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Longitudinal Involvement of the Psychologist in Services for People Born with a Cleft Lip and/or Palate: CLP Series Part 3

Abstract: This paper provides an overview of the longitudinal role of psychologists within the multidisciplinary team (MDT) working with people born with a cleft lip and/or palate and their families. The role of the psychologist is described using a lifespan model, outlining the psychological issues and giving examples of different service models. The role of psychology with special groups of patients, within the MDT and across the broader service network, is also described.

Clinical Relevance: Understanding psychological issues pertinent for people born with a cleft lip and/or palate and their families. Also, understanding the role of the psychologist as part of the multidisciplinary team working with people born with a cleft lip and/or palate and their families.

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The report of the Clinical Standards Advisory Group (CSAG)¹ in 1998 led to a reorganization of Cleft Lip and Palate Services in the UK. The report recommended that Regional Cleft Lip and Palate Services be established and one of its recommendations was that clinical psychologists become established members of the multidisciplinary team (MDT). Since this time, clinical psychologists have become valued members of the Regional Cleft Lip and Palate Services. The roles and functions of the cleft psychologist are broad and varied, incorporating direct work with patients and families; consultation and work with other members of the Cleft Service; and indirect work with the multi-agency network. Cleft psychologists are also involved in audit, research and teaching/training, and this has been reported on in different forums. This paper aims to provide an overview of the longitudinal role of psychologists working

with people born with a cleft and their families across the lifespan, outlining the psychological issues and giving examples of different service models. It will also cover the role of psychology with special groups of patients, within the MDT and across the broader service network.

Role of psychology with new babies and at the point of diagnosis

There are important psychological issues from the point at which the diagnosis of a cleft is made. For the majority of babies born with a cleft, the diagnosis will be made either antenatally (usually at the 20 week ultrasound scan) or close to the time of birth. The bulk of these psychological issues are addressed by specialist cleft nurses as part of their involvement with families at this time.

Cleft psychologists may be involved in a number of ways, for example consulting with cleft nurses around particular families or psychological issues or themes, such as containing other people's distress. Another example of a psychological issue addressed by the cleft nurses is the potential issue of loss in relation to changes in the parents' plans for feeding their baby. Cleft nurses may address this alongside the valuable support and advice they provide in relation to potential feeding difficulties for babies born with a cleft. Additionally, the psychologist may become more directly involved with families where the cleft nurse or the cleft surgeon identifies a psychological concern, such as attachment difficulties.

Parents can have a range of reactions to their baby being diagnosed as having a cleft lip and/or palate including, but not exclusively, shock, disbelief/denial,

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distress and confusion. For all families, however, such a diagnosis will require a process of adjustment. This may involve feelings of loss in relation to the pregnancy they had anticipated and/or the baby or early parenting experiences they had expected. For example, the knowledge that their newborn baby will require surgery or knowledge of potential complications around feeding and whether a mother will be able to breast-feed their baby, can be difficult issues which require parents to process, adjust to and accept an alternative experience than the one they had expected. There is a growing body of evidence² that suggests that, where parents are able to make a successful and positive adjustment to their child having been born with a cleft, this is associated with positive adjustment and positive psychological outcomes for the child.

Other psychological issues for families around the early months of the life of a baby who has been diagnosed with a cleft include:

- Possible psychological or emotional trauma around the experiences of diagnosis and birth;
- Managing the reactions of other people and their own anxieties in relation to this;
- Preparation for surgery; and
- For parents of babies who undergo lip repair surgery, adjustment to the change in their baby's appearance.

Attachment between the primary care-givers and the baby is important, with studies suggesting that, for some babies born with a cleft, there may be difficulties with, or disruption to, the attachment relationship(s) and that the quality of very early attachment is associated with a number of factors, including the adjustment and social skills of the child.³

A number of Regional Cleft Services have a model whereby the psychologist meets directly with all families with a baby born with a cleft. This may happen, for example, as part of a 'New Baby Clinic', pre-admission clinics prior to the baby coming to the ward for surgery, or at the point when families come on to the ward for surgery. The psychologist can have a valuable role to play in supporting families at this time, facilitating adjustment and attachment, validating their experiences and helping families to begin to process any psychological trauma, as well as enabling families to develop coping strategies.

