

Centralisation of cleft lip and palate services in the UK:

The views of adult ‘returners’

Abstract

Background: Since the implementation of centralised services in the UK for those affected by cleft lip and/or palate (CL/P), several studies have investigated the impact of service rationalisation on the delivery of care. While large-scale quantitative studies have demonstrated improvements in a range of patient outcomes, and smaller studies have reported on the benefits and challenges of centralisation from the views of health professionals, little research has attempted to capture the patient perspective. Further, few studies have investigated the views of adult ‘returners’ who have undergone treatment both pre- and post-centralisation.

Methods: Qualitative data relevant to the subject of this paper were extracted from two previous larger studies carried out between January 2013 and March 2014. A total of sixteen adults born with CL/P contributed data to the current study. These data were subjected to inductive thematic analysis.

Results: The findings suggest that centralisation of CL/P services has considerably enhanced the patient experience. Specifically, the overall standard and coordination of care has improved, service delivery has become more patient-centred, and access to professional psychological support and peer support has greatly improved patients’ capacity to cope with the associated emotional challenges.

Conclusions: The data collected provide additional insight into the impact of centralisation from the perspective of a largely unexplored patient population. In combination with other literature, these findings are also relevant to future efforts to centralise other specialist services around the world.

Keywords: centralisation, adult, patient perspective, qualitative, healthcare

Introduction

In the United Kingdom (UK) alone, more than one thousand children are born with a cleft lip and/or palate (CL/P) each year. In the last two decades, services for those affected by CL/P have undergone a significant reorganisation in the UK. Up until the late 1990s, cleft care was delivered in an uncoordinated manner by health professionals with a wide range of experience, leading to suboptimal surgical outcomes, restricted facial growth and poor speech (Sandy et al., 2001). Following the recommendations of both the Eurocleft study (Shaw et al., 1992) and the Clinical Standards Advisory Group report (CSAG; Sandy et al., 1998), a process of centralisation began in the UK, ultimately reducing the number of CL/P operating sites from 57 hospitals to eleven specialist clinical networks. In growing recognition of the psychological impact of CL/P on affected children and their families, a recommendation was also made for psychologists to be integrated into every cleft team (Sandy et al., 1998).

Since the implementation of these recommendations, several studies have investigated the impact of service rationalisation on a range of outcomes. Most notably, a repeat of the original CSAG study fifteen years on demonstrated improvements in children's dentofacial, audiological, speech, and psychosocial outcomes following the standardisation and centralisation of cleft services (Al-Ghatam et al., 2015; Smallridge et al., 2015; Sell et al., 2015; Waylen et al., 2015). In addition, an investigation of hospital episode statistics (Fitzsimons et al., 2012) identified a reduction in the length of hospital stays and more consistency in the timing of primary surgery repairs since the CSAG recommendations were executed. A small number of studies have also explored the impact of centralisation from the viewpoint of health professionals. Specifically, Searle and colleagues (2015) conducted individual interviews with eleven clinical directors of CL/P services in the UK, and found that, despite some ongoing concerns, centralisation has had a positive impact on care delivery. Similarly, Scott et al. (2014) reported that although some variations still exist in the way that cleft teams function, the overall adoption of a multidisciplinary model of care has been successful.

In contrast, little research has investigated post-centralisation CL/P services from the perspectives of patients and their families. While a report led by the UK-based charity, the Cleft Lip and Palate Association (CLAPA, 2007) reflected positive changes in the views of parents whose children had been born with CL/P, this survey has not been recently replicated. Further, only one previous study has specifically explored the views of adult patients with

experience of treatment both pre- and post-centralisation (Searle et al., 2017). Adult patients may return to CL/P services either for further treatment, or as a parent of a child who has also been diagnosed with CL/P. In order to contribute to the small body of literature on patient perceptions of CL/P services, and to offer a qualitative perspective from a unique group of adult ‘returners’, relevant data have been extracted from two previous qualitative studies carried out between January 2013 and March 2014. The aim of this brief paper was to utilise these existing data to investigate the impact of centralisation on the standard of care according to the perspective of adults born with CL/P.

Methods

Data used in this paper were derived from two larger qualitative studies investigating the psychosocial impact of CL/P from the perspectives of adult patients (see Stock et al., 2015; www.clapa.com/about-us/goals-strategies/regional-coordinator-project). In the first study ($n = 8$), adults with CL/P were individually interviewed over the telephone about a wide range of topics, including their experiences of cleft-related treatment. In the second study, adults with CL/P were invited to participate in a focus group ($n = 8$) in which the discussion centred specifically on treatment. The same interview protocol was used in the focus group as in the ‘treatment’ section of the first study. In both cases, a semi-structured interview format was used, in which participants were asked open-ended questions and prompted to provide more details where appropriate. Interview topics included childhood experiences of treatment, experiences of treatment as an adult, and sources of practical and emotional support. A full interview schedule is available upon request. All interviews were conducted by the first author, who is trained in interviewing techniques and conducting focus groups. The data extracted are pertinent to the purposes of the current paper only, and have not been previously reported in any other study.

