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#CleftProud: A content analysis and online survey of two cleft lip and palate Facebook groups

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Keywords:	Parental perception, Psychosocial adjustment, Quality of life, Social support
Abstract:	<p>Background: More than two billion people worldwide now use social networking sites (SNSs), with an increasing number of users accessing these sites to obtain health information and access peer support. Yet, investigation of SNSs in the context of cleft lip and/or palate (CL/P) has been scarce.</p> <p>Methods: Real-time data posted during two weeks in April 2017 were collected from two existing Facebook groups hosted by the Cleft Lip and Palate Association (CLAPA, UK) using video screen-capture software. The number of posts, comments, unique contributors, and post 'likes' were recorded, as well as the type and theme of each post. Data relating to the benefits and challenges of participation in the two groups were also collected via an online survey.</p> <p>Results: A content analysis of real-time data identified perioperative care, associated syndromes and dental health to be particular areas of concern for parents/caregivers. Expectations, experiences and outcomes of further treatment were key topics of discussion for adults with CL/P. Common benefits of the groups included the ability to connect with others, learn about local events, give and receive emotional support, and obtain quick responses to queries in a semi-anonymous environment. Disadvantages of the groups included a reliance upon opinion rather than medical fact, and the frequent use of inappropriate terminology.</p> <p>Conclusions: SNSs appear to be a helpful source of health-related information and peer support for the CL/P population, yet closer monitoring of these groups may be required.</p> <p>Key words: cleft lip and palate, Facebook, social networking, quality of life, support groups</p>

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For Peer Review

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**#CleftProud: A content analysis and online survey of two cleft lip and
palate Facebook groups**

For Peer Review

Abstract

Background: More than two billion people worldwide now use social networking sites (SNSs), with an increasing number of users accessing these sites to obtain health information and engage in emotional support. Yet, investigation of SNSs in the context of cleft lip and/or palate (CL/P) has been scarce.

Methods: Real-time data posted during two weeks in April 2017 were collected from two existing private Facebook groups hosted by the Cleft Lip and Palate Association (CLAPA, UK) using video screen-capture software. The number of posts, comments, unique contributors, and post 'likes' were recorded, as well as the type and theme of each post. Data relating to the benefits and challenges of participation in the two groups was also collected via an online survey.

Results: A content analysis of real-time data identified perioperative care, associated syndromes, and dental health to be particular areas of concern for parents/caregivers. Expectations, experiences, and outcomes of further treatment were key topics of discussion for adults with CL/P. Common benefits of the groups included the ability to connect with others, learn about local events, give and receive emotional support, and obtain quick responses to queries in a semi-anonymous environment. Disadvantages of the groups included a reliance upon opinion rather than medical fact, and the frequent use of inappropriate terminology.

Conclusions: SNSs appear to be a helpful source of health-related information and peer support for the CL/P population, yet closer monitoring of these groups may be required.

Key words: cleft lip and palate, Facebook, social networking, quality of life, support groups

Introduction

In the last decade, social networking sites (SNSs) have gathered astonishing momentum. According to the online statistics portal Statistica (2017), more than two billion people worldwide now use social media. These online communities allow registered users to create profiles, generate content, connect with others via public and private messages, and share photographs, weblinks, and video (Centers for Disease Control and Prevention, 2017). Facebook® is currently the biggest SNS in the world, having accumulated over 1.9 billion users since its launch in 2004 (Statistica, 2017).

Increasingly, SNSs are being increasingly utilized for the purposes of sharing health information (Farmer et al., 2009). Recent studies in the field of chronic conditions have found affected patients and their family members to utilize Facebook forums for the sharing of personal experiences, to request disease-specific guidance, and to give and receive emotional support (Greene et al., 2010; Bender et al., 2011; Merolli et al., 2013). Some previous research has suggested that use of these online communities can result in patients feeling more informed, more confident in their relationships with their physicians, more optimistic in their outlook in relation to their condition, and more socially accepted (van Uden-Kraan et al., 2008; Bartlett and Coulson, 2011); however, understanding of the use of SNSs for health-related purposes remains limited (Merolli et al., 2013).

A cleft lip and/or palate (CL/P) is one of the most common congenital conditions in the world, affecting one in every 600 live births each year (World Health Organization, 2012). Whether antenatal or postnatal, the diagnostic experience is an emotionally demanding time for families, who often express concerns for the child's future (Nelson et al., 2012). As the child grows up, complex multidisciplinary care is liable to form an underlying and unremitting stressor in the family's lives. The cleft can also pose a number of social, emotional and developmental difficulties for those affected, with potential long-term implications for social integration, educational and vocational achievement, and physical and mental health (Stock and Feragen, 2016). Although the routine care pathway typically ends around the age of 18 to 21 years, CL/P is considered to be a lifelong condition, with some patients continuing to experience challenges during adulthood (Stock et al., 2015). Access to appropriate support for all patients and their families across the lifespan is therefore vital to facilitate psychological adjustment and patient-led condition management.

