



An evaluation of pregnant women's knowledge and attitudes about newborn bloodspot screening



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ABSTRACT

Objectives: research suggests that information provided to parents about newborn bloodspot screening (NBS) can be inconsistent. The majority of international NBS programmes recommend that parents should receive information about NBS in the antenatal period, however prior studies have mostly focused on postnatal women's knowledge, with no quantitative study of women's knowledge in the antenatal period conducted to date. Thus, the aim of this study was to determine if antenatal women received information about NBS in the antenatal period and to evaluate their knowledge and attitudes about NBS.

Design/Participants: we conducted a cross-sectional study among antenatal attendees at three maternity hospitals in Ireland. A total of 662 antenatal women (≥ 36 weeks gestation) were recruited into the study (279 primiparous, 368 multiparous). Women were asked to complete a self reported knowledge and attitude questionnaire about NBS.

Findings: primiparity (OR 2.75; 95% CI 1.65, 4.59) lower educational status (OR 1.79; 95% CI 1.02, 3.15) and not having private health insurance (OR 1.84; 95% CI 1.19, 2.85) were independently associated with poor NBS knowledge. Fourteen per cent of antenatal women recalled receiving an information leaflet about NBS, yet over 87 % reported that they would like more information. Thirty four per cent of women agreed that they understand everything they need to know about NBS.

Conclusions/Implications for practice: the process of providing women with information about NBS in the antenatal period is inconsistent; consequently their awareness about NBS is limited. To make an informed choice about NBS women require information to be provided in a more structured format. There are many missed opportunities in the antenatal period for maternity care providers to provide women with information about NBS. Our study recommends that healthcare providers should have a more formal and structured approach with regard to the provision of information about NBS in the antenatal period. This could be achieved by incorporating NBS education into antenatal education classes or through multimedia while women are waiting in the antenatal clinic. Healthcare providers may need education about the importance and benefits of providing women with information about NBS in the antenatal period.

Introduction

Newborn Bloodspot Screening (NBS) is one of the most important public health milestones of the 21st century. It first started in the

United States (USA) in the 1960s with the introduction of screening for phenylketonuria (PKU) (Guthrie and Susi, 1963). Technological advances such as tandem mass spectrometry have allowed for the significant expansion of NBS programmes; in the USA some state

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programmes include over 50 conditions (American College of Medical Genetics Newborn Screening Expert Group, 2006). The majority of developed countries have initiated a NBS programme; conditions that are screened for vary but are usually tailored to a country's specific requirements.

The NBS programme in Ireland was started in 1966 and has recently expanded to include screening for cystic fibrosis (CF); the programme now includes six conditions (PKU, homocystinuria, classical galactosaemia, maple syrup urine disease, congenital hypothyroidism and cystic fibrosis) (National Newborn Bloodspot Screening Laboratory, 2011). In Ireland screening is carried out when the infant is between 72 and 120 hours of age, normally by the Public Health Nurse (PHN) in the infant's home. However, if the woman is still in the maternity unit or if screening is due at the weekend, it is performed in the hospital. Parents are only contacted if the test results are abnormal, usually when the infant is one to two weeks old. The NBS cards are currently stored for ten years and are thereafter destroyed.

The American College of Medical Genetics Newborn Screening Expert Group (2006) and the UK Newborn Screening Programme Centre (2012) recommend that information on NBS should be provided during pregnancy. In keeping with international recommendations, the national NBS programme in Ireland recommends that parents should be provided with information about NBS during the third trimester of pregnancy and again at the time the test is carried out. The majority of studies on parental knowledge and attitudes about NBS have also recommended that the most appropriate time to provide information about NBS is in the antenatal period (Campbell and Ross, 2004; Davis et al., 2006; Parsons et al., 2006; Kerruish et al., 2008; Tluczek et al., 2009; Araia et al., 2012; Nicholls and Southern, 2012). A recent committee opinion published by the American College of Obstetrics and Gynaecology (ACOG) recommends that obstetric care providers should provide women with information about NBS during pregnancy (Committee on Genetics, 2015).

A recent study conducted in Ireland by Larkin et al. (2012) found that women were dissatisfied with postnatal services. Women reported that maternity units were busy and understaffed which was a barrier to woman centred care. Postnatal services in Ireland are quite limited with the majority of women receiving only one postnatal visit from the PHN in the first week following discharge from the maternity unit (Health Service Executive, 2016). This limited service can hinder the opportunity for midwives to provide women with information about NBS prior to the test and reinforces the need for women to be provided with information about NBS in the antenatal period.

