

## **How do parents' experiences compare, when receiving an antenatal versus postnatal diagnosis of complex congenital heart disease for their infant?**

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### **Abstract**

**Aim:** To explore parents' experiences at the time of diagnosis of complex congenital heart disease (CHD) for their infant, and to compare whether experiences differ when receiving an antenatal versus postnatal diagnosis.

**Background:** The time point at which parents receive a diagnosis of CHD has changed over the years due in part to advancements in fetal ultrasound; however, CHD still remains undiscovered until after birth in some cases. The psychological impact of time of diagnosis on parents' experiences has not been well researched.

**Method:** Descriptive and thematic analysis of primary mixed qualitative and quantitative data, collected during 2012-2013, from an online survey of parents (n=28) of infants who had undergone stage one surgery for a functionally univentricular heart.

Findings: Four themes emerged: parents' understanding of the condition, parents' feelings at the time of diagnosis, sources of support and sources of additional information.

Conclusion: There are implications for practice in terms of who provides the diagnosis and more importantly how well this is explained. Professionals need to assess parents' emotional status, information needs and level of understanding irrespective of time of diagnosis, so that support is individualised, sensitive and time appropriate.

## **Introduction**

Congenital Heart Disease (CHD) is reported to be one of the most common forms of congenital malformation affecting newborn infants (Rychik et al, 2013); with prevalence in the UK reported as 6-8 per 1,000 births (British Heart Foundation 2013). Complex conditions, such as hypoplastic left heart syndrome (HLHS), are relatively rare occurring in only 1% of all CHD; with an occurrence of 1 in every 5000 babies (Little Hearts Matter, LHM, 2015). HLHS incorporates a mixture of anatomical problems on the left side of the heart, the severity of which can vary. Generally, the left ventricle is very small (hypoplastic), the mitral and/or aortic valve may be narrowed, blocked or not developed at all; the aorta is often hypoplastic and there could be an atrial septal defect (LHM 2018). The hypoplastic left ventricle is unable to support the systemic circulation after the infant's birth, when normal physiological changes from foetal circulation occur, including closure of the Foramen Ovale and Ductus Arteriosus during the first few days to weeks of life. Post-natal diagnosis occurs when a deteriorating infant presents either before discharge from the Maternity Unit, or is identified by their Community Midwife, General Practitioner or following parents calling for an ambulance via 999 and being transferred to a tertiary centre. Failure to

prenatally diagnose and therefore promptly treat these babies, who have the potential for cardiovascular collapse, is linked to increased mortality and morbidity (Sharland, 2012, Gardiner et al, 2014; Brown et al 2015).

Despite over 25 years of antenatal screening for foetal cardiac anomalies in the UK, standards for correctly interpreting cardiac ultrasound were identified as not being uniform nationally (Sharland, 2012, British Congenital Cardiac Association, 2012), resulting in discrepancies in detection rates at the time of obstetric screening. The Congenital Heart Disease Service Specifications (NHS England, 2016: 215-217), refer to the British Congenital Cardiac Association Fetal Cardiology Standards (BCCA 2012:2) designed for paediatric cardiology tertiary centres offering a fetal cardiology service and the National Standard for Fetal Cardiac Screening (Public Health England, 2015), which set standards for the fetal anomaly scan. The overall aim being to maximise performance of the screening, ensuring timely reporting; hopefully resulting in increased detection and reduced variance across the UK.

As well as improving chances of survival, increasing detection and antenatal diagnosis gives parents more time to prepare for the journey after their infant's birth (Sharland, 2012). In a mixed methods study, now over 10 years old, time to prepare was found to be important to parents who received a prenatal diagnosis, likewise some parents in a postnatal group would have preferred an earlier diagnosis for that reason (Brosig et al, 2007).

Receiving the diagnosis was found to be a critical time for all parents (Brosig et al., 2007), as both prenatal and postnatal groups scored higher on the Brief Symptom Inventory (BSI) than test norms; however, there was no significant difference between groups on the BSI scores. The BSI is a psychological self-report scale with 53 items

each rated on a five-point distress scale and refers to nine dimensions, which provide a profile of the individual's psychological status: somatisation, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism (Derogatis & Melisaratos, 1983). In the prenatal group 58% of parents had clinically significant BSI scores at diagnosis, as did 71% of parents receiving a postnatal diagnosis; there was no clinical significance between the groups for this finding. Qualitatively, similar themes emerged for both groups around anger, fear, disbelief and grief. The BSI was also used to explore the association of timing of diagnosis with parental stress and modifiers of this relationship in another more recent study (Pinto et al., 2016); conversely, parents of prenatally diagnosed infants with CHD were found to have lower anxiety and stress than those diagnosed postnatally after adjusting for severity.