In the UK, the Cleft Lip and Palate Association (CLAPA) is the only national charity dedicated to supporting all those with and affected by CL/P. They represent the voice of patients, families, and a multitude of Health Professionals working in the field. Alongside the multidisciplinary services provided by the UK's seventeen specialist clinical teams, CLAPA's aim is to further improve the quality of life of all those affected by providing effective complementary services in all sectors of the community. In September 2009, CLAPA launched their first Facebook forum, serving two main functions: 1) for support to be given and received mutually between group members and 2) for relevant events and services to be

1 shared and promoted. This initial forum was directed toward parents/caregivers of children born with
2 CL/P. CLAPA subsequently launched two additional forums, one for adults affected by CL/P in
3 December 2011 (aged 18 years and older), and one for young people born with CL/P (aged 13-17 years)
4 in May 2012. Although these groups were set up to support individuals based in the UK, members
5 currently include users from all over the world. In combination, these three groups now comprise more
6 than 10,000 members.
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10 To date, investigation into the use of social media in the context of CL/P is limited to one published
11 study. This study collected 25 survey responses from parents/caregivers of children born with CL/P who
12 were receiving treatment at one craniofacial centre in the United States (Khoury et al., in press). Data
13 included the type of social media used in relation to their child's condition, the point at which the parents
14 had first accessed these sites, the frequency of the parents' social media participation, and their
15 experiences of using SNSs for health purposes. The findings indicated that parents were most likely to
16 use SNSs for educational purposes, as well as companionship and support. As the first of its kind, this
17 study provides important insight into the use of social media among the CL/P population, yet is limited in
18 its sample and scope. In-depth investigation into the content of real-time posts in existing Facebook
19 groups, as well as analysis of the benefits and challenges of these groups according to both
20 parents/caregivers and patients, may provide further understanding of how these SNSs are utilized, and
21 insight into aspects of the condition not previously explored by more traditional methodological
22 approaches.
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32 The primary aim of the present study was to evaluate the contribution of SNSs as a means of health-
33 related information and peer support for the CL/P population. The secondary aim was to identify
34 common topics discussed in the Facebook groups which may provide a focus for future CL/P research
35 and/or intervention.
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42 **Methods**

43 *Procedure*

44 Initially, data were sought from all three Facebook groups managed by CLAPA; parents/caregivers,
45 young people, and adults. Unfortunately, while a wealth of data was available from the parent/caregiver
46 and adult sites, the Facebook group aimed at young people was much less active. The decision was
47 therefore made to concentrate on the two groups presenting with the most data.
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53 In order for real-time data to be collected from the groups, a screen capture programme was used
54 ('SnagIt'). This program creates a video while the researcher scrolls down the Facebook page, clicking
55 on links to reveal additional posts and comments where necessary. This method of data collection allows
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1 for large amounts of real-time data to be captured efficiently, and for data to be coded reliably at a later
2 date.
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4 Data were collected over two weeks during the month of April 2017. A coding protocol (Figure 1) was
5 developed, whereby the total number of posts, comments, post 'likes', and unique contributors were
6 documented. Content analysis was performed by the first author to identify the type and theme of each
7 post. This type of analysis is deemed appropriate when the aim of a study is to succinctly summarize a
8 large body of qualitative data, and when existing theory or research literature on a given phenomenon is
9 limited (see Neuendorf, 2016). First, the data were read and re-read, to establish an overall picture.
10 Following the coding protocol, the 'type' and 'theme' of each post was then categorized. The 'type' of
11 post was defined as 'the purpose of the post', for example, to request information. The 'theme' of the
12 post was defined as 'the main subject of the post', for example, reconstructive surgery. Any posts
13 considered to be irrelevant (i.e. not concerned with CL/P) were excluded. A subset of the data was also
14 coded by a second researcher to assess reliability. Given that the recommended sample for reliability
15 assessment is 30 units (see Lombard et al., 2002), 50 percent of the data were subject to dual coding (80
16 posts by parents; 36 posts by adults with CL/P). These categories were compared using Krippendorff's
17 alpha (Krippendorff, 2011), and initial coding reached satisfactory agreement ($\alpha \geq .898$). Any
18 discrepancies were subsequently discussed by both researchers until full agreement was reached. Finally,
19 frequency counts were calculated and exemplar quotes were selected to illustrate each category.
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31 In addition, an online survey, open to all members of both CLAPA Facebook groups was developed by
32 the authors. The survey was hosted via a secure survey administration website, Qualtrics (see
33 www.qualtrics.com). The link to the survey was posted at regular weekly intervals in both Facebook
34 groups during the study period, to ensure the survey remained prominent in the Facebook feed. As well
35 as demographic information and data relating to the length and breadth of Facebook use, open-ended
36 questions asked about the benefits and challenges of participation in the CLAPA groups. A list of
37 questions included in the online survey is shown in Table 1. Descriptive statistics were carried out on the
38 closed questions, while content analysis was performed on the qualitative data derived from the two open-
39 ended questions. Again, the data were read and re-read, to establish an overall picture, and descriptive
40 notes were made on each response. According to the steps proposed by Neuendorf (2016), similar
41 responses were then grouped together, and twelve main categories were identified. Initial coding reached
42 satisfactory agreement according to Krippendorff's alpha ($\alpha \geq .915$).
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51 *Participants*

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53 At the time of data collection, the parent/caregiver group consisted of 8,348 members, while the group for
54 adults affected by CL/P had 1,579 members. Unique contributors to the data collected during the
55 specified two-week period included 150 parents/caregivers and 64 adults affected by CL/P.
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1 Online survey participants included 39 UK-based parents/caregivers and 22 UK-based adults affected by
2 CL/P. Parents/caregivers were predominantly mothers (77%), identifying as 'White British' (87%), with
3 no known history of CL/P in the family (85%). These survey participants were aged between 26-53 years
4 (mean = 38.5 years; mode = 35 years), and were parents/caregivers to children who were aged between
5 one month-22 years (mean = 6.8 years; mode = 5 years). Adult survey participants were predominantly
6 female (64%), identifying as 'White British' (77%), with no known history of CL/P in the family (73%).
7 These survey participants were aged between 24-57 years (mean = 38.9 years; mode = 37 years). Sixty-
8 four percent of adults had been born with a cleft lip and palate, 18 percent had been born with a cleft
9 palate only, and 18 percent had been born with a cleft lip only.

