desire to share experiences, find and provide support was evident. This ranged from coping with the diagnosis to gaining practical advice about treatment costs, making treatment decisions and opinions about the experience and outcome. Obtaining information from online forums about more sensitive topics, such as stigma and psychosocial effects, may enable clinicians to offer opportunities in consultations that encourage greater patient engagement. Dental care has historically been paternalistic, with an emphasis on outcomes rather than process, and dentists may underestimate the need for support, yet satisfaction with care is determined by treatment experience and effective patient-professional interactions.[22] A better understanding of experience and provision of support to dental patients is likely to improve patient-reported outcomes.

Previous studies of Twitter to explore patient experience support that it is a valuable tool for obtaining information directly from patients. A study of Twitter exploring the impact of third molar experience categorised tweets into quality of life domains and found frequently reported impacts around physical and psychological wellbeing, daily activities and social life. Interestingly, the quality of life impacts found through Twitter were not fully represented in generic quality of life measurement tools, highlighting the scope for gaining condition-specific information from social media[18]. A study of orthodontic-related Twitter posts categorised tweets into 4 domains; excitement at getting the braces off, problems with braces, positive comments and negative comments about braces. This study also emphasised social media as a tool for seeking and providing peer support[16]. A third Twitter study compared two different orthodontic treatments by categorising the tweets into positive and negative sentiment. This highlighted the diversity in patient experience and the volume of data available through Twitter[17].

The majority of content relating to experience was polarised, with users being either well-adapted to their condition and positively sharing their experience, or those who were struggling to understand and accept the condition. This highlights a limitation of social media for research purposes, as self-selection bias would potentially result in skewed population. Existing content in online environments may arise from more active participants who wish to express strong opinions or share unusual experience. “Lurkers” are people who consume content on social media without active engagement. There are many reasons for lurking, including feeling uncomfortable in public, communication overload, wishing to learn from the group and build an identity, fear of responses, a perceived lack of need to participate and group and personal characteristcs.[23] While lurkers may still benefit from social media, it is not possible to know their opinions, experiences and needs, which may differ significantly from those that are seen.

Analysis of the communications around dental experience has identified two key barriers to implementation of evidence-based care; dissemination of understandable information to patients and awareness of patient needs. To integrate this information into evidence-based clinical practice recommendations have been made (Table 4). It should be noted that it was not possible to determine the user demographics for the majority of the data, so further research is needed to determine the generalisability of the recommendations. The location of users was difficult to confirm although the posts or other accessible personal information indicated most were from the USA, with fewer posts from Canada and the UK. The user location and subsequent health care and social system in which the users lives will affect experience of hypodontia care.

Limitations in this method should be considered when interpreting the result. The 167 records arose from 80 unique users, meaning some users posted multiple times. This may be criticised for over-emphasising certain individual's experience, however, qualitative research does not expect the sample to be able to represent all views but rather provide a diversity of experience. Facebook and Instagram reported more hits than were accessible to view and this was attributed to privacy settings restricting access. This may affect the results, as posts that are shared privately may demonstrate different opinions or experiences to those shared publically. The study was limited to analysis of written content and posts from non-professionals. Further studies are warranted to analyse multimedia content, as this is likely to produce complementary data and indicate the role of non-written communication. Examining how dental professionals use online social media platforms would highlight how professionals respond to posts from the public and also assess whether ethical and advertising standards are being met. The ethics of using individual's personal posts from social media networks as research data is yet to be debated. Advice sought from the University of Leeds Dental Research Ethic Committee for this study indicated no ethical approval was required for use of data obtained from publically available sources. However, as the methodology for using social media as a research tool develops further it is likely that an ethical code of conduct will be required to ensure individuals are protected.

Conclusions

Social media online environments are used by patients and their families to address their need for information exchange and peer support. This knowledge can be integrated into evidence-based dentistry through practical recommendations for individual patient care and by driving changes to address patient needs at a service level. Patient-centered e-health (PCEH) is the use of Internet-based technology to deliver patient-centered health services through patient focus, patient participation and patient empowerment. Social media is a valuable tool in PCEH, however, there are challenges ahead for assuring quality information sharing, maintaining confidence in the patient-professional relationship, encouraging participation of less engaged groups and protecting the privacy and confidentiality of those wishing to share personal experience.

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