

# **Promoting Psychosocial Adjustment in Individuals Born with Cleft Lip and/or Palate and their Families: Current Clinical Practice in the United Kingdom**

## **Abstract**

**Objectives:** The importance of psychosocial aspects of care has received growing recognition in recent years. However, the evidence-base for psychosocial intervention remains limited. Specialist clinicians working in cleft lip and/or palate (CL/P) services hold a wealth of knowledge and experience yet to be elicited. The aims of this study were to identify common psychosocial challenges and potential risk and/or protective factors for psychosocial distress from the perspective of specialist clinicians, and to establish the types of interventions currently being delivered in practice.

**Design:** Individual interviews with seventeen Clinical Nurse Specialists and nineteen specialist Clinical Psychologists, representing all sixteen UK CL/P surgical sites. Data were analysed using inductive content analysis.

**Results:** Numerous psychosocial challenges affecting individuals with CL/P and their families were identified across the lifespan. Risk factors were predominantly contextual in nature, while protective factors appeared amenable to intervention. Participants drew upon a range of therapeutic models and approaches to guide formulation and intervention, while acknowledging the lack of evidence to support these approaches in CL/P populations specifically.

**Conclusions:** Findings have important implications for the way in which psychosocial support for CL/P and related conditions is delivered and evaluated. A framework for the standardised assessment of holistic individual and familial wellbeing is proposed. Suggestions for increasing the evidence base for specific psychosocial interventions are made, including enhanced family functioning; social, emotional and appearance concerns; treatment decision-making; and screening for psychosocial and developmental issues.

**Key words:** cleft lip and palate; chronic health conditions; risk and protective factors; psychosocial intervention

## **Introduction**

In the United Kingdom (UK), care for individuals and families affected by CL/P is provided under a centralised model. In addition to aesthetic and functional outcomes, current national service specifications state that every child should be able to function well socially and without disadvantage (NHS England, 2013). To achieve this, all families should receive support from a Clinical Nurse Specialist from the point of diagnosis, and children and their families should be assessed for psychosocial concerns by a specialist Clinical Psychologist at least once before the child's sixth birthday (NHS England, 2013).

Clinical Psychologists were first introduced as a core component of UK cleft teams in the early 2000s, following a national report by the Clinical Standards Advisory Group highlighting the need to address psychosocial concerns (CSAG; Sandy et al., 1998). The role of a Clinical Psychologist is to reduce psychological distress and enhance psychological wellbeing using specialist skills and knowledge acquired from doctoral level training (Law & Laffan, 2015). Previously, low-level emotional support for those affected by CL/P was provided solely by Clinical Nurse Specialists. Today, Nurse Specialists remain the first point of contact for families during the first two years of treatment, and are important gatekeepers in the provision of information, basic emotional support, and practical support with regard to feeding, development, and preparation for surgery (Searle et al., 2018). Nurse Specialists work closely with Clinical Psychologists and refer individuals and families to higher level psychological support as needed.

The number of psychosocial papers published during the last ten years has noticeably increased (Stock & Feragen, 2016). Quantitative and qualitative literature has documented several areas of potential psychosocial concern. For parents, a diagnosis may invoke feelings of shock, guilt, grief, and concern for their child's future (Nelson, Glenny et al., 2012).

Feeding difficulties, other people's reactions to the condition, and conflicting emotions regarding surgery may also cause considerable distress (Nelson, Glenny et al., 2012). As the child grows older, additional challenges related to speech, hearing, and appearance may impact several domains of psychosocial development and wellbeing (Rumsey & Harcourt, 2004; Havstam et al., 2011).

While some studies have observed poorer long-term outcomes among individuals with CL/P and their families when compared to the general population in relation to social engagement (e.g. Marcusson et al., 2001), educational and vocational attainment (e.g. Knight et al., 2015), and physical and mental health (e.g. Demir et al., 2011), other research has reported few differences between those with and without CL/P, and/or superior scores for those with CL/P on a range of psychological outcomes (e.g. Berger & Dalton 2009). Qualitative studies have also highlighted several positive outcomes of CL/P, including heightened empathy for others, increased appreciation of diversity, stronger relationships, and positive growth (Eiserman, 2001).