15 *Ethical considerations*

16 Although ethical issues in regard to utilizing data posted on social media remain contentious, there is an
17 overall view that analysis of SNSs is acceptable, provided that researchers obtain permission from the site
18 administrators, that all of the data collected remains anonymous and untraceable, and that the research is
19 conducted in the interests of the community (Holtz et al., 2012; British Psychological Society, 2013;
20 Golder et al., 2017). In the case of the present study, permission to collect data from both CLAPA
21 Facebook groups, which are closed to the public, was sought from senior staff at CLAPA. Participants of
22 the online survey were asked to indicate their informed consent for their survey responses to be used for
23 research purposes, prior to providing any data. Only the authors had access to the survey results. Ethical
24 approval to carry out the study was obtained via the Faculty of Health and Applied Sciences at the
25 University of the West of England, Bristol, UK.

36 **Results**

37 The following results section provides an overview of the common types and themes of posts shared by
38 Facebook group members during the study period. Table 2 summarizes the types and themes of posts
39 identified, alongside relative frequencies and exemplar quotes. Table 3 illustrates the perceived benefits
40 and challenges of using the Facebook groups, according to online survey participants.

46 *Facebook group for parents/caregivers*

48 Facebook data capture

49 Throughout the two weeks recorded during the month of April 2017, 161 posts were shared by
50 parents/caregivers, predominantly by mothers of young children (66%). Other users who posted
51 infrequently in the group included pregnant mothers, mothers of adolescents, fathers, and grandparents.
52 The most common type of post focused on the sharing of experiences (42%). This most often related to
53 the sharing of good news, or positive messages (24%), as well as expressions of gratitude for the support
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1 offered by the group. These posts were undoubtedly the most popular with other users, receiving a total
2 of 3,709 'likes' and 235 comments. Usually, these comments wished the user well. Parents/caregivers
3 also frequently shared their experiences of their child's primary lip or palate repair (18%). Typically,
4 these posts were accompanied by pre- and post-operative photographs. These posts received 1,806 'likes'
5 and 267 comments. Other users commonly responded to these posts by sharing their own experiences of
6 their child's treatment, including photographs, and offering emotional support.
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10 The second most common type of post asked for guidance from other users (40%). These posts received
11 499 'likes' and 852 comments. Twelve percent of these posts asked other users for guidance on post-
12 operative care, either following a primary cleft repair, or following a bone graft operation. Six percent of
13 posts focused on the etiology of CL/P, or on the diagnosis of associated syndromes. One post, discussing
14 the decision of whether to have an amniocentesis performed during pregnancy, received a particularly
15 high number of comments ($n = 179$). Five percent of posts concentrated on children's dental hygiene.
16 Other posts asking for guidance focused on feeding practices (including how to combat reflux; 3%), ear
17 or respiratory infections (2%), practical information (such as asking for a nurse's contact number; 2%),
18 speech development (1%) or other issues, such as whether it was advisable to take a baby with a cleft
19 onto an aeroplane (9%). Other users responding to posts which asked for guidance usually offered
20 practical information, often referring to examples from their own experience.
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29 The third most common type of post was related to advertising, either promoting an event (11%) or a
30 product (7%). These posts received 133 'likes' and 39 comments.
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33 Of the total 161 posts by parents/caregivers, 58 percent included a photograph(s). Of these, 26 percent of
34 posts included close-ups of the child's face, or were taken of the inside of the child's mouth. One of these
35 photographs showed a 3D scan image of a baby in utero. Fourteen percent of posts included 'then and
36 now' photographs, typically documenting the journey from birth to early childhood. A further 30 percent
37 posts included full body photographs, usually of children engaged in an activity, and six percent of
38 photographs depicted the child with friends and family. Three percent of users posted videos of their
39 child playing. The remaining 21 percent of photographs showed an inanimate object.
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45 Online survey

