



Down's syndrome screening in Northern Ireland: women's reasons for accepting or declining serum testing

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Abstract

Background. The use of maternal serum screening to assess individual risk for Down's syndrome is now standard in many countries. The increased uptake of screening and diagnostic tests has provoked concerns about their potential impact on individuals and societal attitudes. Under the current law in Northern Ireland, women are not given the option to terminate their pregnancy if they have a positive diagnostic test, unless it is in the interests of the mother's mental or physical wellbeing. There is limited evidence regarding the extent to which women's decisions are influenced by the cultural and societal context in which screening is offered.

Objective. To compare women's reasons for having or declining Down's syndrome serum screening in two hospitals with different screening policies in Northern Ireland.

Methods. A prospective cohort study of pregnant women (n=317) offered screening for Down's syndrome in hospital and community settings were interviewed twice using semi-structured interviews. Data collection was from 1 September 2003 to 5 May 2004.

Results. The majority of women declined screening irrespective of hospital screening policy as they felt it would not make any difference to pregnancy outcome. Women who declined also voiced concerns about the emotional impact of testing and about the characteristics of the test on offer. Women chose to have screening because of their family history or age, because they wanted to find out more information and for reassurance. The influence of health professionals was reported by women who chose to have screening and also by those who declined.

Conclusion. The reasons given for declining screening were emotional rather than knowledge based, which may reflect deep-rooted cultural and religious values. Professional awareness of the impact of societal and cultural attitudes on women's decisions about antenatal screening tests is important when introducing screening policy.

Key words: Down's syndrome, pregnancy, midwifery, serum screening, survey, evidence-based midwifery

Introduction

Antenatal screening is an important aspect of maternity care, which enables parents and health professionals to make choices and decisions regarding the management of pregnancy. Down's syndrome screening has been offered to women in the UK since the early 1980s (Cuckle et al, 1984), but the offer of screening has varied geographically. The most recent guidelines from the National Institute for Health and Clinical Excellence (NICE, 2008) recommends that all women should be offered screening for Down's syndrome, either the combined test or the triple test depending on the gestation at which women book for care. Universal screening has been recommended in the UK since 2003 (NICE, 2003).

However, uptake of screening is variable, the National Screen-

ing Committee (NSC) in 2006 reported an overall uptake of 67% in the UK (NSC, 2006). Redshaw et al (2007) conducted a national survey of women's experience of maternity care in the UK and found that 62% of women had screening for Down's syndrome, with 37% having serum screening only. Shantha et al (2009) reported an overall uptake of 28% across three hospitals in the UK, with individual hospital uptake ranging from 20% to 33%. A downward trend has been suspected in the uptake of screening and a recent UK study that evaluated the uptake of serum screening over a 14-year period in one hospital confirmed a decrease of approximately 2% per year (Gidiri et al, 2007). However, further work is necessary to consolidate these findings across all areas of the UK.

The uptake of antenatal screening for Down's syndrome is



usually high where it is considered part of routine care (van den Berg et al, 2005). Other countries with universal screening policies, such as the US, France and the Netherlands have also identified variation in the uptake of Down's syndrome. A similar uptake to the UK is reported in France (Khoshnood et al, 2004), while in the Netherlands it varies from 38% to 86% (van den Berg et al, 2005; Muller et al, 2006), although these studies were carried out prior to the introduction of universal screening. Knight et al (2005) reported an uptake of 61% in a study involving 11,159 women in the US. In Northern Ireland, uptake is difficult to assess accurately as the information is not routinely collected leading to limited availability of published data. A survey of screening services across Northern Ireland by Lynn and Alderdice (2006) indicated that only one unit was able to report a known uptake, which was estimated to be around 14%.

Variation in uptake has been attributed to social and/or ethnic differences between women, however, the evidence is not conclusive. Some evidence indicates that women from Asian backgrounds have a lower offer and uptake rate (Rowe et al, 2008) and those from disadvantaged backgrounds (Dormandy et al, 2005). Conversely, Rowe et al, (2008) and Michie (1999) reported that offer and uptake for the most disadvantaged groups of women were not decreased.