Having a service arrangement where the psychologist meets with all families provides the context for brief psychological input. An example of this would be helping parents to prepare for the

possibility of experiencing mixed emotions following surgery, including relief, positive emotions in relation to the outcome of surgery, as well as emotional exhaustion and feelings of loss and/or grief in relation to the change in appearance. It also allows for an element of screening to identify families who may be having difficulty with any of the issues mentioned above or who may be at greater risk of developing difficulties. A third important aspect to the psychologist meeting with all parents of a baby born with a cleft is that it allows for a positive introduction to psychology which can set the context of psychology being a routine and accessible element of the service which is available to families at any future point.

Role of psychology at the pre-school age

A number of psychological issues can be pertinent for families with a child born with a cleft at the pre-school age. Often, some of the routine developmental challenges at this age, such as weaning, moving from bottles to beakers, sleep, feeding and general behaviour can be more complex for these families. This may be as a result of many factors, such as those directly associated with the cleft, for example feeding issues, as well as more indirect factors. The latter may include, for example, high levels of concern around airways for babies with Pierre Robin Sequence, which can impact on the parents' ability to establish sleep routines. Another common theme is a wish on the part of the parents to compensate for early experiences of stress and perceived distress, which can make the parenting task of establishing limits and boundaries around their child much more difficult. The cleft psychologist may become involved at this stage, working collaboratively with parents to develop parenting strategies and to address the specific complicating factors.

Other psychological issues include the continuing importance of attachment relationships and the child's emerging self-image and awareness of their cleft. Psychologists will work primarily with parents at this age, looking to empower and facilitate them to help and support their child. A big issue for families at this stage is preparing for their child starting at school or nursery. As previously, how the parents feel about this transition is likely to impact on how well the child is able to manage it, so addressing any anxieties, feelings of loss and taking a positive approach to preparing for potential difficulties is paramount.

As reported in a systematic review of the psychosocial effects of cleft

lip and palate,⁴ there is some evidence that children born with a cleft palate in particular may be at greater risk of developmental delay and learning difficulties. The pre-school age may be an appropriate time to carry out a developmental assessment screening, for potential developmental delay or difficulties. This is a role that is often undertaken by cleft psychologists who can then liaise with other appropriate services, such as community paediatricians and pre-school educational services.

For families with a child who is born with a cleft, it is important always to be aware of the burden of care and to avoid adding additional clinic appointments where possible. Two examples of services where the psychologist meets routinely with all families at this stage are a joint appointment with a speech and language therapist when they are due to carry out a 3-year speech assessment, and a joint clinic with the paediatric dentist to see all families when the child is 2 years old. These routine appointments allow for some brief intervention and screening to identify families who may benefit from further input and/or assessment. Additionally, cleft psychologists may also become more intensively involved with individual families when concerns are raised by other professionals or by the family themselves.

Role of psychology with school age children and their families

As the child born with a cleft enters the school age stage, the cleft psychologist may begin to work directly with the child. However, this would almost always also involve the parents. Psychological issues at this stage again cover a broad range. The most frequently raised concern is worries about, and coping with, the reactions of other people, including staring, comments, questions, teasing and bullying. The role of the psychologist may involve helping the child (and/or supporting the parents to help the child) to develop cognitive and behavioural coping strategies. Examples include identifying and shaping the child's understanding of, and attributions about, other people's behaviour, preparing and rehearsing answers to potential questions, explanations and retorts, positive self-talk, as well as how and where to seek support. It may also be important to work with families in helping the child to develop a positive understanding of their cleft and their cleft treatment. The psychologist may also liaise with the child's school, particularly if teasing or bullying is occurring.

Throughout primary school

age children become increasingly aware of appearance and, in particular, any similarities or differences in appearance between themselves and others. This can be particularly pertinent for children who were born with a cleft. Social skills and relationships become increasingly important and increasingly reliant on verbal skills. Again, this can present particular issues for children with cleft-related speech or hearing difficulties. The psychologist may have an important role at several levels, addressing self-esteem and self-image issues, supporting parents in modelling a positive coping approach for their child, developing coping strategies and liaising with schools. It may also be appropriate to work with siblings of the child born with a cleft, who may benefit from input in relation to issues such as separation from parents (eg around hospital appointments and admissions), worries about their sibling and teasing and bullying.

