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Original Article

A cross cultural examination of the experiences of parents of children when being diagnosed with Foetal and Neonatal Alloimmune Thrombocytopenia

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ABSTRACT

Foetal and Neonatal Alloimmune Thrombocytopenia is a rare genetic disorder which is not generally diagnosed until the child has been born, and often not until several children have been affected may the diagnosis be made. Due to its rarity it is not easily diagnosed as the symptoms may be confused with normal birth trauma. Although the disorder has been the subject of medical research, the parents' experiences of diagnosis and thereafter have not been previously studied. The current study analysed stories written by twelve European and North American mothers of babies diagnosed with the disorder, uploaded to an open access website. The findings suggest that there is a lack of information both within the public and medical domain about the condition which make diagnosis problematic. The rarity led parents on a search for further information and subsequent petitioning for prenatal screening to prevent future cases.

1. Introduction

Foetal and Neonatal Alloimmune Thrombocytopenia (FNAIT/NAIT) is a life-threatening blood disorder that occurs due to an incompatibility between parents' platelet-specific antigens which are inherited from the paternal parent but are absent in the maternal parent (Peterson et al., 2013). This mismatch of platelets causes the pregnant mother to develop antibodies against the human platelet antigens which cross the placenta and destroy the unborn child's platelets. This results in a low platelet count in the foetus causing internal haemorrhages (ICH), disabilities and even death (Bussel, 2007). The first cases of FNAIT/NAIT were documented in twins in the early 1950's (Harrington, 1953), but the condition is still relatively unknown even within the medical profession of obstetricians, midwives, nurses and doctors, and no countries currently screen for this condition (Tiller et al., 2017) although non-invasive methods have been successfully developed for high risk pregnancies (Bertrand et al., 2014). It is commonplace that diagnosis of the condition is not given until the second, third, or in some cases the fourth pregnancy as the severity of the condition increases significantly with every subsequent pregnancy (Bussel et al., 1997). Due to a lack of awareness and education, clinicians may interpret symptoms, such as petechiae and severe bruising, as the result of natural birthing trauma (Stone, 2016).

Much of the research into FNAIT/NAIT focuses on the medical issues, such as treatment, management and prevention of the condition (Peterson et al., 2013; Refsum et al., 2017; Taaning et al., 2012). Treatment includes the baby receiving platelet transfusions and may also involve invasive and aggressive medication called intravenous immune globulin (IVIG) which is made from the antibodies of a large amount of blood donors. Antenatally, this treatment is intended to supress the mother's antibodies from crossing the placenta and attaching to the unborn foetus and destroying platelets (Bussel, 2009). Although there is a considerable amount of medical research on the disorder, there is little or no focus on the experiences of the families involved. Therefore the purpose of this study is to examine, and better understand, the experiences of parents of babies born with this relatively rare genetic condition.

Around 95,000 babies cared for in neonatal intensive care units (NICU) in the United Kingdom each year, staying on average for eight days (Bliss, 2018). An estimated 1 in 25 babies (30,000 children) being born in the UK every year that are affected by a genetic disorder (Genetic Disorders UK, 2017), 1 in a 1000 being diagnosed with FNAIT/NAIT (Risson et al., 2012). The experiences of having a child admitted to NICU can be extremely stressful to the parents. One of the sources of stress is linked to the needs of the parents. Research has shown that the priority need for mothers in different hospital settings was firstly information, followed by treatment and nursing care, which was at odds with the perceptions of the nursing team who thought attention to maternal needs would be the mothers' priority (Punthmatharith et al., 2007). Parental anxiety was found to be reduced by keeping parents

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Table 1
Parents' experiences.