In the original two studies, potential participants were approached via advertisements published on relevant websites and social media, such as that belonging to the UK-based charity, the Cleft Lip and Palate Association. A press release calling for participants was also disseminated through the University of the West of England, and the study was subsequently advertised via national and local media. Potential participants who expressed an interest were sent a Participant Information Sheet, containing further details about what participation in the study would entail, and key ethical information such as confidentiality and their right to

withdraw. Those choosing to take part were asked to provide some basic demographic information and a handwritten, signed consent form giving their permission for their data to be used for research purposes, before participating in either study.

In total, sixteen adults born with CL/P contributed qualitative data to the current paper between January 2013 and March 2014. All participants had received their initial treatment prior to the centralisation of services, and had additional experience of post-centralised care in adulthood. Nine participants were male. The age range of participants was 27-63 years, with a mean age of 41 years. The most common cleft type among participants was unilateral cleft lip and palate (UCLP, $n = 7$), followed by cleft palate only (CPO, $n = 4$), bilateral cleft lip and palate (BCLP, $n = 4$), and unilateral cleft lip only (UCL, $n = 1$). Seven participants were also parents to children born with CL/P. All participants were White British except for one participant who identified as Indian. All participants were employed at the time of interview. Participant demographics are provided in Table 1.

On average, individual interviews lasted approximately 59 minutes, while the focus group was 84 minutes in length. Interviews were audio-recorded and later transcribed verbatim. Data relating specifically to the subject of this paper were extracted by the first author, and subjected to inductive thematic analysis. In accordance with the guidelines provided by Braun and Clarke (2006), the following steps were taken: (1) becoming familiar with the data; (2) identifying interesting features of the data; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) producing the report. Analysis was seen as a recursive process, and detailed notes were written throughout. Themes were subsequently chosen for their prevalence and/or their importance (or “keyness”) in relation to the research question. Emerging themes were initially identified by the first author. The data were then also coded separately by a second researcher, and the thematic groupings were compared. Initial coding had an average agreement of 96% (range 89% - 100%). Themes were then checked and discussed until agreement was reached.

Ethical approval for both original studies was granted by the Faculty Research Ethics Committee at the University of the West of England, and is encompassing of the current paper. The ethical guidelines of the British Psychological Society (2009) were followed at all times.

Results

Thematic analysis identified four key themes within the data: Involvement in Treatment Decisions; Integration of Psychological Support; Opportunities to Engage in Peer Support; and Improved Standards of Care. Each theme is described in further detail below and illustrated using exemplar quotes. In order to bring the patient voice to the fore, participants' quotations have been given prominence over the narrative throughout the results section. All participants have been assigned pseudonyms to preserve anonymity.

Involvement in Treatment Decisions

Participants described their lack of understanding and involvement in cleft-related treatment as a child. For some, these memories were quite traumatic.

"I have a burning recollection of going into hospital and being left there for a week, and not knowing what was going to be done to me, and just being absolutely distraught" – William.

"I remember being spoken at, rather than with or to, and my opinions didn't really matter, I was going to have x, y, z whether I liked it or not" – Mark.

"It did feel very much that you were just talked at, decisions were made for you, they were put on you, and you just went with whatever was done" – Ryan.

Participants also discussed the ways in which attitudes toward patient involvement in cleft care had changed, and highlighted the role of the psychologist in facilitating medical decision-making.

"When I was a child, nothing was ever explained to me... Things are so much better now with the health professionals explaining things to you, and I'm so glad that's happened, because it's only really now that I've come to terms with all that" – William.

"Now [health professionals] have a lot more interaction with you, and any concerns that you might have you can actually bring it up with the psychologist, and the psychologist can voice those concerns for you if you don't feel like you can. For me definitely, it has been a big shift and a big change from what I'd experienced previously to what I have now" – Ryan.

"For the last two bits of surgery I had, when I was an adult...I wasn't sure whether to have the treatment...and I spoke to the clinical psychologist when I was in, and they helped immensely... It was a totally different experience to what I'd had growing up" – Mark.

The Integration of Psychological Support

Participants outlined the lack of emotional support they had received as a child, and how they had largely relied upon their own coping strategies to get through difficult times.

“Growing up, the coping mechanisms were invented yourself...that’s how you got through the operations and the treatment and everything, just because you had to find it from somewhere” – Paul.