During this school age phase, many children born with a cleft will undergo further surgery, for example speech surgery and alveolar bone graft (ABG) surgery. The psychologist may play a role in supporting families in diagnostic clinics and offering support around any decision-making. The psychologist will frequently be involved in addressing any issues in relation to procedural and parental anxiety. Again this may involve parenting, cognitive and behavioural strategies. Where appropriate, the psychologist will liaise with other professionals, such as ward nurses, play specialists and anaesthetists.

Where resources allow, children born with a cleft and their families will meet with a psychologist at audit clinics at age 5 and 10 and at MDT review clinics. This allows for brief psychological interventions, as well as for identifying families who may benefit from further direct or indirect input from psychology. As before, the intention is that families feel able to contact the service or the psychologist directly when concerns arise and other members of the MDT will frequently identify concerns and signpost the family to psychology.

A major transition between primary school age and adolescence is the move to secondary school. This can be a stressful and anxiety-provoking time for any family, but again may be particularly difficult for children born with a cleft and their family. Issues include having to meet lots of new people and the associated possibility of an intense period of staring, curiosity, comments and questions from peers. It is also much more difficult to ensure that all teachers are aware of any particular issues, such as speech or hearing

difficulties. Many cleft psychology services have developed services around these issues that are routinely made available to children approaching this transition and their families. This may take the form of a transition/school change group for children born with a cleft, often with a parallel group for parents. An alternative model is to provide resource packs to families with tips and advice for children and parents, with a follow-up pack once the children have moved to secondary school.

Role of psychology with adolescents

Many complex psychological issues and tasks arise in adolescence. Appearance concerns often become increasingly important, with adolescents being exposed to significant pressure culturally and through the media in relation to appearance. For adolescents born with a cleft this can be a difficult period. Research points to a number of protective factors associated with psychological resilience which are relevant to any psychological interventions.^{2,5} Adolescence is also a time of increasing consideration of identity. In relation to this the psychologist may support the family as the young person starts to question and develop his/her understanding of their cleft and its meaning and impact on themselves and their family.

Other issues in adolescence include decision-making about surgery as the young person begins to play a more active part in this, bullying, confidence, self-esteem, social anxiety, interpersonal relationships and individuation from family. Again, for an adolescent born with a cleft these issues may be particularly complex.

As for school age children, the psychologist will, where resources allow, meet all adolescents born with a cleft at audit clinics at age 15. Outside of this, psychology services will tend to be individually shaped to meet the needs of the adolescent and his/her family. Common approaches would include cognitive-behavioural therapy (CBT) focusing, for example, on social anxiety or low mood; solution-focused or problem-solving approaches, which may involve elements of acceptance and a positive focus on a preferred future; and exploratory counselling approaches, helping the adolescent to develop a positive view of themselves, which integrates their having been born with a cleft.

Psychologists may also be involved with adolescents and their families around surgery, such as rhinoplasty or orthognathic surgery, in a similar way to

that outlined above. There is a nationally agreed protocol for the involvement of psychology around orthognathic surgery, which is discussed in more detail below as a special group.

Role of psychology with adults born with a cleft

Regional cleft services will also see adult patients who were born with a cleft. Members of the team often see young adults as treatment such as orthognathic surgery and orthodontic treatment is completed. The psychologist may be involved with these patients as part of this treatment. All young adults born with a cleft will be seen in audit/MDT clinics at age 20 and, where possible, will see the psychologist at this point. This is an opportunity for brief involvement and review, aiming to ensure that having been born with a cleft does not interfere in a negative way with the young person's day-to-day life and future plans. It is also an opportunity to instill the knowledge that psychology is an accessible source of help and support if any cleft-related concerns emerge in future. Outside of this, psychological input again tends to be individually tailored to meet need.

Common psychological themes arising for adult patients are familiar, again including concerns about, and coping with, the reactions of other people, in particular comments, questions and staring. There are also the recurrent themes of decision-making around surgery, procedural anxiety and issues in relation to self-esteem and self-image. There may again be issues and anxieties associated with interpersonal relationships and intimacy.