Women's reasons for having or declining screening tests for Down's syndrome have been reported consistently across studies nationally and internationally. A systematic review of 106 studies (Green et al, 2004) reported a range of reasons as to why women choose to accept or decline antenatal screening. Preparations for the future, finding out more information about their baby, reassurance and the recommendation of a health professional were all cited as reasons to accept screening. Factors reported to influence women who declined screening were anxiety, not wanting to know, test characteristics and individual perception of low-risk status. Additional factors reported by women included religious beliefs and opposition to termination of pregnancy (Press and Browner, 1997; 1998; Sandall et al, 2001; Markens et al, 1999), although the majority of these findings were from studies conducted prior to the introduction of universal screening policy. Other research suggests that women may decline screening based on how society views disability (Bryant et al, 2006) and Gottfredsdottir et al (2009: 4) concludes that the decision to decline is based on a '*complex interplay between personal views, values and social context*'.

The precise relationship between screening policy and the influence on women's decisions has not been extensively researched, however, there is a rising concern that with increasing routinisation of antenatal screening tests, women may not realise tests are optional and remain unaware of the potential consequences of test result knowledge (Suter, 2002). Skirton and Barr (2009) reported similar concerns regarding the lack of clarity reported from both parents and professionals about the purpose and potential of screening tests. Previous research by Santalahti et al (1998) found that in a group of women who had accepted screening, almost half (48%) felt participation was considered to be routine and there was also a lack of recognition that serum screening was different from other routine tests.

This paper has been structured to give a broad overview of screening policy, screening uptake and a summary of re-

ported reasons from women about their decisions to accept or decline serum screening tests. Databases searched included OVID (1966-present), MEDLINE (1966-present), PubMed (1950-present), CINAHL (1982-present), MIDIRS, and the Cochrane Database of Systematic Reviews. The computer-based search was supplemented by a manual search of the references listed. The key words used for the search strategy were 'antenatal and/or prenatal screening', 'Down's syndrome screening', 'Down's syndrome screening uptake' and 'screening policy'. The search resulted in a large volume of literature, which has been detailed in McNeill (2008).

The aims of this study were to describe women's reasons for having or not having screening and to explore whether different screening policies influenced women's decision-making. Data were collected as part of a larger study exploring social inequalities in the offer and uptake of antenatal screening in two hospitals in Northern Ireland (Alderdice et al, 2008).

Method

A prospective cohort study using survey methodology was carried out in two maternity hospitals in Northern Ireland, which involved women being interviewed face-to-face on two occasions in their pregnancy. The first interview took place when women attended for their booking appointment and the second occurred after all screening, including anomaly ultrasound had been performed. The data collection tool was refined as a result of consultation with researchers who had previous experience in this field (J Sandall, personal communication) and pilot work. The final version was approved by the study team, comprised individuals from various disciplines including midwifery, obstetrics and psychology. Ethical approval was sought and granted from the regional research ethics committee, Northern Ireland (application number 378/02) prior to the start of the study.

Setting

In hospital one, the policy was to offer all women serum screening for Down's syndrome when offering other routine screening tests between ten and 14 weeks' gestation. In hospital two, only women aged over 35 or those who had a family history of Down's syndrome were offered serum screening for Down's syndrome at the time of the study. Despite these differences in offer policy, the reported uptake of serum screening following offering of tests for Down's syndrome was similar in both hospitals. In hospital one, 83% (n=285) of women reported being offered Down's syndrome screening, of whom 26% (n=74) chose to have screening. In hospital two, 10% (n=32) of women reported being offered screening of whom 28% (n=9) took up the offer.

Sample

Women were recruited consecutively when they attended the hospital or community antenatal clinic for their booking appointment or dating scan at each of the hospitals from September 2003 until May 2004. Participants were given the option of withdrawing from the study at any stage. A total of 834 women were invited to participate in the larger study, of whom 711 women consented to participate and 45 dropped out, leaving 666 women. The reasons why 45 women dropped out are

reported in full detail in Alderdice et al (2008). Of the women who participated in the main study, 317 reported being offered screening for Down's syndrome. These women form the sample for the study reported here.

Data collection

All women attending an antenatal clinic in the chosen sites for their first appointment were approached by a research midwife, given a leaflet about the study and asked if they would like to participate. Women who gave consent to take part were then interviewed by the research midwife face-to-face. Complete data collection processes for the main study can be found in Alderdice et al (2008). The semi-structured interviews were conducted and completed by one of three members of the project team (JM, PG, FC). Women were interviewed initially at 12 and 16 weeks and secondly between 23 and 26 weeks' gestation. The interviews lasted approximately 15 to 20 minutes and were conducted in a private area of the antenatal clinic. Women's responses to open-ended questions were transcribed verbatim at the time of interview by the interviewers.