	Ref	Details	
America	A1	First child	Undiagnosed at birth but treated with IVIG and platelet transfusions
		Second child	Antenatal diagnosis of NAIT– mother treated with IVIG
	A2	First child	Undiagnosed at birth but treated with platelet transfusion
		Second child	Diagnosis of NAIT at 4 days –treated with platelet transfusion and IVIG
		Third child	Mother had pre-emptive IVIG treatment – healthy baby
	A3	First child	Diagnosis of NAIT at 4 days – treated with multiple platelet transfusions
Canada	C1	First child	Born healthy
		Second pregnancy	Miscarried at 12 weeks
		Third pregnancy	Miscarried at 18 weeks
		Second child	Baby was diagnosed a week after treatment – treated with platelet transfusion and IVIG
	C2	First pregnancy	Miscarried at 7 weeks
		Second pregnancy	Miscarried at 9 weeks
		First child	Born healthy
		Second child	Born healthy but diagnosed with Cerebral Palsy at 2 months
		Fifth pregnancy	Miscarried at 18 weeks
		Sixth pregnancy	Miscarried at 26 weeks – autopsy diagnosed NAIT as cause
		Third child	Mother had pre-emptive IVIG treatment – healthy baby
	C3	First child	Born healthy
		Second child	Born with brain bleed – diagnosed on first day with NAIT – treated with platelet transfusions and haemoglobin transfusions
Ireland	I1	First child	Diagnosed with NAIT – treated with platelet transfusions
		Second child	Mother had pre-emptive IVIG treatment – healthy baby
		Third child	Mother had pre-emptive IVIG treatment – healthy baby
	I2	First child	Diagnosed with NAIT on day 1 - treated with platelet transfusion
United Kingdom	E1	First child	Diagnosed with NAIT at 15 days - treated with platelet transfusions
	E2	First child	Diagnosed with NAIT on day 1 - treated with platelet transfusion
	E3	First child	Diagnosed with NAIT on day 1 - treated with platelet transfusions
		Second child	Mother had pre-emptive IVIG treatment – diagnosed with NAIT on day 4, treated with IVIG
	E4	First child	Diagnosed with NAIT on day 15 - treated with platelet transfusions

fully informed and allowing them the opportunity to be part of the decision-making process (Heidari et al., 2013). Parents who experienced communication problems within the medical setting were reported to have higher levels of stress in follow up studies, highlighting the long-term impact of such experiences (Colville et al., 2009).

The stress of having a child admitted into NICU increases the chance that parents will also experience insomnia, often resulting in fatigue (Heidari et al., 2013). To add to the traumatic experience, Squire (2009) suggests that mothers' separation from their new born baby during this time may prevent initial bonding occurring.

Previous studies have identified that parents strive to gain a distinct cause and diagnosis for their child's disorders, and although parents who have received diagnoses by a genetic counsellor find the experience supportive (Ashtiani et al., 2014), this is not necessarily the case with parents of FNAIT/NAIT babies as the diagnosis may come from a clinician who is not necessarily an expert in the area. If a family does not have a clinician that is dedicated to their case there is the added frustration of parents having to repeat themselves for the sake of each medic, making them relive the distressing experience (Lewis et al., 2010).

Furthermore, parents have found discussions of diagnoses of genetic disorders confusing due to the clinicians' use of terminology (Chapple et al., 1997). Ashtiani et al.'s (2014) study supported the notion that parents struggled to understand the use of technical medical language and perceived themselves as passive information receivers that had no opportunity to raise concerns or ask questions. The parents believed their emotions stopped them from concentrating on the information that was being given.

The aim of this study is to identify whether there are cross-cultural differences in the awareness and diagnosis of FNAIT/NAIT, and the impact such a diagnosis has on the parents and families, and how they confront, adjust and adapt to such a life changing event.

2. Methods

2.1. Design

The study employed document analysis as a method for gathering qualitative data. The documents sourced were the first-hand narrative accounts uploaded to a website by parents of babies had been diagnosed with this serious genetic disorder. Document analysis allows for pre-existing material, created for other purposes, to be analysed for research purposes. This approach was chosen to allow for thorough and in-depth analysis of their thoughts and feelings (Fraser, 2004), unencumbered by the researcher's presence. There has been an increase in acceptance of this type of post-modern research method, and the use of personal storytelling is considered a valid means of gaining knowledge and insight into certain topic areas (Skeggs, 2002).