Particular to this age group are issues of considering parenthood and the possible hereditary nature of clefts. Another particular issue that can arise is dealing with improvements in services and improvements in outcomes. This can provide opportunities for further or revisional treatment, which will need careful consideration. It can also result in some complex emotions in relation to comparing treatment experiences for themselves as children and the treatment experiences of children born with a cleft more recently. This can be a pertinent issue for multiple generations where both a mother and child were born with a cleft. The birth of the baby who has a cleft lip and/or palate can precipitate an often emotional review of the grandparents' experiences of having a baby born with a cleft. There may be an important role for psychology with the extended family in facilitating the process of acceptance and adjustment.

Role of psychology with special groups

There are a number of special groups of patients where psychology will be involved in nationally or locally agreed protocols. An example, as mentioned previously, is patients who undergo orthognathic surgery. Where resources allow, psychologists will routinely be involved with this group of patients pre-treatment, pre-surgery and post-surgery.

The psychologist's role pre-treatment would be to help the person to consider and review factors relevant to the complex process of decision-making in relation to orthognathic treatment. This would include issues such as the person's reasons for opting for treatment, including their expectations of the outcome of surgery. Also important is thinking through the implications of surgery, including major appearance change alongside possible negative changes to speech and the commitment to a lengthy process of treatment, including orthodontic work pre and post-surgery. The psychologist will also explore any concerns or questions the person may have as well as specific issues, such as procedural anxiety. This is also an opportunity to carry out a brief mental health assessment and to consider what support is available to the person.

The outcome from these discussions can contribute to the treatment plan in terms of whether orthognathic surgery is considered to be an appropriate treatment and whether any psychological issues need to be addressed prior to surgery. Similar issues will be considered again pre- and post-surgery, with particular attention post-surgery to whether expectations have been met in terms of the surgical results, as well as any anticipated impact on psychosocial issues such as confidence.

Another special group which cleft psychologists may become involved with is patients with non-cleft velopharyngeal dysfunction (VPD) who often access the service through referral to the speech and language therapists. This group of families will often have a different relationship to the service and different concerns and issues in relation to diagnosis, which typically occurs once the child is older, and treatment decisions. Psychological input can vary from routine support in diagnostic clinics to liaison with other professionals and involvement in individual cases, as appropriate.

A third special group of patients are those with a diagnosis of

22q11 microdeletion syndrome which is associated with cleft palate. Typically, psychologists may be involved in liaison, providing information and advice to families and schools in relation to often complex patterns of learning difficulties or specific areas of difficulty. Diagnosis of 22q11 microdeletion syndrome can occur when a baby is born or at any point throughout childhood. There is a hereditary element to 22q11 microdeletion syndrome and this can have implications for families across the generations that may require psychological support through the process of evaluation and adjustment. Another particular issue for this group of patients and their families is the increased risk of developing a psychological/psychiatric disorder in late adolescence or early adulthood.^{6,7} There is an important role for psychology in addressing a family's anxiety in relation to this, as well as screening individuals and offering interventions or referring to mental health services, as appropriate. Service structure is variable with this group. Some cleft services hold or have input to specific 22q11 microdeletion syndrome clinics. In other cleft services, individual referrals to different disciplines will be made as appropriate.

Role of psychology within the multidisciplinary team and in consultation

As well as having important roles working with people born with a cleft lip and/or palate and their families across the lifespan, cleft psychologists also play a role within their respective cleft services. The psychologists will often play a role in shaping clinics and other service developments. Within clinics, the psychologist may aim to facilitate the patient or family's experience, prompting them to think about what concerns and questions they have for the team and what they would like to get from the clinic. Psychologists also have a role in providing 'on the spot' advice, where appropriate, and supporting people in managing any distress associated with decisions made in the clinic or with regard to issues raised.

Within the MDT, psychologists play an important role in providing an additional, complementary or alternative perspective, taking a psychological approach to an issue. This may be in relation to a patient or family, planning treatment or understanding problems; or may be in relation to a service issue, such as service development or communication within the MDT. They may have a role in

offering consultation and a psychological perspective to MDT members, such as specialist cleft nurses, with other health professionals closely involved with the patients, such as anaesthetists and ward staff, and with other services, such as mental health services. There is also a liaison and link role for cleft psychologists between patients or the MDT and other agencies, such as schools, educational psychologists and social services.

Conclusion

Psychologists are important members of the regional cleft services' multidisciplinary teams. There are psychological issues and difficulties that can occur across the lifespan, which psychologists may address directly or indirectly. They also have an important role within the MDT and across the broader multi-agency network.

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