It is important that parents receive adequate information about NBS in order to ensure the continued success of this important public health programme (Van Der Burg and Verweij, 2012). There are no published refusal rates for NBS in Ireland although the refusal rates are generally thought to be extremely low. A French study by Dhondt (2005) examined the refusal rate following implementation of a change to written informed consent for NBS in France, the study found the number of refusals declined from 0.8% at the beginning of the change to 0.2% at the end of the first year of implementing written informed consent for NBS. Botkin et al. (2016) reported a refusal rate of 1.4% in women recruited to their study which was conducted across three states in the USA. Informed consent to perform the test is required in many countries therefore providing information during the antenatal period allows parents time to process information about NBS and permits time for questions to be answered. Providing parents with information can also help to alleviate parental distress resulting from positive or false positive screening results. A study by Gurian et al. (2006) showed that women who did not know the reason for a repeat NBS test had increased levels of anxiety compared with women that were aware of the reason for a repeat test.

While knowledge of genetic disorders and preparation for screening in the antenatal period will help to improve parental information and reduce anxiety; since the early 1990s studies conducted largely among

women in the postnatal period have indicated that there is a persistent deficit in parental knowledge about NBS (Statham et al., 1993; Campbell and Ross, 2004; Suriadi et al., 2004; Luczek et al., 2009; Lang et al., 2009; Araia et al., 2012; Newcomb et al., 2013). Studies conducted among postnatal mothers from Canada, the US and UK suggests that women are not provided with information about NBS (Parsons et al., 2006; Lang et al., 2009; Araia et al., 2012). These studies have also found the way information about NBS is provided to parents is not well organised and usually provided in the postnatal period or when the test is being conducted (Davis et al., 2006; Parsons et al., 2006). Detmar et al. (2007) found that parents (both mothers and fathers) in the Netherlands received limited information about NBS procedures and the disorders for which screening is performed. Statham et al. (1993) revealed that women in the postnatal period were unsure which specific conditions NBS was testing. The majority of studies examining knowledge and attitudes about NBS have examined women's knowledge and attitudes in the postnatal period and were mainly qualitative studies which limit the generalizability of the findings. Little is known about women's knowledge in the antenatal period, therefore the aim of this study was to determine if women in the antenatal period received information about NBS and to evaluate their knowledge about and attitudes towards NBS. The specific objectives of this study were to:

- (1) Determine the proportion of women that receive information in the antenatal period.
- (2) Determine if the gap in parental knowledge about NBS persists by examining antenatal women's (after 36 weeks gestation) knowledge about, and their attitudes towards NBS.
- (3) Identify factors associated with maternal knowledge about NBS.
- (4) Examine maternal attitudes regarding use of blood spots for research.
- (5) Determine the source of women's information about NBS.

Methods

A cross-sectional study of 693 women in the antenatal period (≥ 36 weeks gestation) was undertaken at two maternity hospitals in the capital city Dublin and one regional maternity hospital in another large city in the south of Ireland. The combined annual birth rate of these hospitals was 22,630; this reflect 33.6% of all deliveries nationally (Department of Health, 2016). Only women in the later stages of the third trimester were recruited into the study in order to allow healthcare providers the opportunity to provide women with information about NBS in the third trimester.

Participants were recruited at their routine antenatal appointments. Women in the antenatal period were eligible to participate in the study if they were 36 weeks gestation or greater; aged 18 years of age and over; and were able to speak and read English. The researchers approached women in the antenatal clinic, provided them with a patient information leaflet and obtained their consent to participate in the study and complete the questionnaire. Participants were provided with an opportunity to read the information leaflet about the study prior to completing the questionnaire. The majority of women were recruited from the public antenatal clinic; the waiting time to see a clinician at these clinics can be quite lengthy. Due to the long waiting times, women had time to complete the questionnaire and reported an interest in finding out more about NBS. Even though many women have private health insurance, most women in Ireland opt for public or semi-private care as the obstetrician's fee is not covered by the majority of private health insurance policies (Carr, 2011). To ensure that women had the correct information about the NBS programme and to alleviate potential concerns about NBS, an information leaflet about NBS and a copy of the completed questionnaire with the correct answers to the knowledge questions were given to each participant following completion of the questionnaire.

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