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47 Thirty-nine parents/caregivers participated in the online survey. The majority of participants had first
48 learned about the CLAPA Facebook group from an online search (33%), while others had first heard
49 about the group from their specialist cleft nurse (21%), or from the CLAPA website (18%). A minority
50 of parents/caregivers had learned about the group from the CLAPA Welcome Pack, which is distributed
51 in the weeks following a diagnosis (8%). Five percent of parents/caregivers were told about the group by
52 another parent/caregiver of a child with CL/P. Three percent had heard about the group directly from a
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1 member of CLAPA staff, while a further three percent had been told about the group by another member
2 of the NHS cleft team. Nine percent of participants did not specify.
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4 Most of the parents/caregivers who participated in this survey had learned about the group shortly after
5 their child's diagnosis (67%), while a minority of parents/caregivers had learned of the group at a
6 subsequent hospital appointment (8%) or via the CLAPA Parent Supporters Service
7 (www.clapa.com/clapa-parent-contacts; 2%). Twenty-three percent of participants stated that they hadn't
8 learned of the group until their child was aged three years or older.
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13 The majority of participants had been a member of the CLAPA Facebook group for parents/caregivers for
14 more than two years (72%). Twelve percent of parents/caregivers had been a member of the group for
15 between one and two years. Eight percent had been a member of the group for between six months and
16 one year, and another eight percent for between one month and six months.
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20 When asked what they believed the main benefits of the Facebook group to be, the most commonly
21 reported response was to connect with other parents/caregivers who are in a similar situation (51%).
22 Many participants also believed that the group was helpful for learning about/advertising local events and
23 fundraising opportunities (44%) and keeping up-to-date with the latest research (23%). Thirty-six percent
24 of participants cited emotional support to be a benefit of the group. Parents/caregivers also believed that
25 the ability to share their own experiences was a benefit of the group (15%). Fifty percent of
26 parents/caregivers also believed one of the main benefits of the group to be the opportunity to ask
27 questions, and to receive a quick response. This guidance was seen to be most valuable when offered by
28 parents/caregivers whose children were further along the treatment pathway. Twenty-one percent of
29 participants specifically commented on the usefulness of available information regarding treatment
30 outcomes. Eight percent also commented on the private nature of the group, and the opportunity to
31 discuss topics that they didn't always feel they could raise with health professionals. Finally,
32 parents/caregivers stated that their engagement with the CLAPA Facebook group made them feel more
33 likely to fundraise and/or make a donation to the charity (87%), and more connected to the charity as a
34 whole (82%).
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45 A number of challenges related to the Facebook group were also identified by survey participants. The
46 most commonly reported difficulty (23%) was that the information shared within the group could not
47 always be relied upon. In addition, some participants commented that given the number of CL/P support
48 groups on Facebook, it could be difficult to know which groups were official (13%). Parents/caregivers
49 also raised the issue of the use of inappropriate, outdated, or offensive language/terminology (31%), or
50 posts that were considered to be overly-negative (8%). Consequently, participants commented on the
51 need for better monitoring of the Facebook group by trained administrators (44%), and felt better
52 screening of potential members was necessary (10%). Similarly, eight percent of participants suggested
53 that legitimate activities and research opportunities could be made more visible in the group.
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Facebook group for adults affected by CL/P

Facebook data capture

Throughout the two weeks recorded during the month of April 2017, 71 posts were shared by adults affected by CL/P. Posts were predominantly submitted by female users (87%). The most common type of post was focused on the sharing of experiences (52%). This most often related to the sharing of good news, or positive messages (29%). These posts were also the most popular with other users, receiving a total of 640 'likes' and 93 comments. Usually, these comments were intended to congratulate the user, or wish them well. Adults affected by CL/P also frequently shared their intentions to return to treatment (15%). These posts received 121 'likes' and 26 comments. Eight percent of adults shared their dissatisfaction with treatment outcomes. Many of these posts were related to aesthetic outcomes, and users often asked other users to evaluate their pre and/or post-op appearance.

The second most common posts were those asking for guidance from other users (31%). Overwhelmingly, this related to queries about CL/P treatment (27%), including how to access medical treatment or information (14%). These posts received 162 'likes' and 204 comments. Users also enquired about other people's experiences of the various available treatments, and how to prepare for an upcoming operation (13%). Other users typically responded by sharing their own experiences and offering guidance, while a minority also offered practical support. A few queries (4%) were related to how to deal with feelings of discrimination, and how to raise awareness among members of the public. These posts received 20 'likes' and 45 comments. Comments on these posts included other users sharing their own experiences of perceived stigma, and offering guidance and/or emotional support.

The third most common type of post was related to advertising, either in regard to promoting an event (11%) or a product (6%). These posts received 103 'likes' and 13 comments.

Of the total 71 posts by adults affected by CL/P, 49 percent included a photograph(s). Of these, 54 percent of posts included close-up images of one or more angles of the user's face, taken by the user themselves. A further 20 percent showed a full-body photograph of the user with friends or family taken by others, and 26 percent showed an inanimate object.

Online survey

Twenty-two adults affected by CL/P participated in the online survey. The majority of participants had first learned about the CLAPA Facebook group from an online search (68%), while others had first heard about the group at a hospital appointment (9%), at a CLAPA event (9%), from the CLAPA website (9%), or via the CLAPA Peer Supporters Service (www.clapa.com/peer-support; 5%).

1 The majority of participants had been a member of the CLAPA Facebook group for adults affected by
2 CL/P for more than two years (50%). Nine percent of adults had been a member of the group for between
3 one and two years, while eighteen percent had been a member of the group for between six months and
4 one year. Another 23 percent of participants had been a group member for between one month and six
5 months.
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9 When asked what they believed the main benefits of the Facebook group to be, the most commonly
10 reported response was to connect with other adults affected by CL/P (77%). A few participants also
11 believed the group was helpful for learning about/advertising local events and fundraising opportunities
12 (18%) and keeping up-to-date with the latest research (14%). Fifty-nine percent of participants cited
13 emotional support to be a benefit of the group. Adults affected by CL/P also believed that the ability to
14 share their own experiences was a benefit of the group (23%). Forty percent of participants believed one
15 of the main benefits of the group to be the opportunity to ask questions, particularly regarding treatment
16 outcomes (27%). Five percent also commented that it was quick and easy to get in touch with peers.
17 Finally, adults affected by CL/P stated that their engagement with the CLAPA Facebook group made
18 them feel more likely to fundraise and/or make a donation (64%), and more connected to the charity as a
19 whole (86%).
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27 Several challenges related to the Facebook group were also identified by survey participants. The most
28 commonly reported difficulty was that misinformation could often be shared (64%). In response,
29 participants commented on the need for better monitoring of the Facebook group by trained
30 administrators (45%), including the need to ensure the use of appropriate language (21%). In addition,
31 participants felt that UK and 'global' users should be separated (27%). Fourteen percent of adults also
32 suggested that legitimate events and research opportunities could be made more visible in the group.
33 Finally, some participants commented that posts could be sometimes by overly negative (18%).
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42 **Discussion**

