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The role of the Clinical Nurse Specialist from the perspective of families of children born with CLP in the UK: a qualitative study

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Abstract

Purpose/aim

This qualitative study explores families' perspectives of the CNS following diagnosis of CLP and while preparing for / following lip or palate closure and other events on the cleft treatment pathway in the U.K, signposting the different ways in which they support parents and families.

Design

Families with children on the 'cleft treatment pathway' were recruited from multiple regions across the UK. In-depth interviews were conducted with 24 parents of children born with CLP.

Methods

Thematic analysis identified four key themes: Relationship with clinical nurse specialist, Information provision, Pre-operative care and MDT, and Post-operative support.

Results

Clinical Nurse Specialists are a highly valued point of contact and act as a trusted mediator between families and other professionals in the

multidisciplinary team (MDT). Clinical Nurse Specialists are important gatekeepers in providing support, information and developing trust following diagnosis, birth and throughout the cleft treatment pathway.

Conclusion

The present findings affirm the emotional, social and informational support that the CNS can offer parents whose children are on a cleft treatment pathway. The CNS is a vital member of the cleft service MDT.

Keywords: Cleft Lip and / or Palate (CLP), Clinical Nurse Specialist (CNS), Cleft Treatment Pathway, Multidisciplinary team (MDT), Centralisation, Qualitative

Introduction

Cleft lip and / or palate (CLP) is a congenital condition that occurs in approximately 1 /700 live births ¹. The cleft may occur unilaterally or bilaterally in either the lip (approximately 25% of cases) or palate (around 40%), or in both (about 25% of cases). In the United Kingdom (UK) a cleft lip is usually diagnosed ante-natally at the 20 week scan allowing for early planning of surgical repair: this can improve overall satisfaction with cleft care ².

After receiving a diagnosis of CLP in the UK, families are referred to the cleft service and contacted or visited by the Clinical Nurse Specialist (CNS) within 24 hours. The role of the CNS is to provide support to parents following diagnosis and after the child's birth, helping them to understand prognostic and treatment implications as well as more specific issues such as feeding. ^{3 4 5} The families' involvement with the CNS continues as the child embarks on the 'cleft treatment pathway'. During these periods of contact parents and nurses explore details of surgical procedures to ensure the family is informed about the care of their child pre- and post-operatively. The cleft treatment pathway can be an overwhelming experience for parents of children born with CLP particularly regarding delivery of information, decision making, and preparation for surgery. ⁶

It is acknowledged that a diagnosis of CLP may register as a stressful event for parents and their families.⁷⁸ The way in which parents adapt to this life event, and the support they receive may influence how they and their child born with CLP adjust to the condition.⁷⁹ Although many studies record the social and emotional support that families and friends can offer families when significant health conditions are diagnosed, families also require communication with the health care professionals who control the provision of information.^{10 11} Families require professionals that are caring, confident and comfortable in sharing their own feelings and who enable families themselves to talk, show their feelings and ask questions.⁷⁸ Furthermore, parents of children born with CLP have high information needs, not only in terms of content (cleft treatment pathway, feeding, surgical options, etc), it also needs it to be 'accessible, individualized, and paced around each family's needs'.¹² This informational support is provided by the cleft service team, and especially the CNS.¹³

It is important to note that families who have a child born with CLP are likely to have their own perceptions about the cause, consequences and treatment cleft lip and / or palate. These 'illness representations'¹⁴ may be at odds with the representation of cleft lip and / or palate in the context of the 'biomedical' model of illness¹⁵ and have implications for communication with health

professionals and treatment for CLP. In addition to providing support for feeding and cleft care in early infancy, the role of the CNS is to help families prepare for their child's surgery, manage expectations of living with a cleft as well as those that are relevant both pre- and post-surgery and communicate with specialist and non-specialist professionals who are treating the child ².