Parental experiences and need for information following a prenatal diagnosis of CHD have been qualitatively explored (Carlsson et al, 2015). Parents had difficulty sorting out information due to their emotional chaos and indicated that early information was crucial. Parents also valued medical specialists who gave honest and trustworthy advice. In another paper, exploring the emotional and cognitive experiences of 12 fathers (Carlsson & Mattsson, 2018), intense emotional shock was also described. These fathers described putting their own needs to one side whilst supporting their pregnant partner; and highlighted the need for joint decision making especially around potential termination of pregnancy. Other studies have focused on parents' experiences of counselling and their ongoing need for support (Bratt et al, 2015); the type of counselling that should be provided, depending on the defect (Gedikbasi et al, 2011); how identifying mortality risk factors can guide counselling (Lynema et al, 2016); parents' perceptions of the meaning of information regarding termination of

pregnancy for HLHS (Hilton-Kamm, Chang, & Sklansky, 2012) and impact of the counselling and demeanour of the Paediatric Cardiologist on parents' perceptions (Hilton-Kamm, Sklansky, & Chang, 2014). However, none of these studies were conducted in the United Kingdom (UK) and therefore a gap in the literature exists.

The aim of this study was to answer the question: *'How do parents' experiences at the time of diagnosis compare when receiving an antenatal versus postnatal diagnosis of congenital heart disease for their infant?'*

### **Methodology and Methods:**

A retrospective survey design, within a dominantly qualitative mixed methods methodological approach, was used (Leech & Onwuegbuzie 2009:271). The survey was phase one of a two phased fully mixed, concurrent, mixed methods study; where integration of the two methods occurred across all stages of the research process (Clarke & Yaros 1988; Leech & Onwuegbuzie 2009). An online approach to the survey was deemed most cost effective, convenient, flexible and timely; given that the sample being invited to complete the survey were geographically disparate across the UK.

*Survey Sample:* This was a convenience sample of all parents who were members of a UK based CHD charity, with children aged between 0-2 years; who had been discharged home from any UK specialist heart centre after the first stage of treatment for a functionally univentricular heart (including hypoplastic left or right heart). There were 62 families that met the inclusion criteria.

*Survey Recruitment:* The 62 families were contacted via email by the charity; provided with information about the survey and invited to participate. The online survey was

available during November 2012-March 2013. Parents could complete the survey independently or as a couple.

*Data Collection Tool:* The survey questions were developed in collaboration with the CHD charity to generate a description of parents' experiences and were built within an online platform using Bristol Online Surveys (Bristol University 2012). A pilot of the questionnaire was undertaken with three volunteer families to check ease of use, sequencing and clarity, before the final version was made available to parents in the study. Parents were asked for their consent to participate as question one, before being asked subsequent questions about their family demographics and their experiences, at four time points:

1. Diagnosis of their infant's congenital heart disease
2. Their infant's first admission to the specialist heart hospital
3. Going home for the first time
4. Now (at time of completing the survey)

This paper presents the findings from parents' responses to questions regarding time point 1 – receiving the diagnosis (see table 1). Other findings from the survey are reported elsewhere (Gaskin, Barron and Daniels 2016).

Table 1. Questions at time point 1 – Diagnosis of their infant's congenital heart disease
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|--|
| <ul style="list-style-type: none"><li>• Who explained what was wrong with your baby?</li></ul> |
|--|

- Where else did you get information from about your baby's heart condition?
- How much did you understand at the time of diagnosis about what was wrong with your baby?
- What factors might have impacted on your understanding at this time?
- Who did you get the most support from after your baby was diagnosed?

*Analysis:* As this was part of a fully mixed, concurrent (QUALquant) mixed methods study; integration occurred in addressing the research objective during the data analysis and inference stages. Analysis of data from timepoint 1 was undertaken individually by two researchers, the Principal Investigator and a Vacation Research Assistant (VRA), enhancing trustworthiness and credibility. Analysis included description of quantitative categorical data as percentages and deductive thematic analysis of the qualitative data collected from open-ended questions, using Braun & Clarke's (2006) six steps. This included: familiarisation with the data, generating initial codes; searching for themes; reviewing themes; defining and naming themes; producing the report. Analysis of the qualitative comments was undertaken by hand, on hard copies of the anonymised parents' responses, using colour coding to generate initial codes. These were reviewed individually and then jointly by the two researchers to define and rename themes. In this instance, NVivo 10 was used only for data management. The findings are presented concurrently, reflecting the methodological stance.