2.2. Sample selection

In order to understand the experiences of parents of FNAIT/NAIT babies, their diagnosis stories were downloaded from the Our Stories page of an open access website of an international charity (Naitbabies.org) run by families affected by FNAIT/NAIT. Due to the rarity disorder, available data is limited, therefore this approach allowed authentic voices to be captured about the experience (Giles, 2017), without the social constraints that may occur if the parents had been interviewed by researchers (Holtz et al., 2012).

The website was selected as it was the only online community aimed solely at this disease. The Our Stories page was selected as this contained the unmediated voices of those who had experienced a FNAIT/NAIT diagnosis. From this page the narratives collected were written by twelve mothers of children diagnosed with FNAIT/NAIT, between 2012 and 2017.

The cross-cultural focus was to establish whether there were differences in the diagnostic experience dependent clinical training and the different healthcare systems, as a means of establishing whether one healthcare system was more efficient in identifying the disease. Therefore, family stories were randomly selected from two different continents; six European accounts from the United Kingdom and Ireland, and six North American accounts from Canada and the United States of America. The European stories tended to be longer (1585 word on average) than those from North America (1173 word on average). Ethical clearance was granted, although the participants were not

approached for permission as the data was in the public domain.

Table 1 highlights their experiences with respect to the timing of the diagnosis and the treatment received, and how this featured across all of their pregnancies, building richer picture of their whole experience.

2.3. Data analysis

Grounded Theory approach (Strauss and Corbin, 1998) was used as an inductive means of analysing data, which involves the initial observation of the originating data, then the focus is applied to identify patterns emerging within the data which may lead to the development of an overarching theory (Stern and Porr, 2011). The use of Grounded Theory in the study was well suited to capturing the in-depth views of the parents involved, as a means of constructing meaning of their experiences in a way not previously captured, to create a theory that reflected their diagnostic journeys (Payne, 2016).

This process was initiated through the open question as to what experiences have parents had after giving birth to a child eventually diagnosed with FNAIT/NAIT, and do these experiences differ based on the health system within that country. Therefore, purposive sampling from the website led to the downloading of the first maternal narrative. Each researcher initially open coded line-by-line using printed copies of the story to identify objects and events that represented participant's main concerns. The codes were then discussed within the research team to ensure inter-rater reliability. Further individual stories were downloaded and scrutinised by this process to make sure all emerging concepts were captured before the next level of coding took place (Willig, 2013). During the open coding process, memos were taken to aid the identification and emergence of the core concepts. Axial coding was then undertaken to show the relationships between each of the emerging themes, which were developed into the theory (Sbaraini et al., 2011).

3. Results

Four core themes emerged from the data which were the *incognizance* of the disorder, the *drive* to understand the diagnosis, how the parents *coped* with the diagnosis, and how they *overcame* the experience (Table 2).

4. Discussion

From these themes the Incognizance Model (Fig. 1) was developed to show how parents constructed meaning from their experiences of the diagnosis, and how they coped with the experience. Analysis showed that there was a great degree of cross-cultural overlap in the feelings and experiences of the parents.

4.1. Incognizance

As no screening is undertaken in either Europe or North America, and due to the relative rarity of the disorder, the parents were shocked by the diagnosis. The shocks often did not end with the diagnosis of the child, but also at the later revelations that miscarriages and conditions affecting previous children may also have been the product of the genetic disorder. This Irish mother (I1) explains what impact earlier knowledge would have had on her second pregnancy, “If I had known [previous child] had 2 bleeds, I'd have insisted I started my treatments far earlier, and more aggressively”. The revelation of the disorder having been the explanation of problems in previous pregnancies and conditions has been previously documented (Bussel et al., 1997), the data therefore presenting experiences that may be quite typical.

It was not only the parents that appeared to be incognizant of the illness, this lack of knowledge stretched to the medical profession on both sides of the Atlantic. This lack of knowledge led to increased worry and confusion over drawn-out processes of diagnosis. The experience of this North American family was typical of the confusion experienced when it was discovered that something is wrong with the baby:

> When we asked what he had, and if we caused it, we were both tested and told that it was just a fluke and we didn't cause his platelets to be low. It was scary not to really have an answer to why our baby was sick. We accepted their assessment, not knowing any better (A1).