While variable findings are in part due to inherent methodological limitations (Stock, Feragen et al., 2018), they also represent the complexity of adjustment to conditions such as CL/P. Adjustment involves an elaborate interplay of physical, cultural, psychological, and social factors, and is known to fluctuate over time and in accordance with different life events, experiences, and contexts (Stock, Feragen et al., 2018). More research is needed to examine potential risk and/or protective factors for psychological distress within the CL/P population, in order to better understand the complexities of psychological adjustment and offer effective interventions. Concurrently, little evidence exists to support specific psychosocial interventions in the field of CL/P (Norman et al., 2015), despite this being the top CL/P research priority as identified by UK patients, families, and clinicians (James Lind Alliance,

2012). This lack of evidence is particularly apparent when compared with other areas of health research (Norman et al., 2015).

An important step toward addressing the need for further evidence is to gain an understanding of what is currently provided in clinical practice. Specialist clinicians working in CL/P services hold a wealth of knowledge and experience, yet the clinician perspective has not previously been presented in the literature. While every member of the team plays a key role in promoting psychological health, Nurse Specialists and Clinical Psychologists are particularly crucial (Searle et al., 2018; Stock, Anwar et al., 2018). The aims of the present study were to identify common psychosocial concerns and potential risk and/or protective factors for psychosocial distress from the perspective of Nurse Specialists and Clinical Psychologists, and to establish the types of psychosocial interventions currently being delivered in practice.

## **Method**

### ***Design***

Individual, semi-structured telephone interviews were conducted with Nurse Specialists and Clinical Psychologists who were currently working in one of the 16 UK specialist CL/P centres, or who had recently retired (<2 years) from CL/P services.

### ***Ethical Considerations***

Institutional ethical approval was obtained from the Faculty Research Ethics Committee at the University of the West of England. Participants were informed that their contribution to the study was voluntary, their data would be stored confidentially, they would not be identified during dissemination of the findings, and they could withdraw their data from the study at any time prior to the completion of the analysis.

## *Procedure*

Potential participants were initially approached through the relevant specialist UK Clinical Excellence Networks (CENs). A CEN is composed of all specialist clinicians working within a particular discipline and field; in this case the Nursing CEN and Psychology CEN were approached. Participants were encouraged to contact the researchers if they were interested in participating. A mutually convenient time to conduct a telephone interview was then agreed. Participants were offered several opportunities to ask questions about participation and gave verbal informed consent before the interview began. Interviews took place between September 2016 and March 2017 and were conducted by the second author. All interviews were audio-recorded with participants' permission. In addition to collecting key demographic information, broad discussion topics included: (i) common psychosocial concerns that individuals and their families encounter; (ii) potential risk and protective factors for psychosocial distress; and (iii) the types of psychosocial interventions currently utilised in clinical practice. The interview schedule was designed by the first and second authors, based on recent literature reviews (Norman et al., 2014; Stock & Feragen, 2016) and consultation with clinicians. Additional data collected from these interviews relate to wider service delivery and will be presented in a separate paper. A full list of interview questions is provided in Table 1.

## *Analysis*

Inductive content analysis was performed independently on the data by the first and second authors, who are trained in qualitative methods. This type of analysis is deemed appropriate when the aim of a study is to succinctly summarise a large body of qualitative data, and when existing theory or literature on a given phenomenon is limited (Neuendorf, 2017). First, the data were read and re-read, to establish an overall picture. Key findings were then extracted

and coded. Any minor discrepancies were discussed between authors until full agreement was reached. Anonymised preliminary findings were presented to all members of the Nursing and Psychology CENs at the annual meeting of the Craniofacial Society of Great Britain and Ireland in April 2017. A focus group discussion with each CEN was facilitated by the first and second authors to ensure the accuracy of the interpretative process and to discuss the implications of the findings. These discussions confirmed the validity of the findings and pointed the researchers in the direction of additional documentation that has been incorporated into the final results. The third and fifth authors chaired the Nursing and Psychology CENs respectively during the study period and were invited to be co-authors to ensure the final papers were representative of the views of the CENs as a whole.

## **Results**

Study findings are briefly outlined below and presented in Tables 2-5. Where differences between disciplines were identified, data are presented separately for Nurse Specialists and Clinical Psychologists. Where themes were comparable across disciplines, data for both disciplines are combined. Themes are listed in order of frequency cited.