*Ethical Considerations:* Ethical approval for the Online Survey was obtained through Coventry University Research Ethics Committee (2012) where the PI was employed and a PhD student at the time of the survey. Ethical approval was obtained for the VRA

through the Institute of Health and Society Ethics Committee, University of Worcester (2015). The VRA scheme provides undergraduate students with an opportunity to join a research team and obtain hands on learning of research techniques. All information collected from parents during the survey was anonymous, the first question asked parents to consent to taking part in the survey. Confidentiality, privacy and anonymity were ensured during the collection of data as well as during storage and publication of research material. Cookies and personal data stored by the parents' web browser were not used in the survey. Only the charity staff have access to parents' personal information, email addresses and other details, data protection was maintained as this information was not available to the research team. The information collected from the online survey was analysed by the research team to draw conclusions.

### **Findings:**

The qualitative and quantitative findings are presented in an integrated format reflecting the fully mixed concurrent approach. Twenty-eight parents participated, equating to a 35% response rate (22 of the 62 families that were invited to participate); from 6 couples (27.3%), and individually 15 mothers (68.2%) and 1 father (4.5%). Five parents (23%) received a postnatal diagnosis compared to seventeen parents (77%) who had received an antenatal diagnosis at the 20 week scan. Care had been provided to these families in 11 different centres across the UK. Descriptive demographic data, at the time of the survey, are presented in table 2.

Table 2 **Demographic data** (at time of survey)



<b>Infant's Age:</b>		
0-1 year	7 (31.8%)	
1 year	14 (63.6%)	
2 years	1 (4.5%)	
<b>Time of Diagnosis:</b>		
Antenatal	17 (77.3%)	
Postnatal	5 (22.7%)	
<b>Infant's Diagnosis (in parents' words):</b>		
Hypoplastic Left Heart Syndrome, including:	14 (63.6%)	
<ul style="list-style-type: none"> <li>Mitral atresia and Coarctation of Aorta</li> </ul> Coarctation and 2 x VSD		
Hypoplastic Right Heart, including:	8 (36.4%)	
<ul style="list-style-type: none"> <li>Pulmonary atresia</li> <li>Tricuspid Atresia</li> <li>Tricuspid atresia with ventricular septal defect</li> <li>Transposition of the Great Arteries (TGA, with double inlet left ventricle, pulmonary stenosis and dextrocardia)</li> <li>TGA and pulmonary atresia, VSD, ASD</li> </ul>		
<b>Parent's Age:</b>	Mother (n=22)	Father (n=21)
22-25	2 (9.1%)	0
26-30	4 (18.2%)	1 (4.5%)
31-40	12 (54.5%)	16 (72.7%)
41-50	4 (18.2%)	3 (13.6%)
51-60	0	1 (4.5%)
<b>Parity:</b>		
Primipara	7 (31.8%)	

Multipara	15 (68.2%)
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Four themes emerged from the detailed parental responses to open ended questions about their experiences at the time of receiving a diagnosis of their infant's CHD, which were:

- Parents' understanding about the condition at the time of diagnosis
- Parents' emotions at the time of diagnosis
- Sources of support at the time of diagnosis
- Additional sources of information accessed after the diagnosis

### **1. Parents' understanding of the condition at the time of the diagnosis**

All parents receiving an antenatal (AN) diagnosis (n=17) indicated that they were given the diagnosis by a fetal cardiologist, whereas parents receiving the diagnosis postnatally (PN, n=5) indicated they were given the diagnosis either by a doctor in intensive care (n=3) or a paediatric cardiologist (n=2). For one family given an antenatal diagnosis, developing an understanding was a gradual process, assisted by a variety of professionals at the time of diagnosis:

*'We were initially told of the diagnosis by a cardiologist at [Local Hospital]. At the time my understanding was very limited just bewildered. I then spent two weeks at home looking on the internet and speaking to [name] from Little Hearts Matter. Gradually my understanding of the condition increased because of that. When we sought a referral*

*to [Specialist Children's Hospital] and saw the Fetal Cardiologist there, my understanding increased much more as he explained everything very clearly to us'.*

Some explained that their lack of understanding was due to the shock of finding out about the diagnosis; the complicatedness of the condition and for some that 'too much information was provided' at the time of diagnosis, as this quote from a parent receiving a postnatal diagnosis demonstrates:

*'[I had]...a lack of understanding of how the heart functions and too much information to digest on what was wrong with my baby's heart and all the options to attempt repairs. Doctors are used to giving this information so regularly that they can forget to break the information down a bit and explain who all the different people involved are, i.e., ITU specialist, cardiologist, surgeons, it can all get a bit confusing. More importantly what the future held'.*

Parents' perceived their understanding at the time of diagnosis differently and this varied between the two groups (see table 3).