Analysis

The reasons women gave for choosing to have or declining Down's syndrome screening were transcribed into MS Word and coded by topic. Question analysis was conducted where all the responses pertaining to individual questions were read and then analysed by content (Morse and Field, 1996). Members of the project team (FA, DM, RR, and JM) conducted coding independently and then met to reach consensus on emerging categories. Consensus of the resultant categories was agreed by all members of the project team. Direct quotations from women are provided, which are representative of each category. Proportions of women giving responses relating to each theme are presented and key sociodemographic variables, such as education and maternal age are attached to quotations. Pseudonyms have been used throughout.

Results

The sociodemographic characteristics of the total sample of women interviewed (n=666) have been published previously (Alderdice et al, 2008). The sociodemographic characteristics of the sample referred in this paper are similar to the overall sample. The age range of women who accepted screening was from 18 to 41 plus years. Overall, the women in hospital one (universal screening policy) who were over 35 and those who had degree-level qualifications were significantly more likely to accept screening. There was also a strong association with level of deprivation: women from more affluent areas were more likely to accept screening. More multiparous women in both hospitals accepted screening compared with primiparous women (hospital one, 58% versus 42%; hospital two, 67% versus 33%); however, the numbers were small in hospital two and this was not statistically significant. Religious denomination was not a significant indicator for screening uptake.

Figure 1 illustrates women's reasons for declining or choosing to have screening. The results section has been divided primarily into women who declined screening and women who chose to have screening, followed by further subdivision by hospital.

Women who declined screening

Women from both hospitals (hospital one: 74%, n=211; hospital two: 72%, n=23) who were offered screening for Down's syndrome but declined were asked about their reasons for declining. All women who reported an offer of screening but declined (n=234) responded to this question. The predominant themes emerging from women's comments were similar in both hospitals despite different screening policies. Reasons reported included concerns about the test, they felt it would not make any difference to pregnancy outcome, concerns about the emotional impact of the test, influence of health professionals and perception of individual risk. A small number of women in hospital one also reported their beliefs as a reason to decline screening.

Common themes in hospitals one and two

Concerns about the test

This was the most common reason why women declined screening in both hospitals (67%). Concerns were related to the type of test on offer, that the test could only indicate the woman's 'risk' of having an affected baby and perceived fear of miscarriage. Some women (33%) also commented that the nature of the test – a non-diagnostic test with a potential false-positive result influenced their decision not to undertake screening. Fiona, a 23 year old in her first pregnancy said:

"One of the midwives recommended that it was not necessary because it only gave risks and there was no definite result. The test was explained clearly, but I didn't know what would happen if the result was high risk. I wouldn't have an amniocentesis because of the risk of miscarriage but if I had a baby with Down's or spina bifida I would have done something about it. The test only gave me a likelihood."

A small number of women in hospital one (10%) reported confusion about the type of screening test they had been offered. These women thought they had been offered an amniocentesis instead of a serum-screening test and subsequently declined due to the risk of miscarriage with amniocentesis. There was no confusion reported by women in hospital two between serum testing and amniocentesis, although the overall number of women offered the test in hospital two was small. Frances, a 27 year old educated to degree level in her first pregnancy from hospital one said:

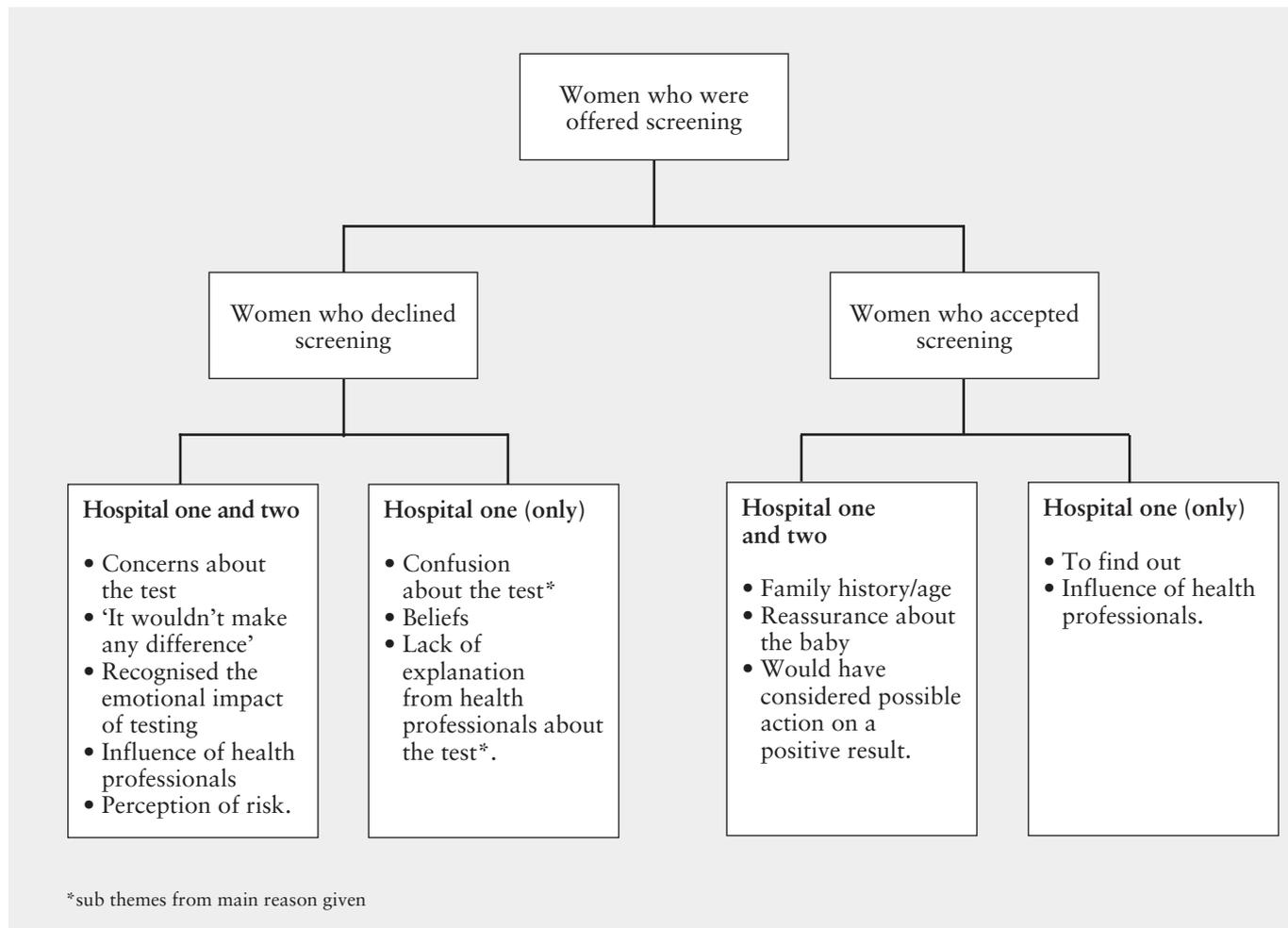
"I didn't realise there was a single blood test for risks. I thought it was an amniocentesis. The risk of miscarriage would have worried me. I wouldn't want to know because I wouldn't do anything about it. I would maybe have accepted the triple test if I had realised it was a blood test."

'It wouldn't make any difference'

This was a common reason given by almost half of the women (48%) in the total sample. Women who said 'it wouldn't make any difference' fell into two categories: those who said they would accept the baby regardless of any abnormality and women who said they would not act on a high-risk serum result or a potential positive amniocentesis result. Mary, a 43 year old in her second pregnancy:

"[I] was happy to accept the baby regardless of any problems [and] therefore I didn't feel screening was necessary."

Figure 1. Women's reasons for their screening decisions



Emotional impact of the test

Recognition of the emotional impact of accepting screening was reported by 30% of women across both hospitals. A number of women said they felt that accepting screening would increase their anxiety levels during pregnancy and that they did not want to know if there was any abnormality in pregnancy. Katie, a 25 year old with two children said:

"I thought it better not to know. Maybe I should think about it more, but I don't really want to.... it's tempting fate. I think pregnancy is stressful enough without that."

Women reported they felt reassured by their structural scan and if there was an abnormality present, it would be identified when they had their scan. Maria, a 35 year old educated to degree level said:

"I felt reassured by my scans and therefore was not overly worried about having the Down's syndrom/spina bifida blood test."

The influence of health professionals

A number of women in both hospitals reported the impact of the discussion with health professionals about screening as a reason to decline (26%). This was generally in two ways: either by directly influencing women in their decision-making or by not giving enough information about the screening tests on offer.