“There was a total lack of any support, other than self-support, up to probably the last four years of my life...it was a bit hit and miss, and a bit fortunate I suppose that my self-support got me where I am today, but I sometimes wonder what it would have been like if I hadn’t done the things that I’ve done to get me through” – Gerry.

Participants identified the school years to be an especially difficult time in coping with cleft-related challenges, particularly in relation to explaining CL/P treatment to others, and experiencing teasing and bullying.

“All that treatment I had when I was at school... One summer I had my rhinoplasty operation, so you go back to school in September and you look different, and how are you supposed to cope with that? How do you communicate to your friends, how do you communicate to your teachers, and what about those kids that pick on you anyway, because you used to have a crooked nose and now you haven’t? And there’s a whole load of things around that which, had there been some support, that would have been really useful, but at the time it wasn’t there” – Adam.

Participants also described their experiences of growing up with CL/P to be ‘emotional baggage’ which they still carry around.

“I was part of a generation where you just get on with it, you don’t dwell on it, and I think sometimes when you’re a sensitive person, like I am, I found that quite hard actually, in fact I still find it very hard, I still struggle with everything that happened to me” – Nadine.

“Even now there are certainly things that push my buttons and make me upset... Someone just has to say ‘how do you feel about that?’ and whoosh, tears everywhere, I’m blind-sided by it” – Paul.

Finally, participants discussed the integration of clinical psychologists into routine CL/P care, and the importance of offering professional emotional support to those affected.

“For me, there didn’t seem to be the emotional support that there is now, you had to grin and bear it...there was never any talk of going to see a psychologist or anything, that was never available...so that’s the most positive change that I can see” – Toby.

“I’m talking more about my cleft now than I ever have... I think people coming through the system now are probably more confident in dealing with the cleft and the cleft issues, because they’ve had that emotional support all the way through... So the fact that there is a clinical psychologist dealing with these issues now, that is one of the best things that could have happened” – Paul.

Opportunities to Engage in Peer Support

Many participants in this study had not met another person born with CL/P until they had come back into contact with the service as an adult.

“I’ve never actually met or spoken to someone else with a cleft until four years ago, when I was put in touch with the cleft team and finally got that opportunity” – Gerry.

“Things like CLAPA and the cleft teams didn’t exist when I was younger...not even the internet existed, so it was hard to get in touch with people...there wasn’t really that external support network” – Toby.

Participants believed that access to peer support had improved as a result of changes in the service.

“The cleft teams these days...they’re very well connected...they can put you in touch with all sorts of networks” – Sandra.

“Everything’s a lot more linked up now, compared to when I was growing up... There are events and meet-ups, everything is much more visible” – Jessica.

Participants also emphasised the importance of having the opportunity to meet others affected by CL/P.

“Meeting other people who have the same condition as me, that’s really opened my eyes... I used to genuinely think I was the only one in the world with this. Now I know how common it

is, how accepting people are nowadays...I can share my experiences and know that others can relate” – Jake.

Improved Standards of Care

Participants perceived many benefits to the service as a result of health professionals developing specialist knowledge of CL/P.

“They didn’t have specialised plastic surgeons who dealt with clefts like they do now, and it’s really showing because considering what my son looked like before, to what he looks like now, it’s incredible...you can hardly even tell he had a cleft” – Toby.

“[The health professionals] who look after you all specialise in cleft now...the treatment results are so much better for that... I would support the NHS until the end because I really feel that it’s really moved on, and if it keeps moving on and keeps developing through research then so many children...and families are going to benefit” – Nadine.

Participants also described feeling well informed and supported by their cleft team, largely due to the centralised coordination of multidisciplinary services.

“The set up when they’re little now is amazing...as soon as you find out about the diagnosis, someone comes to your house, they talk you through everything, and at every operation they come and see you, and our cleft nurse is really good and on the ball and lets you know what’s going to happen... My mum and dad never had that, and that’s a vast improvement” – Caitlyn.

“It’s a whole different ball game to when I grew up... My daughter has an outreach nurse who comes down to see us...and when we go up to meet the team everyone is in there, including the outreach nurse and the surgeon and everything...it’s a real team effort now and it feels almost like a family” – Tara.

Participants explained how their views toward starting their own family had changed since they learned that treatment and support from specialist teams was now available.

“Because of my own experiences, I didn’t really want to have a family in the beginning... I thought ‘I don’t want to put anybody else through this’... Now it’s getting on to 40 years of research and streamlining processes and improvements, and I know that my son is in great hands” – Toby.