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44 This study is the first to carry out in-depth investigation into the content of real-time posts in two existing
45 Facebook groups, as well as analysis of the benefits and challenges of these groups according to both
46 parents/caregivers and adult patients. The aims of this study were to evaluate the contribution of SNSs as
47 a means of health-related information and peer support for the CL/P population and to identify common
48 topics discussed in the Facebook groups which may provide a focus for future CL/P research and/or
49 intervention.
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54 *The contribution of SNSs*

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56 The most frequent type of post across both the parent/caregiver and adult groups were those which shared
57 personal experiences. Often, this included sharing a positive message, or recent experiences of treatment,
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1 along with a photograph(s). Accordingly, survey participants identified the main benefits of the groups to
2 be the opportunity to connect with others in a similar position, and to see how other people are
3 progressing, particularly in relation to treatment outcomes. Facebook users also accessed the CLAPA
4 groups to ask others for guidance. Although survey participants generally felt this guidance was
5 informative, provided emotional support, and could be accessed quickly, they were also concerned that
6 this information was based upon opinion rather than medical fact and that posts by different members
7 could offer conflicting guidance. Other positive outcomes of the group included learning about research
8 opportunities and events, having an increased connection with CLAPA, and experiencing a greater
9 motivation to fundraise. Yet, survey participants believed it to be difficult to identify which groups were
10 'official', felt that the UK users could be separately from those living elsewhere, and that more
11 appropriate terminology should be enforced. These findings suggest that while SNSs can be a helpful
12 source of condition-specific information and peer support, as well as offering promotional opportunities
13 for charitable organizations and researchers, closer monitoring of these groups may be warranted, to
14 ensure users access reliable information and feel comfortable in the online environment.

23 The results of this study add further insight to the previous social media study by Khouri and colleagues
24 (in press), as well as contributing to the wider body of research relating to the value of peer support in the
25 context of health conditions. Literature in the fields of mental health, disability, chronic illness, and other
26 craniofacial conditions have demonstrated the psychological benefits of both receiving and providing peer
27 support via telecommunication (Lauckner and Hutchinson, 2016), peer-led self-help groups (Mahlke et
28 al., 2014), mentoring programs (Tully et al., 2017), therapeutic residential weekends (Tiemens et al.,
29 2006), and support conferences (Bogart et al., 2016). The potentially positive impact of sharing
30 experiences with others in a similar situation has also been highlighted in both quantitative and qualitative
31 studies on CL/P specifically (e.g. Douglas, 2012; Stock et al., 2016). According to broader psychological
32 theories of stress and coping, perceived social support can help to buffer the negative effects of acute and
33 chronic stress. In the present study, many positive and motivational messages were shared across both
34 groups, which may have encouraged group members to appraise their situation more positively (Cohen
35 and Wills, 1985). In addition, the act of participating in group conversations and shared activities is
36 thought to impact positively on the regulation of emotions (Lakey and Orehek, 2011), while information-
37 sharing is known to increase a person's sense of control over their situation (Peterson et al., 1993). As the
38 groups appeared to have multiple functions (including offering emotional support and sharing
39 information), they are likely to encourage both emotion- and problem-focused coping (Lazarus and
40 Folkman, 1984), and appeal to members with a variety of concerns at numerous time points during their
41 journey. Group members were also keen to share their own experiences; a factor which has been
42 identified in the therapeutic reduction of depression and anxiety in other health populations (e.g. Klemm
43 et al., 2003). Taken together, these findings suggest that peer support is an important tool in the
44 facilitation of psychological adjustment, and offers a complementary method of support to that offered by

1 clinical teams. While more research on the mechanisms and consequences of peer support in this context
2 is needed, SNSs could provide an additional avenue to accessing this type of support.
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4 *Potential areas for further investigation*