Some women reported that health professionals had directed them away from testing (29%) by saying 'well you wouldn't really want it anyway' and that discussion about the tests available were vague. Amanda, a 28 year old educated to degree level in her first pregnancy felt:

"The doctor seemed to suggest that the blood test [for Down's syndrome screening] had no real benefit and that put me off going for it. The doctor in [hospital one] only talked about it because we asked, I felt patronised. If it [the result] had come back high risk, I'm not sure I would liked to have known either way."

Several women also suggested that the level of information was not sufficient from health professionals about the test on offer. In hospital one, where there was a universal offer of screening, a definite lack of explanation from health professionals about the triple test on offer was identified. In some cases women initiated discussion about screening themselves. The comment below is from Karen, a 37 year old woman who had two previous pregnancies and was educated to GCSE level:

"Although I brought up Down's syndrome and spina bifida screening with the consultant [obstetrician], there was no big discussion given regarding these genetic tests. He simply said 'go away for a few days and think about it', if I felt I wanted these tests to let him know. In the end I decided myself not to have

these tests as I wouldn't act on any result positive for Down's syndrome. If women wouldn't act on a positive result, information should still be given about the tests."

Perception of risk

A small number of women in both hospitals perceived their individual risk as low and subsequently declined serum screening (16%). Women's perception of individual risk was related to having no family history of abnormality, their own age and eligibility for low-risk care. The majority of women in the study were defined as low-risk in terms of organisation of care and therefore eligible for shared care between their GP and midwife or midwife only. Some women felt being defined as 'low risk' in terms of organisation of care carried over into risk status in relation to screening. Kathy, a 31 year old with one previous child said:

"I didn't want to know the result and I felt I wasn't in a high-risk group. I have no family history and one previous successful pregnancy."

Hospital one: themes for women who declined screening Beliefs

Beliefs, either moral or religious, were reported by a small number of women (7%) as a reason why they did not accept screening for Down's syndrome. Brenda, a 27 year old with two children said:

"I suppose I would be affected by the way I was brought up and what I believe. I didn't have it done with the other two and they were fine. My religion would also prevent me from having them and wouldn't have done anything about it"

Women who chose to have screening

Women who chose to have some form of screening for Down's syndrome (n=83) were asked why they had made this decision. Despite the different policies in the two hospitals, the uptake in both hospitals was similar (hospital one: 26%, n=74; hospital two: 28%, n=9). Women's reasons for having screening showed similarities and differences between the two hospitals. Overlapping themes were age/family history, reassurance and women who would have considered acting on a positive test result. Two themes emerged specifically from hospital one (universal policy offer), which indicated that women who had accepted screening did so because they wanted to prepare for the future and were influenced by health professionals.

Themes common to hospital one and hospital two

Family history/age

A proportion of women in both hospitals (31%) accepted screening mainly due to their increased risk associated with age or family history. Women perceived they were in a higher-risk group and therefore should avail of serum screening on offer. More women in hospital two accepted screening for this reason compared to hospital one. These results are not surprising particularly in hospital two given the high-risk screening policy at that time and the small number of women who chose to have screening.

Gillian (39) who was educated to A-level standard with one daughter said:

"[My] age, and I have a three year old. My husband and I, we are older parents and I would like to know and plan for the future. It would have affected my decision regarding the outcome of the pregnancy.... I probably would have terminated depending [on the result]."

Reassurance

A number of women (20%) indicated they had accepted Down's syndrome screening tests for the purpose of reassurance. Women included in this category felt the test gave them 'a peace of mind' and in several cases acknowledged they were a low-risk group with no family history, but still wanted to have screening. Eva, a 29 year old with a degree-level education was having her first baby and said:

"[There is] no family history, just to allay fears. If you have a choice, you want to check the baby is normal."

Women who considered acting on a positive screen test result

A small number of women who accepted screening in both hospitals indicated they had accepted a serum-screening test, with a view to termination of pregnancy if the results were positive.

Joanne a 35 year old in her first pregnancy educated to A-level standard:

"In the initial stages of my pregnancy, this baby was unwanted. I wanted to make sure my risk factor for Down's [syndrome] was low and also to eliminate any other concerns about the baby. If the result was high risk, I would have had an amniocentesis and would have terminated [the pregnancy] if the result of the amniocentesis was positive for Down's syndrome."