### ***Participants***

Seventeen Nurse Specialists and nineteen Clinical Psychologists participated in this study, totalling 26 participants. All sixteen specialist UK CL/P sites were represented. Both disciplines were represented across all sites, with the exception of one team who did not have a Clinical Psychologist in post during the interview period. In some cases, more than one representative from each site participated.

Two of the Clinical Psychologists were male, and the remaining participants were female. Nurse Specialists reported an average of 31.2 years since qualifying as a registered

practitioner (20 years – 49 years), with an average of 15.5 of those years spent working in CL/P (range 4 years – 31 years). Clinical Psychologists reported an average of 13.7 years since qualifying as a registered practitioner (range <1 year – 41 years), with an average of 7.4 of those years spent working in CL/P services (range <1 year – 20 years). Interviews with Nurse Specialists lasted ~57 minutes on average and interviews with Clinical Psychologists were ~63 minutes on average.

### ***A Multifaceted Role***

Table 2 presents the multiple responsibilities reported by both Nurse Specialists and Clinical Psychologists within their current roles. In relation to patient assessments and the delivery of psychosocial support, participants reported clearly defined roles with some complementary overlap. As the first point of contact following a diagnosis, Nurse Specialists were responsible for confirming the diagnosis and introducing the family to the CL/P care pathway. Unless particular concerns were raised, Clinical Psychologists usually became involved at a later stage. Although Nurse Specialists described their work as largely concentrated on the first two years following the diagnosis, some were also involved in the care of older children, particularly if access to psychologists was limited within their team. Participants also described contributing to the overall development of the service and its staff. Both Nurse Specialists and Clinical Psychologists reported contributing to multidisciplinary team clinics, attending conferences and CEN meetings, and liaising with external agencies, in addition to providing internal and external supervision and consultation. Nurse Specialists also described training non-specialist staff (e.g. midwives and health visitors) and Clinical Psychologists played a key role in increasing psychosocial knowledge within the wider multidisciplinary CL/P team.

### ***Common Psychosocial Challenges***

Table 3 shows the wide-ranging psychosocial challenges identified by participants as being common to individuals and families affected by CL/P. Challenges arose throughout the lifespan, indicating a potentially considerable and ongoing impact of CL/P and its associated treatment.

### ***Potential Risk and Protective Factors***

Table 4 details potential risk and protective factors for psychosocial distress among individuals born with CL/P and their families, as identified by participants. Several were contextual in nature (e.g. socio-economic status) and not CL/P-specific, while others were directly related to the condition itself (e.g. appraisals of the condition and its perceived impact on life). Protective factors constituted adaptive processes, which suggests they would be amenable to change through psychological support and intervention.

### ***Approaches to Intervention***

In order to address these concerns, participants drew upon a wide range of therapeutic models, as shown in Table 5. The most cited model by Clinical Psychologists was Cognitive Behavioural Therapy (CBT), particularly for reducing procedural and general anxiety, while informal counselling, supported by a range of practical methods, was the approach most commonly adopted by Nurse Specialists. When working with parents and/or children, most Clinical Psychologists reported using a systemic model to guide formulation and intervention. Nurse Specialists also discussed the importance of providing support to all key members of the family. The delivery of psychosocial support could take place in person (one-to-one, groups), or remotely over the telephone. Some participants travelled to local clinics or families' homes. All participants emphasised the importance of offering integrative and flexible care based on the needs of the individual.



## **Discussion**

The aims of this qualitative study were to identify common psychosocial concerns and potential risk and/or protective factors for psychosocial distress from the perspective of Nurse Specialists and Clinical Psychologists, and to establish the types of psychosocial interventions currently being delivered. The findings demonstrate the complexity and necessity of the role of both Nurse Specialists and Clinical Psychologists within cleft teams, in line with previous research (Searle et al., 2018; Stock, Anwar et al., 2018). The findings also offer a comprehensive understanding of intervention delivery in current clinical practice, and direction for future research into the provision of evidence-based psychosocial support. Findings are discussed in more detail below and summarised in a framework presented in Figure 1.