The CNS' role should be to ensure a smooth progression from diagnosis to delivery and then on throughout the treatment pathway and continuing care in the community. In addition, they are well-placed to encourage compliance with treatment protocols e.g. to enhance wound healing.⁴

Despite the specialised and supportive care provided by CNS', little research has been devoted exclusively to recording and exploring the emotional, social and informational support they provide. Nelson and Kirk's qualitative research with 27 families revealed the high esteem and respect attributed to CNS' by the families they work with:¹⁶ *'having one dedicated and available person in each cleft team who parents can contact when needed could be a valuable investment in parents' adjustment to the child's diagnosis and may possibly strengthen the treatment-related cooperation between parents and health professionals* (Feragen et al, 2017, p.78).¹⁷ However, in each of these studies the CNS role was reported as a secondary or incidental finding.

Our study offers a point of departure by attending primarily to the role of the CNS, as a key provider of social and informational support, to families with children born with CLP. Moreover, we contend that the CNS can be a gatekeeper of medical knowledge whose approach can help to circumvent the top-down, hierarchical social structure of the CLP treatment pathway, as perceived by parents and families.¹⁸ The CNS has to make important decisions regarding the dissemination and content of information between the MDT and families. They determine what information to share as well as how, when and where to share it.¹⁸ This qualitative study explores families' perspectives of the CNS following diagnosis of CLP and while preparing for / following lip or palate closure and other events on the cleft treatment pathway in the U.K, signposting the different ways in which they support parents and families.

Method

Procedure

This study is nested within a programme of qualitative research undertaken to develop the Cleft Lip and Palate module for www.Healthtalk.org¹⁹ Participants

were recruited through a variety of methods including social media including the Facebook pages of organisations such as CLAPA (Cleft Lip and Palate Association) and www.Healthtalk.org. All potential participants were sent an information sheet via email by AS. Participants were given a period of 1-2 weeks before they were re-contacted by AS for their agreement to be interviewed either by video or audio only. Those agreeing to participate signed a consent form prior to interview.

In-depth interviews were conducted in two parts. First, parents were invited to tell their story of having a child born with CLP. Second, a topic guide was used to further probe and prompt participants, to generate richer data about their experiences. An advisory panel of lay people with personal experience of CLP, HCPs and academics assisted in the development of the topic guide which included topics pertinent to the diagnosis and birth of a child with CLP and engagement with cleft services in the UK.¹⁹

Ethical approval for the study was granted to www.Healthtalk.org / Health Experiences Research Group (HERG), University of Oxford by Berkshire Research Ethics Committee for Health Research.

Participants

Twenty-four parents with a child born with CLP were interviewed by AS.

Fifteen mothers and two fathers were interviewed alone and eight people took part as couples. The age of children with CLP ranged from 7 months to 19 years and they were born with a mix of cleft formations (see Table 1).

Twenty-two interviews were conducted face-to-face in video or audio format in family homes and two were telephone-based interviews.

Analysis of interview data

All transcripts of the audio data were transcribed verbatim. A thematic analysis was undertaken following the guidelines for thematic analysis stipulated by Braun & Clarke (2006).²⁰ Thematic analysis is described as a flexible and useful research tool for psychological research, which can potentially provide a rich and detailed, yet complex account of data.¹⁵

First, the analysts AS and SR read and reread the transcripts to familiarise themselves with the dataset. Initial codes were identified and an initial coding frame was developed on a sub-sample of 4 interviews. Code discrepancies were discussed until consensus was achieved and a definitive coding frame was generated comprising 17 codes. Next, all transcripts were coded using

NVivo, Version 9. ²¹ AS and SR identified emerging themes and these too were reviewed and discrepancies discussed until consensus was achieved. Finally, four themes emerged that were pertinent to the role of the CNS in the cleft treatment pathway:

- Relationship with Clinical Nurse Specialist
- Information provision
- Pre-operative care and MDT
- Post-operative support