What became evident within the texts was an absence of knowledge and training within the medical profession with regard to diagnosis of FNAIT/NAIT. For example, eight out of the twelve families report their children showing petechiae and hydrocephalus, but these symptoms were interpreted as normal birth trauma (Stone, 2016), suggesting that the condition is not well known amongst medics in these hospitals (Peterson et al., 2013). This lack of knowledge potentially led to late diagnoses being made, where several of the families were not given the correct diagnoses until a fortnight after birth (E1 and E4). In some cases wrong diagnoses were made through incorrect procedures being undertaken, as this American mother (A1) indicates that she “found out that the wrong [blood] tests were ordered” and after her and her partner were tested they were told that “it was just a fluke and [you] didn't cause his platelets to be low”. The doctor of this Canadian family (C1) suggested their child “had a virus which was likely from a farm since we were from rural PEI. We don't live on a farm!”

The confusion over the cause of the low platelet count seemed to create communication barriers between the medical team and the parents, as this English family (E4) found, “The doctors were rather vague. They weren't sure why he had a low platelet count, and they began to do more tests on him to look for one of a number of diseases”. The clinicians' confusion exacerbating parental stress levels as seen in research by Colville et al. (2009).

4.2. Drive to understand

Once diagnosed there was a drive to understand what the disorder was, how could it be treated, and ultimately the reflection as to why

Table 2
Key themes.

Themes	Subthemes	Explanations
Incognizance	Clinicians' knowledge	The lack of knowledge by the medical team resulting in some late diagnoses.
	Parents shock of diagnosis	Parents' shock as no problems had been identified throughout the pregnancy.
	Parents shock of previous pregnancies	Parents' shock at realising this may have been the cause of problems in previous pregnancies.
Drive to understand	Information searching	Internet and medical journal searches to understand the disease.
	Searching for medical support	Searching for clinicians who can provide medical assistance.
	Searching for emotional support	Searching for those who had been through the same experience.
Coping	Family support	How families had supported them.
	Support group	How the support group had support them.
Overcoming	Reducing incognizance	The desire to inform so diagnoses are made more swiftly.
	Managing future pregnancies	Taking steps to avoid future occurrences of FNAIT/NAIT.