### ***Screening for Psychosocial Distress***

A broad range of common psychosocial challenges were identified by Nurse Specialists and Clinical Psychologists, with a high level of agreement between the two disciplines. For parents and families, areas of concern were predominantly focused on the first few years following diagnosis. A family needs assessment, feeding and interaction assessment, and consideration of the need for genetic counselling therefore seem warranted during the first year, alongside an assessment of parental wellbeing. An additional assessment of child development is indicated at 18 months, to screen for early indicators of developmental delay. Further assessments of child wellbeing may be necessary between the ages of 7-8 years, to identify any perceived teasing/bullying, between the ages of 12-15 years to highlight any appearance concerns and/or emotional distress, and toward the end of the standard care pathway to ensure a positive transition into adulthood. Individuals returning to CL/P

treatment at a later stage should also receive a comprehensive psychosocial assessment as part of routine practice.

While standard protocols for the multidisciplinary care of families affected by CL/P have been published in the UK (NHS England, 2013), exact details of the psychosocial constructs that should be measured, when, and how, is currently lacking. Further, based on the evidence presented in this and other studies (Stock & Feragen, 2016), the most critical times in the developmental trajectory for the assessment and management of psychosocial distress fall between the existing national CL/P audit points (age 5, 10, and 15). This suggests that the current protocol for monitoring psychosocial wellbeing may need to be reconsidered. A series of measures with scientific and clinical utility, based on a conceptual framework and selected by CL/P stakeholders, have been recommended for use in CL/P research (Stock, Hammond et al., 2016). With further refinement, these measures could be piloted for use in routine practice.

### ***Intervention Delivery and Available Evidence***

#### ***Support Following a Diagnosis***

In the current study, diagnosis was identified as a particularly challenging period. Whether antenatal or postnatal, a diagnosis of CL/P can invoke feelings of shock, guilt, grief, and anxiety among families (Nelson, Glenny et al., 2012). A sensitive, accurate, and timely diagnosis is therefore essential for helping parents to make realistic appraisals of their child's condition, to instil confidence in the medical team, and to support long-term psychosocial adjustment (Aspinall, 2002). In the current study, Nurse Specialists reported utilising informal counselling skills, information provision, and pre- and post-surgical photographs to reduce parental anxiety and normalise concerns. Nurse Specialists also directed families toward peer support, which has been shown to improve parental wellbeing in a number of

CL/P and wider studies (e.g. Bogart & Hemmesch, 2016). Clinical Psychologists also identified a range of more intensive interventions at this time, should additional support be necessary. While care from specialist CL/P teams is often highly rated (Knapke et al., 2010), several studies have been indicative of parental dissatisfaction with non-specialists, including sonographers, midwives, health visitors, and General Practitioners (Tierney et al., 2015; Searle, Ryan et al., 2016). Training for health professionals who come into contact with families affected by congenital conditions is therefore recommended (Lalor et al., 2007). Further work is needed to develop and evaluate materials for both qualified and trainee health professionals.

### *Enhancing Family Functioning*

All participants in this study discussed the importance of taking the psychosocial wellbeing of every family member into account. While most studies in the broader literature have focused on the development of resilience in individuals, recent calls have been made to adopt a systemic approach, in which the resources of the whole family unit are considered (Walsh, 2016). Previous research has demonstrated the importance of the relationship between parents of children with CL/P for family wellbeing (Zeytinoğlu et al., 2016; Stock et al., *in press*), in addition to the positive contribution that wider members of the family, such as grandparents and siblings, can make (Guest et al., 2019; Stock, Stoneman et al., 2016). Further exploration of the factors contributing to family resilience, and interventions shown to be effective in the general population may be applicable in CL/P.

### *Parent-Infant Interaction*

While some previous literature has postulated a greater risk of dysfunctional attachment representations between infants born with CL/P and their mothers (e.g. Despars et al., 2011), other studies have reported few differences between families affected by CL/P and unaffected

reference groups (e.g. Murray et al., 2008). In the current study, Nurse Specialists and Clinical Psychologists highlighted bonding as a potential concern for parents, both in relation to parental anxiety during the pregnancy and actual bonding difficulties once the baby had been born. Where problems are identified, Murray and colleagues (2008) proposed that bonding may naturally stabilise by the age of 18 months. Feeding has been identified as an important facilitator of bonding, and several studies have focused on optimising feeding for infants with CL/P (Bessell et al., 2011). A randomised controlled trial to improve the quality of mother-infant interactions in CL/P was recently completed in the UK, and will have implications for future psychosocial intervention in this area ([www.isrctn.com/ISRCTN36848750](http://www.isrctn.com/ISRCTN36848750)). Interventions from the broader literature, including psychoeducation, psychotherapy sessions, video feedback, infant carrying, infant massage, and improved access to community services have also shown promise (Wright & Edginton, 2016), and may provide CL/P clinicians with additional strategies.