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6 As also indicated by Khouri and colleagues (in press), one of the most frequently discussed topic in both
7 groups was that of CL/P treatment. Parents/caregivers' experiences of treatment were often positive, yet
8 there was evidence of procedural anxiety, and burden of ongoing care. Previous research has shown
9 parents to experience conflicting emotions in relation to their child's CL/P treatment, and in sanctioning
10 multiple surgeries (Nelson et al., 2012). Further, parents are acutely aware of the physical toll that
11 treatments take on their children, particularly in relation to post-surgical discomfort, and can find this
12 very distressing (Nelson et al., 2012). Parents/caregivers may therefore require additional resources and
13 professional emotional support to help them prepare for their child's treatment, and to manage the care of
14 their child post-operatively.
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16 For adults, discussions around treatment focused on the expectations, experiences, and outcomes of
17 returning to treatment in adulthood. Recent research has suggested that adults with CL/P may lack
18 awareness of the care they are entitled to during adulthood, and/or the knowledge of how to access further
19 treatment should they desire it (Stock et al., 2015). Social media may offer a new avenue by which adults
20 can access up-to-date information about their condition, learn about the treatment that is available to
21 them, and see images and testimonials of adults who have undergone additional surgeries. Yet, in the
22 Facebook group, several adults identified a tension between the need for self-acceptance and the desire to
23 improve their appearance through modern surgical techniques, with some explicitly stating their
24 dissatisfaction with recent surgical results. Further investigation is needed into adults' surgical
25 expectations, appearance concerns and psychological needs, as well as how to best facilitate fully
26 informed, shared decision-making between patients and health professionals (Cook et al., 2003).
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28 Another topic raised in the Facebook group for parents/caregivers was the complexity of genetics and the
29 challenges surrounding the diagnosis of associated conditions. A particularly emotive topic, these posts
30 highlighted the lack of research into the experiences of families who are affected by a syndrome, and/or
31 other conditions in addition to a cleft. It is possible that families also affected by an associated condition
32 may experience extra challenges. Further, previous research has suggested that patients with additional
33 conditions fare worse than their peers in regard to longer-term psychosocial outcomes (Feragen and
34 Stock, 2014). Studies have also emphasised the importance of access to genetic counseling for the
35 craniofacial population (Monlleó and Gil-da-Silva-Lopes, 2006), as well as appropriate follow-up to
36 facilitate the coping process (Broder and Trier, 1985; Li et al., 2016). The utilization of social media for
37 the purpose of seeking diagnostic information in the context of CL/P was also identified by Khouri et al.
38 (in press). Additional investigation into the experiences and support needs of this subpopulation is clearly
39 warranted, as is further research into the impact and management of the antenatal diagnosis.
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1 Also of concern for parents/caregivers was their children's dental health, where overcrowding, brushing,
2 and extraction of teeth appeared to cause distress for both children and their parents. Good oral hygiene
3 is especially important for children born with CL/P, since they are prone to dental caries and other
4 complications, yet understanding of best practice for these children is limited (Smallridge et al., 2015;
5 CRANE Database, 2016). Further research into the risk factors for dental caries, and the psychological
6 impact of poor oral health in the CL/P population is needed, to inform the development of resources and
7 guidelines for parents/caregivers. In addition, training of non-specialist dental practitioners may be
8 warranted to provide early intervention and specialist referral where necessary.
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14 Finally, a small number of posts in the group for adults with CL/P indicated that some patients may face
15 stigma in their adult years. The transition into adulthood involves interaction with new environments and
16 people, whether through the workplace or higher education. Given the lack of knowledge about CL/P
17 among the general public, and the negative attitudes often held toward those affected by appearance-
18 altering conditions (Goode et al., 2008; Pausch et al., 2016), adult patients may encounter comments,
19 questions, and inaccurate assumptions regarding their condition (Rumsey and Harcourt, 2004). An
20 investigation of adults' experiences of entering the workplace and/or higher educational setting, as well as
21 implementation of social skills training to prepare patients for difficult social situations (Kapp-Simon et
22 al., 2005), may be necessary.
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29 *Methodological considerations*

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31 Although a relatively new research methodology, internet-mediated studies have the potential to access
32 'naturally' occurring data, which are subject to fewer social constraints and are typical of the
33 community's discourse (Holtz et al., 2012). Analysis of real-time data collected from existing Facebook
34 groups, as well as an online survey eliciting users' views of the challenges and benefits of the groups has
35 provided unique insight into the way these groups are utilized, and the common topics that are discussed,
36 which may not otherwise be available. Nonetheless, a number of limitations of the present study must be
37 acknowledged. First, a limit of two weeks' worth of data were set for each group. Due to the large
38 amount of data available during this short time period, the authors considered further data collection to be
39 beyond the scale of the current study. Second, and despite the large membership of both groups, only a
40 small number of unique users shared posts (150/8,348 parent members and 64/1,579 adult members),
41 indicating that a considerable proportion of members did not actively contribute to the group during the
42 two-week study period. These observations suggests that the posts shared within the groups in the
43 specified time period may not be wholly representative of the group's membership, or of the CL/P
44 population. Future research could consider the triangulation of different information sources (Holtz et al.,
45 2012), as well as longitudinal analysis of SNSs, and/or a more in-depth investigation or conversational
46 analysis of the dynamic interactions that occur. Finally, it was not possible to capture data from the
47 Facebook group for young people with CL/P, due to the low level of current activity. Consideration of
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1 other forms of social media and/or peer support used by young people may be necessary to gain further
2 insight into the needs of this group.
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4 **Conclusions**

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6 This study is one of the few to evaluate the contribution of SNSs as a means for accessing health-related
7 information and peer support for patients affected by craniofacial conditions and their families. Despite a
8 number of clear benefits of these groups, closer monitoring by trained administrators may be required. In
9 addition, the identification of common issues discussed within both groups has highlighted a number of
10 potential areas for future research and/or clinical intervention.
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30 **Figure 1:** Coding protocol used to analyse extracted Facebook data from both groups

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32 **Table 1:** Questions included in the online survey advertised to both groups

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34 **Table 2:** Results of the content analysis of the Facebook data extracted from both groups

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37 **Table 3:** Benefits and challenges of using the Facebook groups according to online survey participants
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Figure 1