Themes specific to hospital one

To find out

In hospital one, 34% of women suggested they had accepted screening because they had concerns about the future, a desire to 'prepare for the future' or 'to find out or know what was ahead'. Within this group there were three subgroups of women: those who felt they might consider termination of pregnancy, women who wanted to know so that they could consider all of their options during pregnancy and women who wanted to know, but definitely were not going to act on the results. Deidre, a 17 year old in her first pregnancy who had just undertaken her GCSEs felt:

"I wanted to know if anything was wrong so that I could make choices. It's good to have an option on whether to do something about the pregnancy and it also prepares you."

Influence of health professionals

The influence of health professionals was evident in the responses of a small number of women who accepted the offer of screening in hospital one only. Health professionals were influential either directly or more covertly in that a test offer was perceived by women as a recommendation to take the test. Catherine, a 23 year old with one previous child and A-level education said:

"...because the midwife recommended it and I wanted to know."

For the majority of women the health professional concerned was a midwife, although women who had private antenatal care also mentioned the influence of their consultant obstetrician.



Many women felt that if the tests were offered to them by health professionals, it was in a routine context and they therefore accepted them. The majority of women stated that it was part of their care, that they 'just had it' and did not question exactly why they were having tests.

Some women reported more detailed explanations from specialist health professionals such as midwives, obstetric consultants or genetic consultants who work exclusively in this area. Lynn, a 37 year old who had three children and was educated to A-level standard said:

"[A] genetic doctor took our family history at the antenatal diagnosis clinic and explained in great detail about the blood tests."

Discussion

The two main reasons why women declined screening in this study were because of concerns they had about the test and that knowing the tests results would not make any difference to the outcome of their pregnancy. These reasons have been cited previously in the literature (Green et al, 2004) as to why women decline serum screening.

Women who accepted screening gave reasons such as family history, age and the possibility of taking further action depending on the test result. The reasons reported by women who accepted or declined screening were similar in both hospitals despite different policies. However, the study included only a small number of women in hospital two who were offered screening. In addition, the interview included questions about why women decided on screening rather than how the decision was made. Although this study did not examine the decision-making process specifically of women in relation to serum screening for Down's syndrome, the reasons given by women for their choices give some insight into the process. It was interesting to note the similar uptake rate in both hospitals, despite the offer to a higher-risk group of women in hospital two.

This is one of the few studies to investigate the universal offer of screening in a country where termination of pregnancy is available in very limited circumstances and, until recently in Northern Ireland, there were no published guidelines available to assist professionals when discussing this issue with women (Department of Health, Social Services and Public Safety, 2009). Termination of pregnancy and provision of antenatal screening tests raise ethical dilemmas for parents and significant personal or professional conflict for practitioners (Garel et al, 2002). As a result, difficulties may emerge when implementing a universal screening policy in a country where termination of pregnancy is not legal. It remains to be seen how the new guidance will affect or influence professionals when counselling women about screening. Many countries have adopted universal serum screening policies; however, the individual benefit for women is debatable if the cultural context in which screening is offered is not taken into account.

Women's decision-making

Attitude to termination of pregnancy has been cited previously as an indicator of how women will decide about testing (van den Berg et al, 2008) and a positive attitude to termination is more likely to predict uptake of screening (Green et al, 2004). Although women were not specifically asked about

their view on termination of pregnancy, it was rarely reported as a factor in their decision. These findings may reflect superficial consideration by women of information about the test and also wider implications of accepting or declining screening tests. However, there is also the possibility that religious and moral beliefs are so deeply embedded in Northern Irish society that they do not surface as explicit reasons for decisions about testing.

Etchegary et al (2008) proposed that experiential knowledge of women plays an important role in decision-making about antenatal screening. Their study indicated that although women had technical knowledge about the tests, it was interpreted by women in relation to their experiential knowledge – that is previous experience of pregnancy and screening, experiences of friends and relatives. Similar themes were identified for women who accepted a screening test in this study, demonstrating consistency with this theory (Etchegary et al, 2008). These results highlight the importance of an individualised approach for women as they are counselled, advocated by van den Berg et al (2008) and Boyd et al (2008), resulting in a greater consideration of the values and social context of pregnant women during counselling.

Communication about screening

The offer of screening tests for Down's syndrome took place in both hospitals at booking or the first hospital visit. Women need to be informed at the first visit about various aspects of their care and pregnancy, but there may be little opportunity for the assessment of individual needs within a busy clinic of scheduled appointments. Women's responses indicated that many were not clear what test, that is serum screening or amniocentesis, was being offered or about the associated results. Evidence from previous research suggests women's understanding of screening tests is questionable (Pilnick et al, 2004; Smith et al, 1994). Seror and Ville (2009) have indicated that women are often unaware of the full implications of screening – this resonated with findings from Santalahti et al (1998).