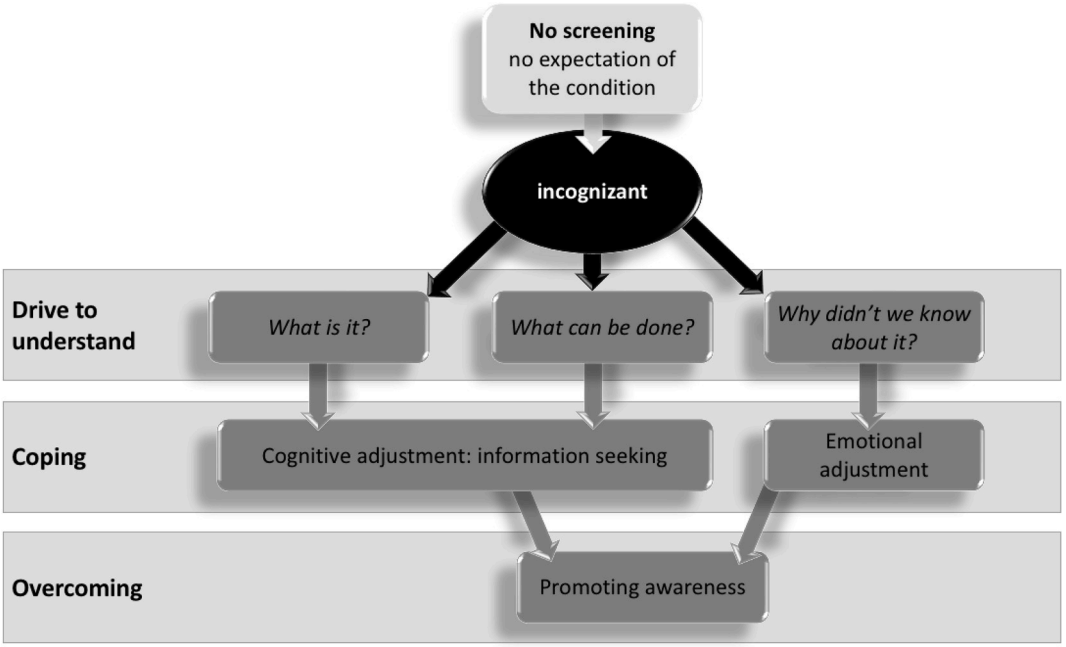

Fig. 1. Incognizance model.

they did not know about it before. The drive to understand was expressed in various ways. Primarily the parents talked about their information seeking behaviour, although one family (E2) regretted independently searching for more information, as they reflect here, "I had stupidly Googled low platelet counts, and trust me I didn't want the answer to be any of the results that came up". Others approached the task using more informed sources, "I started searching medical journal articles and research papers to find out as much as I could. It took a long time to find up to date research that gave information about current treatments" (E1). Some of the approaches were quite collaborative as this American family (A1) expressed, "I switched to a different doctor and told him about my previous pregnancy. He was very perceptive to my story and told me that we needed to do some research".

The North American families spoke more frequently about the information they had gleaned from the Naitbabies website, this Canadian family (C2) demonstrating how the site helped them, "I asked plenty of questions and members from the group provided me with information I would never have known to ask my doctor". European families were more likely to use other sources of information. This included requesting the medical records of their child to find out what had really occurred, reference to medical journals and the subsequent contact with the authors of the papers, and at a more practical level learning how to do CPR on babies.

Some of their research focused on what the opportunities were for future births as this American mother illustrates, "As I started to do more research, I started to become more scared but there was a glimmer of hope as I read that by receiving treatment, there was a 95% chance that I could have a healthy baby!". Unfortunately the information they received from their enquiry was not always accurate as this English (E1) mother shows, "I asked about treatments for it and was told by the consultant that they weren't aware of any antenatal treatments, just platelet transfusions once they were born".

Gundersen (2011) argues that knowing is the start of the road to recovery from the emotional turmoil of genetic disorder diagnoses. This drive to know was also observed by Punthmatharith et al. (2007) whose research showed that mothers deemed information as their primary need, as this allows for informed decision making (Heidari et al., 2013). Proactive information seeking has been observed in previous studies as parents' means of coping with postnatal diagnoses (Lewis et al., 2010). The activity allows parents to feel busy and occupied, whilst the search for information may be a means of striving towards some solution.

4.3. Coping

More difficult was the emotional reconciliation of what had occurred. Even before diagnosis many of the mothers indicated that they felt it must have been something that they had done throughout pregnancy that had led to the condition, as this Irish mother (I1) explains:

> NAIT was maybe mentioned but all I kept hearing was two strokes and brain damage, I felt so sick. Had I caused this? Did I do something wrong during birth/pregnancy? Should I have been in the hospital sooner? The list was endless of the questions and blame I put on myself.

On realising the actual genetic cause, more guilt was expressed by all, a finding common with parents of children with genetic disorders (Heidari et al., 2013), which adds to the stress experienced (Kawafha, 2018).

The mothers' negative experiences were exacerbated by their stay in hospital, where they were in wards full of mothers with healthy babies, leading to loneliness and distress. To overcome the emotional side most parents talked about the support of family and friends. A cultural difference that did emerge from the narratives were the means of support, where the North American families highlighted how their faith played an important role, whereas the European families were more likely to refer to the Naitbabies group support. The impact of having a group of people that really understood what the parents were going through cannot be underestimated as this American mother (A1) indicates, ''I found the yahoo FNAIT/NAIT group. These ladies saved me. It was like having a hand to hold when no one else around me understood what I was going through". Due to the rarity of the disorder it is unlikely that parents would ever have met other parents that had been through the same experience, but through the use of the technology the website has allowed parents to share their experiences and gain strong connections. The subsequent advice and current knowledge has been a great means of support, as this English mother (E3) expresses:

> Luckily, had found the yahoo group … I was so thankful to everyone on there for their support and advice. I felt that I, and they, knew

more about NAIT than some of my doctors/consultants did – some had never even heard of NAIT, so I was very glad I'd found people that knew exactly what I was going through and could offer me such excellent advice!

