Communicating with Health Care Professionals:

Experiences within the Cleft Care Service

Andrea Waylen, Sarah Ryan and Aidan Searle
Overview

• What do we know already?

• Methods
  – Cleft Care UK
  – healthtalk.org

• Findings
  – Diagnosis and feeding

• Conclusions and implications
Previous Research

• **1998 CSAG report**
  – Centralisation
  – Multi-disciplinary teams

• **Patient-clinician communication (cleft)**
  – Diagnosis: ante-natal / post-natal
  – Lack of clinical knowledge
    • Feeding, child’s health, treatment and cause
  – Additional information (Google)
Standards and Guidelines

Standards:

1. All babies born with a cleft lip and/or palate are to be diagnosed at birth.
2. All babies are to be referred by a relevant professional to the cleft team within 24 hours of diagnosis, including antenatal diagnosis.
3. A Clinical Nurse Specialist (CNS) should visit within 24 hours of receiving the referral, or where there has been an antenatal diagnosis, make contact within 24 hours.
4. All babies should have a nationally agreed feeding assessment prior to the introduction of assisted feeding.
5. At the first visit a feeding plan which supports the mother's preference for feeding, should be devised and documented.
6. All mothers who choose to breastfeed should be offered an electric pump for as long as they require, at no cost to themselves.
7. All parents are offered:
   - Counselling and support
   - Verbal and written
   - Contact with a family
   - Written information
8. All babies affected by orofacial clefts need access to a multidisciplinary service.
9. All babies should be visited at home by the CNS within one week of discharge.

TABLE 1 National standards for care of a baby with an oral cleft.

Academy of Breastfeeding Medicine

A worldwide organization of physicians dedicated to the promotion, protection and support of breastfeeding and human lactation.

UKSBM Conference December 2014
Methods

• **Quantitative study (2010 - 2012)**
  – Cleft Care UK
    • Centre survey (N= 141 self-report questionnaires)
      – Satisfied with communication and support

• **Qualitative study (2012 – 2014)**
  – 24 interviews with parents
    • Children aged 6 months -13 years
  – HTO module
23 Topics:

- **Diagnosis** (6)
- **Birth and early years** (3)
- **Treatment for cleft** (8)
- **Growing up with a cleft** (4)
- **Advice for others and professionals** (2)
Diagnosis 1

• **Ante-natal:**
  – 20 week scan: (cleft lip only) Sonographer – sometimes Paediatricians
  – Clinical Nurse Specialist – contact / visit family within 24 hours of diagnosis

• **Post-natal**
  – Duty to detect isolated cleft palate by torch test
  – Often goes undetected despite feeding problems
Diagnosis and communication

Yeah they were saying that the cleft was very wide [um] and they were saying that there were other syndromes they could be involved in, like breathing problems, the baby might not be able to breathe, you know. RM: And eating. RF: [um] And then they, yeah, just presented us with three options… [um] The top one being termination. And then it was, “Go [er go, go away for the weekend and think about it (Andy and Diane)"

And she came and she kind of [um] [pause 2secs] gave us a lot more information and kind of [pause 5secs] sort of talked us through a bit more what to expect. …… so when I’m looking up online I see lots of children with cleft lips, looking sort of quite scary some of it, and what she had was [um] before and after pictures. She had, “Look, here it is, child born with cleft lip, looks pretty scary, this is what they look like three months later.” I’m like, “Oh well that’s kind of OK.” And that was really helpful kind of going actually, you know, that’s [um] [pause 2secs] can be fixed. ………And, and she sort of talked us through, yeah, a bit more what to expect.
Diagnosis 2

• **Ante-natal:**
  – 20 week scan: Sonographer – sometimes Consultant (cleft lip only)
  – Clinical Nurse Specialist – visit family within 24 hours of diagnosis

• **Post-natal:**
  – Duty to detect isolated cleft palate by torch test
  – Still may be undetected despite feeding problems
Feeding a baby born with cleft

- Some mothers experienced depression
  - Inability to breastfeed
- Positives of bottle feeding
  - Fathers can get involved
  - Parents knew babies were getting sufficient milk

But if [pause] if there is a problem with feeding, why isn’t the mouth looked inside straight away? .... When I think back, yeah, when I think back I was given, you know, “Keep trying. Try a breast pump, express and we’ll feed the baby for you. You’re not doing it right.”

[um] The lead speech and language therapist. [er] She came to see us, 24 hours later she said, “Right, I’ve looked at this baby,” she was fantastic. She saw the tube, she said, “Oh no, we don’t need a tube here. We’re going to try to do it together.” And, yeah, and they took the tube out, she was there, and she helped me with that [er] feeding technique, using the bottles, and he was, he was, he was [pause] I managed to, to learn, and they discharged us.
Conclusions and Implications

• **Divergent findings**

• **Continued training for appropriate HCPs**
  – Compassionate, knowledgeable
  – Continuing development of standards
    • And use of those that already exist

• **Comprehensive written information and photographs**
  – At time of diagnosis / soon after birth
  – Reliable websites for “googling”
Acknowledgments

• All families who took part in the CCUK study
• All families who participated in the HTO interviews
• Steering group for the HTO project
• NIHR RfPB Project Grant (PB-PG-0110-21049)
• NIHR Programme Grant for Applied Research scheme (RP-PG-0707-10034)
• Pauline Nelson
Thank you

Any questions?

andrea.waylen@bristol.ac.uk