Discussion

This brief qualitative paper is one of the first to capture patients' views about the centralisation of CL/P services in the UK since the CLAPA report ten years ago (CLAPA, 2007). It is also one of the first papers to specifically explore the views of adult patients who have experience of both pre- and post-CSAG services. The data collected provide additional insight into the impact of centralisation from the perspective of adult 'returners', including those who have gone on to experience post-CSAG services as a parent of a child with CL/P. The findings of this study suggest that centralisation of CL/P services has vastly enhanced the patient experience. Specifically, participants felt that the overall standard and coordination of care has improved, that services are now more patient-centred, and that access to professional psychological support and opportunities to meet others affected by CL/P have greatly improved patients' capacity to cope with the associated emotional challenges.

Participants in this study also identified a growing momentum in relation to CL/P research. In a brief paper, Sandy and colleagues (2012) described how service reconfiguration has generated new opportunities for research in the UK, and created an invigorated research culture to which multiple stakeholders now contribute. Similarly, and with the introduction of psychologists to CL/P teams, more than 150 papers investigating the psychological impact of CL/P have been published in the last decade (see Stock and Feragen, 2016); a considerable increase compared to previous years (see Hunt et al., 2005). While the primary rationale for centralisation was to improve the standard of care (and therefore outcomes) for those affected by CL/P and their families, national programmes of research, with the potential to inform healthcare worldwide, are now possible in the UK (e.g. Stock, Humphries et al., 2016).

These qualitative data complement the information already available within the literature, including quantitative studies comparing pre- to post-CSAG structural, functional, speech and psychosocial outcomes (Al-Ghantam et al., 2015; Smallridge et al., 2015; Sell et al., 2015; Waylen et al., 2015), studies examining the views of CL/P specialist health professionals (Scott et al., 2014; Searle et al., 2015), and improvements in care as demonstrated by hospital episode statistics (Fitzsimons et al., 2012). In combination, these findings are also relevant to future efforts to centralise other specialist services across a range of conditions around the world.

A number of limitations of the current study must be outlined. First, and while a total sample of 16 participants is generally considered adequate for a small-scale qualitative study (Morse, 2000), the data were derived using two different data collection methods. Data collected in a private one-to-one dialogue may differ from that collected in a group setting. In addition, and although combining different methods in one study is not uncommon (Creswell and Plano-Clark, 2011), this is not usually done retrospectively. Nonetheless, common themes were observed across data collected from all participants, and the findings contribute a valuable perspective which has not previously received much attention. In addition, and for transparency, full participant characteristics have been provided in Table 1. Second, and although qualitative approaches can contribute a rich and complementary perspective to quantitative literature, the data collected in the present study relied upon participant recall of past events, and narrative which has been constructed through participants' attempts to make sense of their experiences. Ultimately, longitudinal research is needed to understand the complexities and fluctuation of psychological adjustment to CL/P, and the outcomes of CL/P treatment.

Building on the findings of this small-scale study, future research may wish to consider ways of monitoring and measuring clinical teams' progress toward ensuring patient satisfaction at every stage of the treatment pathway. While the challenges of achieving consensus in relation to outcome measurement has been well-documented (Hunt et al., 2005; Klassen et al., 2012; Antonarakis et al., 2013; Maliepaard et al., 2014), some progress has been made in the UK and elsewhere (e.g. Stock, Hammond et al., 2016). A clear priority for the field over the next decade is for teams around the world to agree upon and adopt patient-centred measures, so that data can be compared. Clinical teams also require a general awareness of patients' support and information needs, as well as good communication skills, to support patients to feel empowered in making informed and realistic treatment decisions (Knapke et al., 2010; Nelson et al., 2012). As the current paper suggests, involving a psychologist in the decision-making process may help to alleviate emotional distress and improve patient advocacy. Finally, peer support has previously been shown to have the potential to improve overall wellbeing among those affected by a range of health conditions, and to offer complementary support to that offered by the clinical teams (e.g. Tiemens et al., 2006; Mahlke et al., 2014; Tully et al., 2017). Lay-led organisations, such as CLAPA in the UK and the Cleft Palate Foundation in the US, may provide an avenue through which patients and families are given the opportunity to meet one another and share experiences.

Conclusions

This brief qualitative study assessed the impact of the centralisation of UK cleft services from the perspective of sixteen adult patients who have undergone treatment both before and after services were reorganised. The findings suggest that centralisation has improved the patient experience by enhancing the overall standard and coordination of care, encouraging a more patient-centred approach, and providing access to professional psychological services and peer support. In combination with existing literature, these findings are also relevant to future efforts to centralise other specialist services around the world. Future research could further evaluate the impact of shared treatment decision-making, the role of lay-led organisations in providing peer support, and ways of monitoring and measuring clinical teams' progress in meeting patient standards of care.

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Table 1: Participant characteristics