

Pregnant women's perceptions and decision-making about antenatal screening for Down's syndrome: a meta-synthesis

By Dr Bernie Reid, Professor Marlene Sinclair, Professor Owen Barr, Professor Frank Dobbs and Dr Grainne Crealey.

Introduction

This paper is a shortened version of a meta-synthesis published in *Social Science and Medicine* in 2009 on pregnant women's decision-making processes with regard to antenatal screening for Down's syndrome.¹ It includes a brief introduction to meta-synthesis as a methodology and then focuses mainly on the emergent findings, based on nine primary qualitative research studies. Readers who are interested in the methodology will find further details in the full paper.¹ In some parts, language has been changed from the original for the NCT audience of specialist workers and parent advocates.

The potential of antenatal screening for Down's syndrome to enhance pregnant women's reproductive choices is well-documented.^{2,3} Simultaneously, concerns remain that such screening may contribute to the emergence of new and complex ethical, legal and social dilemmas for women.^{4,2} Indeed, Rapp argues that:

'...the construction and routinization of this technology is turning women to whom it is offered into moral pioneers: situated on a research frontier of the expanding capacity for prenatal genetic diagnosis, they are forced to judge the quality of their own foetuses, making concrete and embodied decisions about the standards for entry into the human community.'⁵

In consequence, there have been several studies focusing on pregnant women's decision-making processes about screening for Down's syndrome, many of them qualitative. Each qualitative study may offer insight into women's screening decisions yet do not always contribute significantly to a full understanding of women's decision-making processes.⁶ To create a more comprehensive understanding, the findings of several single studies may be

considered together and synthesized into thickly descriptive and comprehensive understandings of women's decision-making processes which, in conceptual terms, are greater than the sum of the parts.^{6,7,8} Thus, Estabrooks et al.⁹ and Paterson et al.⁶ point to the significance of synthesis in attaining a level of conceptual development beyond that achieved by any individual study as a means towards strengthening and facilitating the greater use of qualitative findings in midwifery and healthcare practice. This paper presents a synthesis of qualitative research studies relating to pregnant women's decision-making processes about screening for Down's syndrome.

Methods

Meta-synthesis is 'research of research'⁶ which provides a critical re-interpretation of the findings of existing qualitative studies.^{10,6} It must be emphasised that the process is not one in which summation of meanings are valued over the rich and thick descriptions of individual studies,¹¹ but rather seeks to 'carefully peel away the surface layers of studies to find their hearts and souls in a way that does the least damage to them'.¹²

Noblit and Hare's classic method was adapted to undertake the meta-synthesis.¹³ Each stage will now be briefly outlined.¹³

Stage 1: Defining the meta-synthesis question

The meta-synthesis question was defined as: 'What factors influence pregnant women's decisions to accept or decline maternal serum and/or nuchal translucency screening for Down's syndrome?'

This question was considered broad enough to capture the attributes of women's decision-making within the context of antenatal screening for Down's

syndrome but narrow enough to create a feasible limit to the number of existing qualitative studies, to be included in the meta-synthesis.⁶

Stage 2: Searching for studies

The search for studies was limited to those which focused on decision-making about antenatal screening for Down's syndrome from the perspective of pregnant women themselves, and not as predefined by professionals, researchers or policy makers. All relevant English language qualitative research studies published in peer-reviewed journals between January 1999 and January 2008 were retrieved. A wide range of search terms was identified, including terms for the topic, the decision-making theme including women's experiences, and methodology. Ten electronic databases were searched together with a hand-search of eleven journals. Full details of the search terms, databases and journals are included in the original article.

Stage 3: Selecting studies

The total number of published works retrieved amounted to over 12,000. The overwhelming majority of these were excluded as the title indicated that they did not meet the study criteria. A total of 189 abstracts were reviewed and 180 were subsequently excluded on the basis that they did not include pregnant women as participants; they focused on women's health screening where distinctions could not be made between decision-making about antenatal screening and cancer screening; or they were mixed-method studies in which qualitative findings could not be separated from quantitative findings. The nine studies selected for inclusion in the meta-synthesis reflected an international perspective on pregnant women's decision-making with regard to screening for Down's syndrome (Table 1).