#### *Pre- and Post-Surgical Care*

In support of previous literature, the current study suggest that primary surgery may be a particularly stressful time for parents of children with CL/P. Several studies have reported on the conflicting emotions parents may experience in “sanctioning” surgical intervention, and in relation to their child’s change in appearance post-lip repair (e.g. Nelson, Kirk et al., 2012). Parents’ experiences of post-operative care have been cited as potentially distressing in the current study and elsewhere (e.g. Chuacharoen et al., 2009), yet little psychosocial research regarding interventions in infancy is available (BPS, 2010). In the current study, interventions used prior to surgery focused on reducing parents’ procedural anxiety. Evaluation of these and other psychosocial resources to help parents prepare for their child’s treatment, and to manage the care of their child post-operatively may therefore be justified.

### *Suspected Developmental Delay*

In the present study, early indicators of developmental delay were reported in children as young as 18 months of age. In the general population, several conditions are known to impact children's psychosocial and cognitive development, including autism spectrum disorder, attention and/or hyperactivity disorders, specific language impairment, dyslexia, learning difficulties, and global developmental delay. A higher prevalence of these conditions has been identified in children born with CL/P, in addition to genetic syndromes (Feragen & Stock, 2014). Recent research has also identified a trend in lower academic outcomes in the CL/P population (Knight et al., 2015), which points to the importance of early identification of developmental concerns. Some, but not all Clinical Psychologists in the current study reported using formal developmental assessments and only a minority of Clinical Psychologists reported screening for developmental concerns routinely. Several measures have been used with the craniofacial population to assess developmental concerns in infants and toddlers (Collett & Speltz, 2006). Consensus between Clinical Psychologists and Nurse Specialists is needed to implement brief, yet sensitive screening tools which complement the national screening programme carried out by UK Health Visitors to support the early identification of developmental concerns, and to offer support for this potentially vulnerable subgroup.

### *Speech, Hearing, and Behaviour*

Despite the potential impact of communication difficulties on overall psychosocial adjustment, few interdisciplinary studies have been performed (Stock & Feragen, 2016). Those that have discuss the need for an awareness that children with communication difficulties may be psychosocially vulnerable, and for appropriate multidisciplinary intervention to be offered (Feragen et al., 2017). In the current study, parenting strategies and

psychoeducation were reported by Nurse Specialists and Clinical Psychologists for addressing communication and behavioural challenges, and Clinical Psychologists occasionally liaised with local schools. A minority of Clinical Psychologists also reported delivering shared sessions with Speech and Language Therapists in their team. Again, limited evidence of intervention for communication and/or behavioural difficulties exists (Bessell et al., 2013), and a range of additional school and home-based interventions may be necessary (Stock & Ridley, 2018). Resources offered by external organisations, such as the National Deaf Children's Society may also be informative (<https://www.ndcs.org.uk>).

### *Social Experiences*

Due to differences in their appearance and/or speech, individuals born with CL/P can experience curious looks, questions, and comments from members of the public, which some find difficult to manage (Rumsey & Harcourt, 2004). Individuals may also experience teasing/bullying, which can have a long-term impact on self-perceptions and psychosocial wellbeing (Feragen & Stock, 2016). In the current study, Clinical Psychologists reported using social skills training and CBT to improve social interaction. Some evidence has been identified to support these two approaches in CL/P (Norman et al., 2015). Additionally, a combined framework for the assessment and formulation of psychosocial support for teasing in CL/P has been proposed (Hearst et al., 2008), and could form the basis for intervention evaluation in this area. Supporting parents to provide their children with a clear narrative about their condition may help children to respond to questions and comments with confidence. Research has also indicated that friendships can be protective against psychosocial distress, and that receiving peer support from others born with CL/P can help young people to feel less isolated (Feragen et al., 2010). Further evidence for the role that schools and charitable organisations play in exposure to positive social experiences is therefore needed.