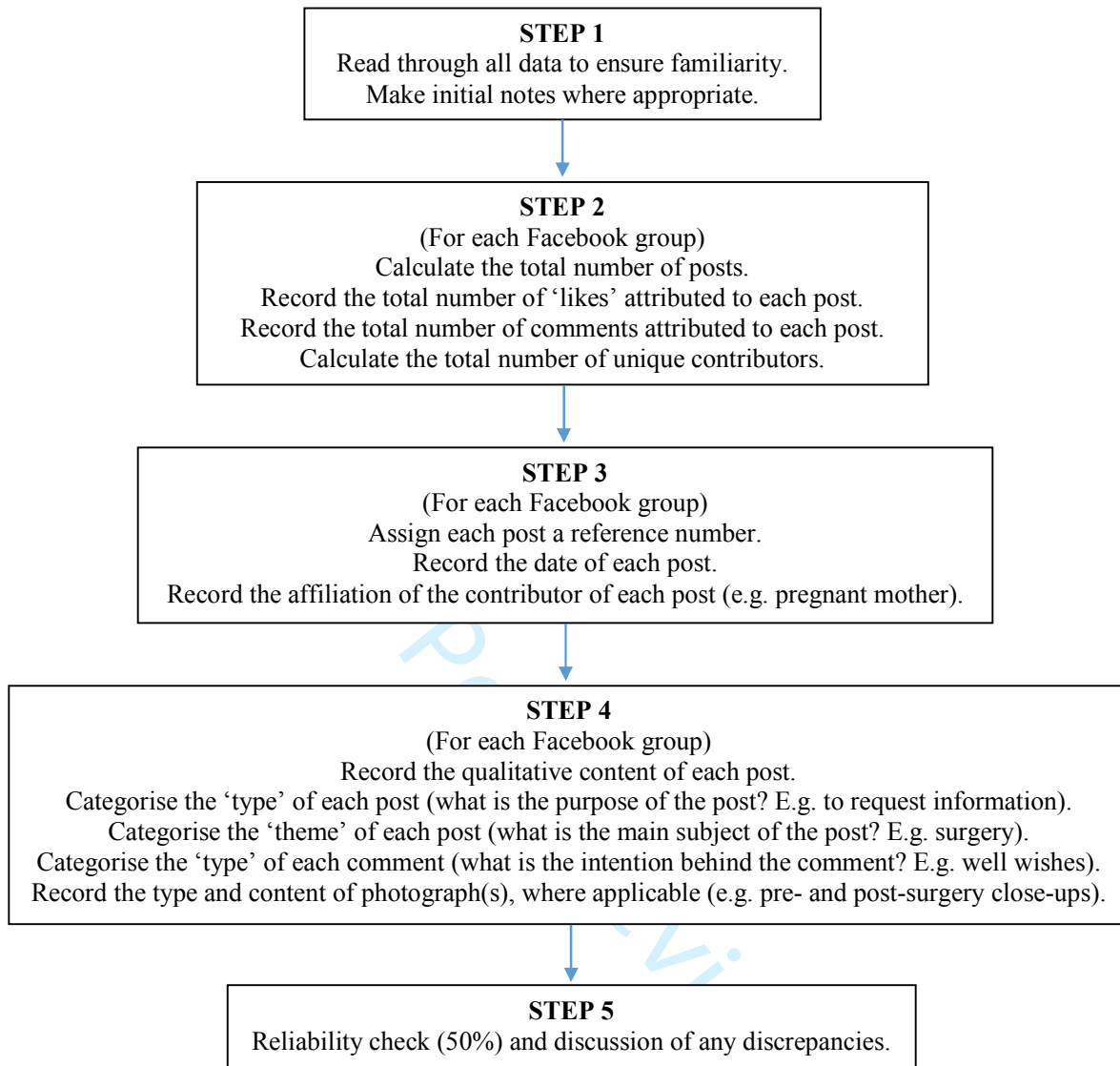


Table 1

Demographic information	Relationship to child (parents only) Gender Date of birth Ethnicity Cleft type (adults only) Child's date of birth (parents only) Family history of CL/P
Closed questions	How did you first learn about the CLAPA Facebook group? (12 response options) When did you first learn about the CLAPA Facebook group? (5 response options) For approximately how long have you been a member of the CLAPA Facebook group? (5 response options)
Open-ended questions	What do you think are the main benefits of using the CLAPA Facebook group? Is there anything you would change about the CLAPA Facebook group?

For Peer Review

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Table 2

Facebook group	Type of post	Theme of post (relative frequency)	Exemplar quotes
Parents/Caregivers	Sharing experiences (42%)	Positive messages (24%)	"It's not until I look back at my daughter when she was born that I realise just how much she has changed and remember what she has gone through in her short life. She is growing up to be a very caring and confident little girl and she makes me proud every day."
		Primary lip/palate repair (18%)	"My son underwent his first operation on Monday...I wanted to share a 'before and after' picture with you all, hoping that anyone who is waiting for the first operation gets a little comfort from it. This is four days after the operation and he is back to his usual happy, energetic self!"
	Asking for guidance/support (40%)	Post-operative care (12%)	"My son hasn't slept through the night since his palate repair just over a week ago. Anyone else experienced sleepless nights after an operation?"
		Aetiology/associated syndromes (6%)	"Anyone else gone through genetic testing? What did it involve and did your cleft team refer you?"
		Dental care (5%)	"Her teeth are so crowded, she complains of pain, and her teeth are starting to twist. I have spoken to her dentist but he doesn't seem to be concerned. What should I do?"
		Feeding practices (3%)	"My son is really struggling with food coming out of his nose and he isn't swallowing food properly. Can anyone offer any guidance? We've tried everything!"
		Ear/respiratory infections (2%)	"My little girl has constant ear infections...I'm running out of ideas. Does anyone else have this problem?"
		Practical information (2%)	"Does anyone know the number for the cleft nurse at (hospital)?"
		Speech development (1%)	"Did your little one need special surgery to help improve their speech? My son is 3.5 and is considered severely speech delayed."
	Advertising	Other (9%)	"Is it possible to take a one-year-old with cleft on a plane?"
Advertising an event (11%)		"Don't forget there's a sponsored walk this weekend to raise money for CLAPA!"	
		Advertising a product (7%)	"Hi everyone, I found this swimming cap online which is