4.4. Overcoming

To help overcome the distress of the experience, the parents wish to reduce the incognizance of the disorder through screening at pregnancy to prevent future occurrences and make the medical profession more aware of the problem.

Many of the parents stated that they were more than aware of the risks of having future children:

> We were told that we shouldn't get pregnant because of the high risk of it happening again and that we were in the 100% range of having another affected baby that we may also lose and if I got pregnant we would have to have IVIG treatment which was very risky for both me and the baby. We were told if we really wanted a baby together we should consider a sperm donor (C2).

After the trauma of receiving a FNAIT/NAIT diagnosis there were mixed feelings about the future. This North American family (C1) are unsure if they could cope with the possibility of losing another child, “the specialist crew explained the IVIG treatment for any future pregnancies. What a long scary pregnancy that must be. I would love to have more children, but I just don't know if I can do it”. This conclusion was not universal. Those who had had treatment had successfully brought healthy children into the world and were passionate that this should be better promoted as this European mother (I1) claims:

> We'll keep fighting until NAIT is screened for routinely in pregnancy, and one day I do believe it will be. More and more people are coming forward, and it makes me believe 100% that this disease is nowhere near as rare as some doctors' claim.

4.5. Limitations

Although this was a relatively small study, the key features were evident across the narratives suggesting parity of experience. The forum posts were all written by mothers with F/NAIT children for the purpose of sharing their stories with others, and as such there is an authenticity to the voices, but it must be noted that their experiences may not necessarily represent the paternal experience as previous research has shown that men are less satisfied with neonatal care than women (Tsironi et al., 2012).

5. Conclusion

This research has uncovered some features of mothers' experience of their child's FNAIT/NAIT diagnosis, similar to those experienced by other parents whose children are admitted to NICUs. The similarity in cross-cultural experiences suggests that its rarity may create problems for diagnosis in both North America as well as Europe. This was demonstrated, not only by the protracted experience of the diagnosis, but also by the retrospective indication that complications of previous pregnancies may have been a result of FNAIT/NAIT. The lack of understanding drove parents to seek information from a range of sources to better understand what had occurred before, and what can be done for the future. This drive to seek explanation may have been a means of managing the guilt that many mothers reported experiencing. Mothers reported coping through the support they received, not only from family and friends, but also from the specialist support groups where a shared understanding of the experience and issues helped them make decisions about future children.

Receiving such a diagnosis is never going to be an easy experience but keeping the lines of communication open with the parents is vital, especially when they are not completely certain of the diagnosis. How the process is experienced may be reliant on how vital information is communicated, where the medical team need to be aware of how they communicate complex medical information (Chapple et al., 1997; Ashtiani et al., 2014). In addition, consideration should be made of the mother's situation, being in a ward with mothers of healthy babies may not be sensitive to her current predicament, and separation from the child impacting on bonding (Squire, 2009).

With respect to the future, systematic reviews suggest that screening for FNAIT/NAIT reduces morbidity levels (Kamphuis et al., 2010), a finding refuted by Lines and Pittam's (2016) report for the UK National Screening Committee, who concluded that they could not find an effective screening protocol for first pregnancy risk. Such findings indicate why there is no mandatory screening in the UK at least. But while screening may remain controversial, prevention for *at risk* families, through weekly antenatal IVIG treatment is effective (Winkelhorst et al., 2017). The problem is that whilst screening is not mandatory in the countries examined here preventative means cannot be taken, although the evidence suggests hopeful outcomes for those that are aware that they are at an increased risk level.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jnn.2019.01.004.

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