### *Appearance Concerns*

In the general literature, awareness of societal appearance ideals has been identified from as young as five years of age (Dittmar et al., 2006). In the current study, although teasing and bullying (with a typical onset of seven years) occasionally drew attention to ‘differences’, self-reported appearance concerns specific to CL/P were not typically evident until the age of eleven years according to participating clinicians. In addition to appearance becoming a more prominent focus in early adolescence, this is the age at which children start to prepare to transition to secondary school in the UK, which could explain a heightened sense of appearance concerns around this time.

Interestingly, the objective severity of an appearance-altering condition is a poor predictor of psychosocial adjustment (Appearance Research Collaboration, 2009). Consequently, interventions have attempted to target unhelpful cognitive processes and beliefs, such as high appearance salience and fear of negative evaluation (Rumsey & Harcourt, 2004). Evidence of effectiveness has been demonstrated in both clinical and self-help formats, and continues to develop (e.g. Williamson et al., 2015; Clarke et al., 2013). Correspondingly, CBT was the most commonly reported model to address appearance concerns in the current study. Broader societal campaigns and school-based interventions to challenge appearance ‘ideals’ have been suggested and warrant further assessment (Diedrichs & Halliwell, 2012).

### *Treatment Decision-Making*

Previous research has demonstrated that both parents and individuals affected by CL/P may experience conflicting emotions regarding surgical intervention, particularly when surgeries are elective (Nelson, Kirk et al., 2012). Additionally, patients may perceive aesthetic surgery to be unnecessary or ‘superficial’ in comparison to surgery to improve function (Stock et al., 2015). Studies have suggested that patients’ expectations of surgical outcome may exceed

reality, resulting in post-surgical dissatisfaction and psychosocial distress (Liddle et al., 2015). In the current study, participants reported assessing psychosocial wellbeing and surgical expectations prior to surgical intervention, and occasionally advocated to the surgeon on the patients' behalf. In the broader literature, tools to facilitate shared decision-making have been shown to have potential benefits for both patients and clinicians (Austin et al., 2015). Adaptation and evaluation of these tools for use in CL/P should therefore be considered, alongside evaluation of psychosocial screening for surgical readiness.

### *Transition*

As in the present study, extant literature has identified two predominant transition points for individuals born with CL/P. First, transition to secondary school (US middle school) may present challenges, as young people try to 'fit in' with their new peers (Stock & Ridley, 2018). Although this transition affects most adolescents to some degree (Zeedyk et al., 2003), CL/P may heighten fears of social rejection and additional preparation may be necessary (Marshman et al., 2009). Second, the transition from child to adult services in which young people have an increasing responsibility for their own healthcare has been highlighted (Stock et al., 2015). In the current study, participants used a combination of psychoeducation and CBT to facilitate transitional periods, while a minority of Clinical Psychologists offered information packs or "transition workshops" (e.g. Holman & Keen, 2012). Reviews of existing evidence have reported some promising interventions to facilitate transition to adult care (e.g. Chu et al., 2015) that may also have application in CL/P.

### *Complex Trauma*

Complex trauma is defined as a form of acute stress which occurs repeatedly and cumulatively, usually over a long period of time and within specific relationships and contexts (Law and Laffan, 2015). Some Clinical Psychologists had encountered complex trauma in



adults returning to the service later in life, though not formally diagnosed. Participants suggested this trauma could develop through repeated incidents of rejection, exclusion and bullying, and/or the effects of medical treatment. While individuals with CL/P are at risk of emotional distress throughout the lifespan, adults returning to the service may represent particularly complex cases (Stock et al., 2015). This is also reflected in previous reports of a higher incidence of psychiatric conditions (Demir et al., 2011) and poorer overall quality of life (Queiroz-Herkrath et al., 2015). Routine psychosocial support is a relatively new addition to CL/P services, and as such, many adults currently living with CL/P in the UK are unlikely to have received psychosocial input (Stock, Anwar et al., 2018). Offering adults a space to articulate their story and providing them with coping strategies are therapeutic techniques which require more investigation.

### ***Future Aims***

#### *Addressing Gaps in the Evidence Base*

Based on the results of the current study, areas for further study include training for non-specialist health professionals, investigation of optimal pre- and post-operative care, and the application of tools to assist the early identification of developmental concerns are warranted to improve psychosocial outcomes within the first two years. During childhood and adolescence, the evaluation of multidisciplinary interventions to address social, physical, and appearance-related concerns, alongside support for transition is needed. Finally, further work to understand the complex needs of adults returning to the CL/P service is imperative.