The uptake of serum screening for Down's syndrome was significantly lower in this study than has been reported in other countries, despite the test being offered in a routine way alongside tests for HIV and syphilis. Press and Browner (1997) specifically noted that the test was often incorporated into the routine offer of other screening tests and that portrayal of the test as routine did not connect it with termination of pregnancy. The low uptake of serum screening in this study may suggest some insight by women about the test they were offered or more likely that the test was offered from a negative perspective by professionals reluctant to enter into discussion, as suggested by additional research (McNeill and Alderdice, 2008; McNeill, 2008).

McNeill and Alderdice (2008) and McNeill (2008) reported that midwives felt conflict between the time they had to explain serum screening and the actual time necessary to discuss the test fully. Subsequently, the test was offered in a routine way, which did not highlight the full implications of accepting screening possibly directing women to decline screening. Midwives also reported the lack of discussion around termination of pregnancy and observed that it rarely entered into the discussion with



women when offering serum-screening tests. Despite this, some women mentioned that they would actively seek termination of pregnancy. The Office of National Statistics (ONS, 2009) reported approximately 17% (n=1173) of non-resident abortions were to women from Northern Ireland who had travelled to England and Wales for a termination.

Role of health professionals

The influence of the health professional was the only theme that featured in the responses of both women who declined and accepted screening. Existing research has suggested that the personal attitude or opinions of the health professional can affect the decision-making process of women (Bernhardt et al, 1998; Bishop et al, 2004; Lewis et al, 2006). Poor knowledge has also been demonstrated by health professionals (obstetricians and midwives) who were involved in offering screening tests to women (Smith et al, 1994; Skirton and Barr, 2009). This has the potential to impact on women's knowledge and capacity to make an informed choice. Other factors such as the time available to discuss the test and the organisation of care may also affect the discussion with women. Many comments from women indicated that directional counselling by health professionals had influenced their decision-making, which is supported by other research (Marteau et al, 1992; Levy, 1999; Simpson et al, 1998). It has also been suggested in the literature (Press and Browner, 1993; Pilnick et al, 2004; Smith et al, 1994) that the decision to have screening is not always a premeditated conscious decision by women, therefore increasing women's susceptibility to influence.

Genetic counselling aims to be value neutral and non-directive; however, there is debate about the reality of this in practice. A recent study in Hungary (Tóth et al, 2008) demonstrated that approximately 68% of patients undergoing genetic counselling wanted the decision-making process to be shared by their counsellor. If decision-making is to be shared between parents and professionals, it is vital that health professionals are appropriately trained and prepared for this role. Existing evidence indicates training is not a priority for professionals working in

this area (Sandall and Grellier, 2001; Harcombe and Fairgrieve, 2004; Cleary-Goodman et al, 2006). Lynn and Alderdice (2006) conducted a regional survey across Northern Ireland and found that training needs of antenatal staff were met predominately on an ad hoc basis indicating a clear need for more comprehensive training. This highlights the importance of appropriate and relevant training for staff as new tests, screening programme and counselling approaches are introduced.

Conclusion

This study adds evidence to the existing literature on women's reasons for their decisions about screening for Down's syndrome and considers their reasons in the context of different screening policies and against a societal background where termination of pregnancy is not available. Women's reasons for having or declining screening differed little from previous studies and did not seem to vary with different screening policies, however, it is difficult to draw firm conclusions from the data given the small number of women who accepted screening in hospital two. These findings are important in the absence of regional screening policy and where NICE guidelines are implemented on a good practice basis only (NICE, 2008).

The aim for future practice should be individualised counselling with consideration given to women's values from health professionals who are supported by clear policies and guidelines on antenatal screening and termination of pregnancy. Further research focusing on educational interventions for midwives in relation to discussing screening tests with women and also investigation into the most effective mode of delivering screening information to women are essential in order to ensure informed choice for women and their partners.

The study highlights the need to take into consideration the constraints of the current law and the general context of care. Introducing universal antenatal screening in a context where termination of pregnancy is not available is fraught with difficulty for women and health professionals. In this study this was reflected in low uptake, confusion about the test and lack of discussion with women about the implications of antenatal screening.

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