Table 3 Parents' rating of their understanding at time of diagnosis (AN = antenatal; PN = Postnatal)

<b>Understanding:</b>	<b>nothing</b>	<b>some</b>	<b>most</b>	<b>all</b>
<b>Mothers (n=22)</b>				
AN	0	7(31.8%)	8 (36%)	2 (9%)
PN	1 (4.5%)	4 (18%)	0	0
<b>Fathers (n=10)</b>				
AN	0	4 (40%)	2 (20%)	1 (10%)
PN	0	3 (30%)	0	0

## **2. Parents' emotions at the time of diagnosis**

Factors impacting on parents' understanding at the time of the diagnosis included their emotional response: stress, shock and fear for the future. Shock was described by all parents receiving a PN diagnosis (n=5) and over half of those receiving an AN diagnosis (n=11) as these quotes demonstrate:

*"my emotional response to the situation affected my perception of the information I was given but .... I felt I fully understood" (AN diagnosis)*

*"[I was] ...too distressed and emotional to really listen" (AN diagnosis)*

*"I was so shocked to find out my child was sick and to what extent, it affected how I thought for a while" (PN diagnosis)*

Other initial feelings described by parents included bewilderment, their general emotional state and concern for their partner. One father stated *"adrenaline takes over and you have a responsibility not only for the baby but for your partner"* (PN diagnosis) and another felt a fear they *"could have lost our baby's life any time after she was born"* (AN diagnosis).

## **3. Sources of support**

Parents were asked to identify their top three sources of support at the time of receiving the diagnosis. Most parents found their partner to be the main source of support (n=12 AN; n=3 PN group), followed by grandparents (n=4 AN; n=4 PN group),

and extended family members (n=4 AN group). When identifying support from professionals, parents reported that they received support from hospital staff (nurses and doctors) at paediatric cardiac units (n=11, 50%), hospital staff (nurses and doctors) at their local hospital (n=3, 13.6%) and four (18.2%) reported receiving support from other professionals such as their GP, midwife or health visitor.

#### **4. Additional sources of information**

Other sources of information for the parents were the internet (n=9, 40.9%), parent information leaflets (n=9, 40.9%), parent support groups (n=3, 13.6%) and the remaining other sources of information, such as congenital heart disease charity website and telephone help lines (n=5, 22.7%), and their cardiac liaison nurse (n=1, 4.5%). One parent (PN diagnosis) explained that they were '*told to be careful*' about where information was sourced; likewise, one parent stated, "*there was also a lot of misleading information on the internet*" (AN diagnosis).

#### **Discussion**

The main finding was that parents in both groups reported feeling overwhelmed and not able to absorb all of the information provided at the time of the diagnosis, due to the shock and stressfulness of the situation. This reflects the findings of Carlsson et al (2015) who interviewed parents that had received an antenatal diagnosis of CHD and found that sorting out information was difficult at a time of emotional chaos. The implications of this finding for practice reflects the benefits of implementing supportive

interventions shortly after exposure to a traumatic event, such as when receiving a diagnosis of CHD (Bryant, 2003; Bryant, 2006; Solberg, 2011). Initial responses to extreme events can subside without intervention. However, if responses do not remit they can be followed by prolonged mental health disorders as individuals who experience an extreme event can express biological and mental responses related to adaptation and survival (Shalev, 2002). Evidently it is critical for professionals to assess parents of infants diagnosed with CHD, to categorise those who will experience transient stress reactions and those who are experiencing reactions which could persist into a long-term disorder such as post-traumatic stress disorder (PTSD). Not receiving the required support after a traumatic event is known to be a risk factor for PTSD (Shalev, 2002). Furthermore, not recognising the risk factors will not only have a detrimental effect on the mental health of the parents; increased levels of maternal stress may complicate the postpartum period and can affect the mothers' mental health (Solberg et al, 2011). These risk factors can also become an additional burden for infants with CHD and could lead to disturbances in their long-term development (Solberg et al, 2011).