Relationship with Clinical Nurse Specialist

Following diagnosis

Following a diagnosis of a cleft at the 20 week scan, family care shifts from the sonographer to the CNS who usually makes contact within 24 hours of referral. After receiving such a diagnosis, families report that the CNS provides valuable and appropriate family-centred support:

And that was, that made all the difference, that first telephone call with the cleft team, because she (CNS) was able to reassure us..... she was fantastic, she was really, really good. And I think that's, that's invaluable: I think that

first point of contact, I think for every parent, once the baby is diagnosed um you want to be put in touch with the cleft team. (25MN, Mother)

In this way, the CNS is perceived as someone who has access to medical knowledge but doesn't exude the cultural authority of doctors and other senior healthcare professionals that can be intimidating for parents.

After the initial uncertainty following diagnosis, many families found that meeting with the CNS was a reassuring experience.

We were given a leaflet. And we were told that a cleft nurse would give us a call to arrange a meeting and discuss it further..... [she] actually rang us that exact day and she popped over and she went into a lot of detail and some pictures and stuff. (16KR, Mother)

These parents valued the personal contact they have with their CNS, offering both emotional support to them at the early stages of diagnosis.

After the birth

Once a child with CLP is born, care needs to be more specialised and the role of midwives and health visitors is usually superseded by the CNS. This recognition of the expertise of CNS regarding the care of CLP babies in post-natal care can help parents adjust to being new parents:

Further down the line the health visitors were always quite hesitant to give me advice with [name]. They'd always be very much, "Well, you know, because she's got a cleft palate I don't really want to say too much," would always be kind of referring me back to the cleft team. So in a way my the specialist nurse in the cleft team became a bit like, you know, my midwife, health visitor, kind of [laughs] she, you know, she was everything. (31JK, Mother)

The relationship with the CNS continued to develop to the extent that some families considered the CNS to be a friend.

I honestly think that they were amazing. I don't think they could do any more. I, I think they just need to keep doing what they're doing. They make you very aware of what's going to happen. They look after you whilst you're going through surgery and everything. And you actually kind of end up making a bit of a friendship with your cleft nurse. (016KR, Mother)

Families also felt that the CNS knew their child and what potential treatment they were likely to need in the future.

Yeah because she gets, they get to know your son, so they, they've known about your child before they were even here. They meet them, they help them, you know, feed and get through the hard times. And you, I don't know, they're just really great. They're just really good: they're really helpful, and any worries or concerns you have they just clear it straight up. (016KR, Mother)

Families felt comfortable with phoning their CNS with any concerns they may have knowing the CNS would be available to talk to them.

Well I have a cleft nurse assigned to us as a family. So I have her mobile. I text her occasionally if I'm worried about [name] feeding, or the way that she is, and she's always available for me to talk to. (RL005, Mother)

Support from the CNS could also be of a practical nature:

I mean when the cleft nurses come round, like sometimes they used to like take him for me so that I could run to the toilet, or I could run and heat up my food

and bring it back to the bed. So I mean they've just been supportive in any way, every way you can imagine they've been supportive. (17SS, Mother)

Thus parents clearly expressed the quality of their relationship with the Cleft CNS. Indeed, the CNS is acknowledged to be knowledgeable and a reliable source of information but the emotional and social bond that parents describe moves the parent-CNS relationship beyond the conventional patient-HCP relationship. CNS' are described as akin to friend and become members of the patients' social network. The legacy of the relationship with their CNS can be profound and long lasting.

Information provision

If CLP is not detected at a pre-natal scan then the care of an infant born with CLP usually starts with non-cleft specialists such as midwives. These HCPs may lack detailed knowledge about cleft care and the treatment pathway and may struggle to provide detailed guidance or explanation. Many parents in this situation reported searching online for information about CLP, often raising more questions than answers and, not surprisingly, adding to the distress felt.