	(18%)		supposed to be good for children who have had grommets.”
Adults with CL/P	Sharing experiences (52%)	Positive messages (29%)	"What a year! New teeth, new home, new job, now new hair. I may have had challenges to overcome but proud to say I am facing them."
		Intention to return to treatment (15%)	"Today was the first day of what I hope will be a successful journey...I have an appointment to see what can be done to improve the shape and breathing of my nose. I just want to thank everyone for...giving me the courage to return to the cleft team after 11 years away."
		Dissatisfaction with treatment outcomes (8%)	"Feeling really depressed with this fistula. After three operations it's still not fixed...don't think I can handle another op."
	Asking for guidance/support (31%)	How to access treatment/information (14%)	"Does anyone know if there is an adult cleft team in my area? ...I'm wanting advice on lip fillers and dental work that I may be eligible for."
		Other's experiences of treatment (13%)	"I'm super excited for my nose and lip to be re-repaired...but I'm scared how different I'll look. How did you feel about your appearance after a surgery?"
		Perceived stigma/discrimination (4%)	"One of those days where I'm looked at weird and treated as less by a co-worker who doesn't even know me...it gets me so mad. How are you supposed to deal with that?"
	Advertising (17%)	Advertising an event (11%)	"We are looking to arrange a CLAPA Adult Meet Up soon...anyone interested?"
		Advertising a product (6%)	"Now the kids are back at school I'm back to making my cuddly cleft toys. Click on the link to buy one now!"

Table 3

Perceived Benefits	Exemplar quotes
Connect with others (61%)	<p>“To speak to someone who has actually been through it themselves and to know you are not alone” (parent/caregiver)</p> <p>“It’s a community of people who have shared similar experiences...you can stay in touch and you feel less alone” (adult with CL/P)</p>
Learn about local events/opportunities (34%) and the latest research (20%)	<p>“It’s a great way to keep informed about what is going on in my area and nationally” (parent/caregiver)</p> <p>“It offers an environment where events can be shared and meet-ups can be arranged” (adult with CL/P)</p>
Emotional support (44%)	<p>“Emotional support from people who understand, and reassurance that everything will be OK” (parent/caregiver)</p> <p>“Sharing our struggles, learning how it affects others, receiving help with difficulties” (adult with CL/P)</p>
Opportunity to share own experiences (18%)	<p>“I can share my own experiences and my child’s progress in order to help others” (parent/caregiver)</p> <p>“I use it to help give others a boost and answer their questions if I can” (adult with CL/P)</p>
Receiving a response to queries (46%)	<p>“The forum is always open and you get an immediate response” (parent/caregiver)</p> <p>“It’s easy and instantaneous to get in touch with others” (adult with CL/P)</p>
Relative privacy (5%)	<p>“It bridges a gap by being semi-anonymous, especially for those who don’t want face-to-face support from their cleft team” (parent/caregiver)</p> <p>“I think the page is quite a safe and private space to talk about difficult issues” (adult with CL/P)</p>
Increased connection to the charity (79%) and more likely to fundraise (84%)	<p>“CLAPA is based in London and I live in (<i>city in the North of England</i>), so the Facebook page is a nice way to connect remotely” (parent/caregiver)</p> <p>“I feel part of a community and more likely to take part in activities or fundraising” (adult with CL/P)</p>
Perceived Challenges	Exemplar quotes
Information is unreliable (30%)	<p>“A lot of it is anecdotal advice and opinion as opposed to clinically accurate information” (parent/caregiver)</p> <p>“At times there is some incorrect information on there. There are also loads of cleft groups, so it’s quite hard to tell which one is official” (adult with CL/P)</p>
Inappropriate language/terminology used (28%)	<p>“I would have ‘People First’ language enforced with zero tolerance – also, words like ‘clefty’ and ‘hare lip’ appear on a regular basis” (parent/caregiver)</p> <p>“The terminology some people use is out-dated” (adult with CL/P)</p>
	<p>“There are so many posts it can be hard to find things” (parent/caregiver)</p>

<p>Important information can get lost (10%)</p>	<p>“Events and research opportunities get drowned out amongst all the other posts – any way of making them more prominent?” (adult with CL/P)</p>
<p>Potential members should be screened (16%)</p>	<p>“I think it needs more policing in terms of who can join” (parent/caregiver)</p> <p>“The non-UK members should possibly be steered away – it’s nice to share experiences but cultural differences can be awkward, especially because we have the National Health Service” (adult with CL/P)</p>
<p>Posts/comments can be overly-negative/unhelpful (13%)</p>	<p>“If someone says something well-meaning but unhelpful in a comment it can be quite upsetting” (parent/caregiver)</p> <p>“Some adults can be quite self-pitying...I find this really sad and want to help but it’s not helpful for me to see this all the time” (adult with CL/P)</p>

***Note:** Participants were able to provide more than one response; thus, the percentages do not equal 100. The percentages of parents/caregivers and adults have been combined above.