The CHD standards and service specification document (NHS England 2016:149) has outlined national standards for ongoing care at the time of a prenatal diagnosis and states that the appropriate paediatric cardiac services will 'provide patient-centred services, sensitive to the individual's physical, psychological and emotional needs and supported through the provision of patient-appropriate information'. Additionally, a standard has been set for each Specialist Children's Surgical Centre to employ practitioner psychologists at a ratio of 0.25 whole time equivalent (WTE) per 100 children undergoing cardiac surgery each year (NHS England 2016; 186). A further minimum of 1 WTE practitioner psychologist must be employed to support the service

across the network (NHS England 2016; 186, standard B30 (L1)). This recognises the need for psychological support, however the impact of implementing these standards will require evaluation in the coming years.

The second main finding from this study was that generally, parents receiving an antenatal (AN) diagnosis perceived that they 'understood most' or 'all' about their infant's diagnosis, compared to postnatal (PN) parents who generally felt they only 'understood some'. Additionally, parents receiving AN diagnosis were seen by a fetal cardiologist for a specialist scan during the pregnancy. Therefore, the information given may have been more detailed and in a less rushed manner, allowing them time to ask questions and to develop their understanding over time. Conversely, a PN diagnosis may have necessitated faster decision making due to the deteriorating clinical condition of their infant, and therefore, less time to provide detailed information and to ensure that parents fully understood.

Some parents in the AN group described the gradual increase in understanding as they gained information from different sources, including the specialists, the internet and parent support groups. Some parents also recognised how misleading the information available on the internet could be. Some parents (from both groups) described the confusion created through the use of medical terminology by health care professionals, whereas some parents explained that information from charities was written in a language that could be easily understood. Those parents that had some previous knowledge of biology felt the professional providing the information explained it well and that they were able to translate it into lay terms for their partner. For some parents in the AN group, being provided with all of the surgical options and potential outcomes, including the worst-case scenario, led to anticipatory grief; one couple felt that they '*had already lost their baby*'; whereas another couple described being aware

that they could lose their baby '*any time after she was born*'. For others the worry was more long term regarding their child's quality of life.

It has been suggested that the way information is delivered to parents and the individual's knowledge of the management strategies could worsen the initial psychological impact of the diagnosis, especially if the first contact provider appears to have any uncertainty in the diagnosis or what outcomes there may be (Rychik et al, 2013). Furthermore, highly anxious individuals are less able to apply their mind to the explanation and this lack of understanding can contribute to increasing the levels of anxiety (Rosenberg et al, 2010). A section around communication has been included in the CHD standards (NHS England 2016:206-210). This includes a specific standard that states 'a Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care, but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care'(NHS England 2016:H26, L1, 210). Again, the impact of these standards needs to be evaluated in the future.

Thirdly, most parents described getting the most support from their partner, grandparents and extended family; however, they were not asked what type of support they were referring to, such as: physical, emotional or social. It could, therefore, be that parents who indicated that they received the most support from the specialist hospital were referring to a different type of support and that the question had been interpreted differently by these parents to those that described receiving more support from family.



## **Conclusion**

The key message is that healthcare professionals (HCPs) need to assess parents' emotional status, information needs and level of understanding irrespective of time of diagnosis, so that support is individualised, sensitive and time appropriate. Given that the infants had received care at varying centres across the UK, the findings have implications for practice in terms of national consistency, who provides the diagnosis and more importantly how well this is explained. Fetal Cardiologists or Fetal Cardiology Nurse Specialists may be better prepared to inform parents in an unrushed, sensitive and understandable way. The recent CHD standards (NHS England 2016), published since this study was undertaken, aim to address these issues.

Parents will access information in a variety of formats and from a variety of individuals and therefore HCPs can help parents to access the most appropriate condition specific information written in simple terms. Additionally, HCPs may require psychological first aid training to enable them to identify when the 'shock' being experienced is a normal reaction and can be self-managed with appropriate strategies compared to when there is a need to refer or sign-post parents to professional psychological support.

Limitations of the study include the fact that all parents were members of a charity and therefore may have been the more proactive or vocal parents who wanted to share their experiences and only a third of families invited to participate did so. The demographic of families (age, parity, diagnosis, time of diagnosis) that completed the survey may not be representative of the whole population and there were more parents in the AN group than the PN group. The age of the infant at the time of completing the survey might have affected parents' recall of the time of diagnosis, and the amount of time that has passed since they received the diagnosis, resulting in a demand

characteristic effect (Barriball and While 1994) rather than providing trustworthy data. Therefore, consideration needs to be given to the possibility of recall error, arising due to variances in imprecision or extensiveness of recall to memories of earlier events (Last 2000). Whilst there are advantages of retrospective designs, they take less time and are more cost effective; a disadvantage is the possibility of recall bias, which exists wherever self-report information of a person's past, is acquired from the participant (Raphael 1987).

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