....and especially before we spoke to anybody from the regional cleft team, you know, we didn't, we didn't know anything about this condition that we'd been told she had. And so we were just left to kind of flick through a ring binder of strange diagrams and you know, browse the web to see what information we could glean from various websites. But it was really daunting. We didn't know anything about it, and we didn't even know what was going to happen to [name] and how it was going to progress. So, yeah, it was, it was very scary.

(17SS, Mother)

It is not until families meet with CNS that they are able to fully comprehend what the diagnosis of CLP means for the future health of their child. Although the CNS' also provide leaflets and booklets, in addition they can give detailed and realistic explanations of potential impairment and treatment needs:

The cleft nurse was brilliant at explaining it and gave us some booklets about it. So that kind of helped us to get our heads round it. And then we thought well, you know, because we were having problems with feeding, we were kind of like, "Well that's the bit we need to think about." And we kind of the two things that we knew to think about for further down the line were the possible

glue ear and the speech problems. And we knew that she would be facing surgery when she was kind of six months.” (31JK, Mother)

Pre-operative care and MDT

After providing initial support and information about diagnosis of a cleft, the birth and how to feed a child with CLP, the CNS is also responsible for introducing families to other cleft specialists and the multi-disciplinary team (MDT). Families’ first experiences of the MDT can be scary and overwhelming due to the number of different specialists involved and the discussion of potential treatment:

There was the surgeon, the surgeon’s trainee woman, a speech therapist, a dentist, [name] our cleft nurse, and other, there were just loads of people.

And it was scary, and I don’t think they should have done it that way.

Yeah it is a bit daunting that, I suppose, yeah, obviously sat in a room full of people all. Phew obviously it’s a bit of an upsetting situation going in and Dr [name] telling you about, you know, what they’re going to do with your son, operate on him, and this, that and that. And then you’ve got plenty of people sat round that you’ve never met before all, you know, staring at you, taking notes. (10MQ, Father with cleft lip)

However, most families reported that they felt well supported in managing their perceptions and expectations both prior to the child's operation and during the initial surgery.

The lead up to the operation was the most awful two weeks ever, because we only got two weeks' notice. But if it's got to be done, it's got to be done. I suppose it being so soon it didn't give you as much chance to worry and think about things. But our nurse came out and gave us a run through of what would happen when we got to the hospital, and the post-op, and then actually going up onto the ward and seeing the anaesthetist. (32LS, Mother)

The CNS was seen as a mediator between the families and other specialists within the cleft team so families knew what to expect and when.

We were told that they were going to refer us to the Hospital, and it wasn't until the nurse arrived the following day from the Children's Hospital that we really started to see what was going to happen, and she talked us through what the pathway was, you know, what all of the different appointments would be for [name] along the way, and when she was likely to have an

operation. And, you know, it was we were a lot more clear about what, what we were going to have to kind of go through. (18MH, Mother)

Mother: They (CNS) were the ones who'd got answers basically to everything and they were the ones that dealt with it first-hand.

Father: and if you've got any worries or, you know, any queries about anything, you contact them and they'll put you in contact with the team get you an appointment with the right team and the right person and the surgeon if you need to so...

Mother: They're on the doorstep if you want them as well. That's good, you know, they come to your house, you know. Yeah they arranged a couple of appointments and brought, you know, even brought things a little bit forward as well so (023AC, Mother and Father)

Families believed the CNS was the most trusted source of information available to them regarding CLP:

I would say have as much contact with your cleft nurses, like your cleft team as much as possible. And they are kind of, rather than speaking to other people who don't really know what you're going to be going through, I would advise to

Speak to your cleft team, because they know everything, they have the answers to everything, they can prepare you a lot more than other people. Rather than asking your friends or your family that hasn't been through it. Obviously friends and family are a good support network. (17SS, Mother)

Post - Operative support

Families received support from the CNS following the first operation and the CNS also advised them about care for their child following surgery:

And they (CNS) explain to you what can be eaten and everything after the surgery, because it has to all be pureed, and how they drink and things like that. So it was it helped a lot because it gave me such a clear view of exactly what was coming. They explained everything like, "You're going to be sat, you have to hold them, have the gas mask over their face, and then we'll take them away." (24DB, Mother)

When comparing the level of care received after diagnosis of CLP up to the first operation some families reported that they had less face to face contact with the CNS after their child's surgery but that s/he was still available on the phone.

