



ORIGINAL ARTICLE

Health professional communication and the diagnosis and care of infants born with cleft lip and palate in the U.K.

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Abstract *Objectives:* A qualitative study was conducted to explore family experiences of communication with health care professionals following the diagnosis and birth of a child with cleft lip and/or palate in the United Kingdom. Twenty four interviews were conducted with families who had a child born with cleft lip and/or palate. Analysis of the data revealed that a diagnosis of cleft lip and/or palate may not be handled sensitively by the non-specialist health professionals who are providing care. Furthermore, a lack of knowledge and inadequate support may continue after the child is born as some health professionals do not provide accurate or appropriate advice relevant to this condition.

The findings have implications for current clinical practice with regard to the diagnosis and care of infants born with cleft lip and/or palate in the United Kingdom. These implications are discussed within the context of improving and developing communication in the diagnosis and care of children with cleft lip and/or palate and Experienced-Based Co Design.

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Introduction

Cleft lip and/or palate (CLP) is a congenital condition that occurs in approximately 1/700 live births (Mossey et al., 2009). The cleft may be found, 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 (U.K.) a cleft lip is usually diagnosed ante-natally at the 20 week scan and therefore a sonographer is the most likely health professional to break this news to parents. Evidence suggests that pre-natal diagnosis enables the parents to prepare for the unique neonatal feeding requirement of infants with cleft, allows for early planning of surgical repair and can improve overall satisfaction with cleft care (Robins et al., 2010). However, cleft diagnosis during ultrasound may sometimes be missed due to lack of attention to the face in the absence of risk factors, position of the foetus, maternal obesity, multiple pregnancies, reduced amniotic fluid and the reduced skill of the sonographer or other diagnostician (Klein et al., 2006). Consequently, an isolated cleft palate may not be diagnosed until a neonatal examination is conducted. Even then, a cleft palate may be missed if the examination is not thorough (Habel et al., 2006).

Support following a diagnosis of cleft lip and palate

The way a diagnosis of CLP is delivered can have long-term effects on how families adapt to their child's condition (Fallowfield, 1993; Krahn et al., 1993). A sensitive and effective diagnosis is important for the development of cooperative relationships between families and their health care providers (Forth, 2003). Alternatively, an insensitive diagnosis of CLP may result in high levels of anxiety and stress, possibly initiating feelings of grief due to the loss of a 'perfect' child (Forth, 2003); the associated distress may be comparable to trauma or bereavement (Aite et al., 2011; Farrimond and Morriss, 2004). Regardless of whether diagnosis occurs pre-natal or at delivery, parents may express dissatisfaction with the way it is managed (Nusbaum et al., 2008). At this time, parents want to communicate and share information with knowledgeable and sympathetic medical staff (Robins et al., 2010) who are in control of the informing conversation, who are caring, confident and comfortable in sharing their own feelings and who enable the parents themselves to talk, show their feelings and ask questions (Byrnes et al., 2003;

Fallowfield and Jenkins, 2004). They require support and accurate information, delivered in a manner that acknowledges the emotional and also the 'biographical' disruption of the pregnancy (Nelson et al., 2012a,b; Strauss et al., 1995) and which allows them to ask questions (Strauss et al., 1995; Harrison and Walling, 2010). They require clear written information and details of how to contact support groups and others in a similar situation (Nelson et al., 2012a,b). Delivering unwelcome news in this way provides better outcomes for parents by reducing the amount of stress and anxiety they perceive (Strauss et al., 1995).

There are a variety of guidelines for breaking bad news (Harrison and Walling, 2010; Baile et al., 2000; SCOPE, 2003; Rabow and McPhee, 1999) but there is also evidence that some healthcare professionals are unaware of them (Fallowfield and Jenkins, 2004). Furthermore, health professionals may misunderstand parental needs at this time (Berk et al., 1999; Forth, 2003) and they may have little knowledge about the treatment and prognosis of specific congenital conditions. Sonographers have reported that they are most concerned about time constraints and the unpredictability of women's reactions when breaking bad news; however, they also note that their own perceptions of stress at this time are reduced if they worked in an institution where disclosure guidelines are in place and followed (Hammond et al., 1999).

After receiving a diagnosis of CLP, families should be referred to the cleft service and contacted or visited by the Clinical Nurse Specialist (CNS) within 24 h. 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 (Bannister, 2008; Beaumont, 2012; Bessell et al., 2010).

Post-natal support

Breastfeeding support is an integral part of post-natal care for all mothers and should comprise appropriate advice, support and encouragement (Beaumont, 2012; Lindberg and Berglund, 2011). Unfortunately this is not always provided and parents of children born with a cleft have, historically, expressed dissatisfaction with the way that breastfeeding support and information is provided, often because staff lack knowledge and expertise (Nelson et al., 2012a,b; Lindberg and Berglund, 2011). Infants may experience difficulties in latching on and creating an effective seal on the breast and co-ordinating sucking, swallowing and

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