#### *Exploring Alternative Approaches*

Although the predominant approach to psychosocial intervention reported in the current study was CBT, Clinical Psychologists also frequently discussed using third-wave behavioural approaches. Compared with traditional CBT, third-wave therapies prioritise the holistic

promotion of health and wellbeing and are less focused on reducing psychological and emotional symptoms (Law & Laffan, 2015). Participants reported using elements of Acceptance and Commitment Therapy (ACT), particularly with adolescents and adults. Clinical Psychologists reported finding clinical utility in focusing on patients' values, by taking attention away from physical appearance and toward the things that matter most to them. The use of ACT in CL/P remains largely unexplored, as is the case with other appearance-altering conditions (Zucchelli et al., 2018). However, ACT has shown promise in its effects on mental health (Ost, 2014), body image dissatisfaction (Griffiths et al., 2018), parenting children with chronic conditions, and disease self-management (Graham et al., 2016). A recent survey of European psychology practitioners supporting patients with appearance-altering conditions found that over one third of participants drew from ACT to inform their work (Harcourt et al., 2018). The potential contribution of this and other third-wave behavioural approaches to the field of CL/P could therefore be a valuable focus for further research.

### *Promoting Resilience*

In addition to addressing psychosocial challenges, there is a pressing need for the promotion of resilience. Rather than adopting a pathologising approach as has often been the case in the literature to date, a better understanding of how CL/P and its treatment interacts with common life experiences may provide a more balanced perspective (Stock, Feragen et al., 2018). Further, the evaluation of potential interventions to resilience among individuals and families may reduce the need for psychosocial intervention at a later stage.

### *Measuring the Impact of Psychosocial Intervention*

In the current study, participants emphasised the need to offer patient-led flexibility, and to utilise an integrative approach based on individual need and psychosocial formulation. While

such an approach to intervention is advocated, it also poses an inherent challenge to building an evidence base. Further, participants noted the difficulties of measuring the impact of everyday interactions and more basic forms of intervention, such as normalising parental concerns. Nonetheless, certain aspects of care may still be suitable for clinical trials, such as the effectiveness of interventions for reducing CL/P-related procedural anxiety and the testing of psychoeducational resources to promote resilience and ease periods of transition. The use of observational studies will also allow for ‘within cohort’ trials to be conducted in future. Where ‘higher level empirical evidence’ is not considered obtainable, alternative methods of evidence, such as Goal Based Outcomes and clinical case series may be viable (Mercer et al., 2015). The development of a stepped approach to intervention dependent upon the level of need may also be helpful, such as that advocated by the National Institute of Clinical Excellence to address mental health concerns (NICE, 2011), and the model employed by the Centre for Appearance Research at the University of the West of England (Clarke et al., 2014). Finally, some participants reported that specific interventions are currently being trialled by cleft teams, yet these evaluations rarely appear in the literature. Dissemination of such activity is important, and initiatives to support clinicians to become more involved in research are underway (Sainsbury et al., 2019). A key future challenge will be to effectively balance clinical effectiveness with scientific evidence.

### ***Methodological Considerations***

Although all Nurse Specialists and Clinical Psychologists working in specialist CL/P services were invited to participate, not all were able to commit within the study’s timescale. This opens the possibility that not all views are represented. Nonetheless, a large dataset was obtained, and all UK CL/P sites were represented. Members of both CENs participated in focus groups to validate the interpretation of the findings. The study presents the clinician

perspective, which is important in understanding what is currently provided in clinical practice, and which has not been previously offered.

## **Conclusions**

This qualitative study identified common psychosocial concerns experienced by individuals and families affected by CL/P, alongside associated risk and/or protective factors for psychosocial distress, as identified by Nurse Specialists and Clinical Psychologists working in UK CL/P services. Current provision of psychosocial intervention to address these concerns has been described, and existing evidence both within and outside of the field of CL/P was examined. The findings present a comprehensive understanding of current clinical practice in the UK, and a framework for the standardised assessment of holistic individual and familial wellbeing has been proposed. Suggestions for increasing the evidence base for specific psychosocial interventions have been made, including enhanced family functioning; social, emotional and appearance concerns; treatment decision-making; and screening for psychosocial and developmental issues.

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