....she would come the first few weeks she came every week and since then she's come the week after each operation to check the stitches or whatever, and that's been about it really. (TP004, Mother)

You get given all the leaflets when you're in hospital: what they can eat, what they can't eat, and then after X amount of weeks that changes and then you can introduce different foods, so you've got all that. Then the cleft nurse comes out to check and see how it's healing. They're always at the end of the phone, so if I had any questions or concerns: pick up the phone and ring her straight away and she comes, she's usually there within the next day or two. If it's urgent she'll try and make time to come straight away or go to the hospital. So it was brilliant. After the operation you don't see the cleft nurse very much though. (24DB, Mother)

We were really surprised. Obviously he was uncomfortable and it wasn't very nice for him, but within a couple of days it was like he hadn't even had the operation. Yeah, yeah we were pleased with how they were dealing with us. Our cleft nurse was really helpful: if we had any questions we could ring her. (008MT, Mother)

Discussion

This qualitative study explores families' perspectives of the CNS following diagnosis of CLP and while preparing for / following lip or palate closure and other events on the cleft treatment pathway in the U.K, signposting the different ways in which they support parents and families.

In-depth qualitative interviews were conducted with families of children born with CLP who were receiving or had received care from cleft services in centres across the UK. To our knowledge, there have been no studies that have primarily explored families' experiences of the role of the CNS in the cleft service in the UK although similar work has been undertaken regarding families' experiences of the UK cleft service in general.¹²

The interviews with parents suggest that the CNS' are a highly valued point of contact and a trusted mediator between themselves and specialists within the MDT. Families appreciate the high level of practical and emotional support following diagnosis and birth of their child which is focused on skills for feeding and information about the cleft treatment pathway. However, after the early surgeries, ongoing face to face support from the CNS was perceived to be less accessible to families.

These accounts document the extent of ‘informational support’ or information provided by the CNS for parents and families across the cleft treatment pathway.¹³ This type of support was helpful when key decisions about the child’s treatment were needed. The CNS’ ability to ‘translate’ medical information and jargon for a lay audience also registers as a form of ‘appraisal support’ such that it involves the communication of information relevant to self-evaluation.¹³ Indeed, the way in which the CNS communicate serves to empower parents and demystify the cultural and medical authority of the medical institution. In both ways, the CNS’ provide a tangible service or instrumental support for parents.¹³

Previous research and implications for cleft service

Previous research has highlighted implications for policy and clinical practice in the domain of cleft care regarding families’ experience of emotional and social wellbeing throughout the cleft treatment pathway.^{17 18.}

Our findings suggest that the CNS may be considered as a ‘pivotal gate keeper’, controlling and interpreting the flow of information and its content between the MDT and parents.²² Their role is to process and modify medical knowledge and by doing so create a social relationship with parents that challenges the

top-down, paternalistic and hierarchical model of communication which the parents are encountering for the first time. The CNS becomes a mediator for aligning families' perceptions re: the cause, consequences and treatment of cleft lip and / or palate¹⁴ in the context of the 'biomedical' model of illness.¹⁵ The advantage of the CNS enables parents to participate in the medicalisation process rather than being passive recipients.

Our study provides further evidence that emotional support is provided by the CNS within the first 18 months of a child's life.¹⁶ However, our findings suggest the opposite of Nelson's conclusion that a 'an extended, flexible program of emotional and practical support around the families' needs on an ongoing basis'.¹⁶ Despite the emotional and practical support families receive from the CNS following diagnosis, birth and leading up to first surgery, those in the present study perceived that post-operative support was not available following surgery. Thus it is postulated that a reduction in face to face contact may be a consequence of limited nursing resources resulting in increased reliance on telephone support at the request of families.

The close relationships that often develop between CNS' and their families during the first year of the child's life may give the CNS' a greater awareness of

families at risk of future emotional and affective issues²³. They could be supported in this screening role through collaboration and training with psychologists in the cleft service in order to provide counselling to families as appropriate. This could be particularly beneficial in cleft teams that do not have psychologists due to disparity in cleft services commissioning in the UK.²⁴

Strengths and limitations

A major strength of this study is that the interviews were conducted with families from multiple cleft centres across the UK whereas previous research has examined the provision of treatment and support in individual cleft services.¹⁶ Furthermore, recruitment to the study was facilitated through a variety of national strategies rather than through cleft HCPs and so this provides a more representative (although still self-selected) sample. A limitation is the self-selected sample may overrepresent positive communication experiences with a CNS or conversely families with particularly negative experiences of the cleft service.

Conclusions and future directions

The present findings affirm the emotional, social and informational support that Cleft CNS' offer to parents whose children are on a cleft treatment

pathway and highlights their role as vital members of the MDT. Within their professional role the CNS acts as a mediator for aligning families' representations of CLP in the context of the 'biomedical' model of illness in which they operate. However, there is a perceived need for ongoing parental support after treatment has begun, potentially including psychological support for some.

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Disclosure statement

The authors declare that they do not have any financial interests or other benefits relating to this research.

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Table 1. Details of parents of children born with cleft (N= 24).

| Interviewee | Mother / Father | Age | Child / Cleft type | Ethnicity |
|--------------------|------------------------|------------|-------------------------------|------------------|
| Christie | Mother | 41 | Son with Cleft lip and palate | White British |
| Natalie | Mother | 46 | Son with Cleft lip and palate | White British |
| Mandy | Mother | 29 | Son with Cleft Palate | White British |

| | | | | |
|--------------------------------|-----------------------------------|---------|---|------------------|
| Tamsin and Andrew | Mother / Father | 29 /33 | Son with bilateral cleft lip and palate | White British |
| Rhiannon | Mother | 27 | Daughter with cleft palate | White British |
| Matt | Father | 29 | Daughter with cleft palate | White British |
| Rebecca and Russell | Mother / Father | 23 / 30 | Daughter with cleft palate | White British |
| Michelle | Mother | 33 | Son with cleft lip and palate | White British |
| Paul | Father | 33 | Son with cleft lip and palate | White British |
| Milly and Michael | Mother / Father (cleft lip) | 20 / 23 | Son with cleft lip and palate | White British |
| Mally | Father (cleft lip) | 62 | Son with cleft lip | White British |
| | Mother / Father | 37 / 36 | Son with cleft lip and palate | White British |
| Alison and Chris | Mother / Father | 39 / 44 | Son with cleft lip and palate | White British |
| Iva | Mother | 29 | Son with cleft lip | Bulgarian |

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| Kerrey | Mother | 27 | Son with bilateral cleft lip | White British |
| Safiya | Mother | 21 | Son with Cleft lip and palate | Mixed White and Asian |
| Maria Z | Mother | 32 | Daughter with cleft palate | White British |
| Suzi | Mother | 51 | Daughter with cleft palate | White British |
| Diane and Andy | Mother / Father | 31 / 36 | Son born cleft lip and palate | White British |
| Della | Mother | 24 | Son and daughter born Cleft palate and PRS /Sticklers Syndrome | White British |
| Mary Y | Mother | 46 | Son born with cleft lip and palate | White, Australian |
| Maria | Mother | 41 | Daughter born cleft palate / late diagnosis Stickler syndrome | White-Chinese |
| Jenny | Mother | 36 | Daughter with cleft palate | White British |

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| Laura | Mother | 22 | Daughter with cleft palate | White British |
| Mary W* | Mother | 53 | Daughter with cleft lip and palate | White British |