Table 1: Studies selected for inclusion

Author	Year of publication	Location of study	Quality rating
Markens et al. ¹⁴	(1999)	US	C
Lewando-Hundt et al. ¹⁵	(2001)	Israel	C
Liamputtong et al. ¹⁶	(2003)	Australia	C
Pilnick et al. ¹⁷	(2004)	UK	C
Williams et al. ¹⁸	(2005)	UK	B
Chiang et al. ¹⁹	(2006)	Taiwan	D
Heyman et al. ²⁰	(2006)	UK	B
Remninnick ²¹	(2006)	Israel	B
Garcia et al. ²²	(2008)	Netherlands	B

Stage 4: Appraising the quality of selected studies

The studies in this meta-synthesis were subjected to a detailed quality assessment using a framework developed specifically to appraise qualitative research.²³ This framework assessed the appropriateness and coherence of the study's scope and purpose; methodology; methods including sampling strategy, data collection methods, ethical dimensions, analysis and interpretation; relevance and transferability; and researcher reflexivity. A summary quality grade was then allocated to each study with grade A denoting no or few flaws, the study credibility, transferability and confirmability are high; grade B having some flaws, unlikely to affect the credibility, transferability, dependability, and/or confirmability of the study; grade C having some flaws which may affect the credibility, transferability, dependability and confirmability of the study; and grade D having significant flaws which are likely to affect the credibility, transferability, dependability and/or confirmability of the study. The quality of the studies was generally fairly good, with some weaknesses in the use of techniques to ensure the transparency of methodology; sampling strategy and analysis; and in accounting for ethical dimensions and reflexivity.

Stage 5: Analyzing and synthesizing the selected studies

Appraising quality was the first phase of repeated reading of the studies leading to the identification of recurring key themes across studies. The first iteration of key themes was derived from both the verbatim text of participants in the studies

and from the themes identified by authors of the studies. Key themes were then examined in relation to others in the selected study and across studies – a process analogous to the method of constant comparison used in qualitative data analysis. This led to the final iteration of key themes.

By examining the studies in relation to one another, it was possible to establish relationships between the nine studies. The studies' findings did not necessarily disagree or refute one another but rather seemed to be directly comparable or reciprocal of one another. By considering each key theme in turn and using them as building blocks, a first iteration of five core concepts was derived. A final iteration of core concepts was developed using key phrases borrowed from English literature. Taken together, these five core concepts represent the synthesis achieved.

Findings

The findings of this meta-synthesis are presented in terms of five emergent core concepts. These core concepts are: destination unknown; to choose or not to choose; risk is rarely pure and never simple; treading on dreams; and betwixt and between. The key themes constituting each core concept are outlined. The essence of each concept is summarized in a section entitled 'synthesis'. Finally, the five core concepts are taken together to propose a conceptual framework representing women's decision-making processes with regard to screening for Down's syndrome.

Destination unknown Anxiety

Pilnick et al.¹⁷ reported that women

accepted screening in anticipation of abating their anxiety and receiving reassurance about fetal health and well-being. Yet other women pointed to the potential anxiety provoked by screening: anxiety focusing on the stress and worry experienced while awaiting screening results, distressing decisions about diagnostic testing, and perceptions that anxiety will continue through pregnancy even in the event of low risk result. As one participant in Remninnick's study stated: 'Truth is, I will worry till I get the results, only then I'll be able to sleep quietly ... for some time at least, since I have many other tests waiting ahead ...'²¹

Indeed Markens et al. noted that women declined screening because of the potential anxiety it may pose for them:

'I have my reasons for not having certain testing ... An unnecessary anxiety in a lot of cases. I think that it can cause anxiety rather than reassure'.¹⁴

Views on abortion

Women framed their decisions about screening within the context of potential future decisions about abortion. While some women's views on abortion were based on religious beliefs,^{15,16} others were based on personal beliefs and values.¹⁸

Williams et al. highlighted most women's uncertainty about what they would do:

'... but that's why the test would be so hard for me, because I wouldn't be straightaway, oh, if there's something wrong, I'm not having it'.¹⁸

Nevertheless, some women were very clear that they would not choose to have an abortion, thereby perceiving screening as pointless.^{14,20,21} As one participant stated:

'... the test might as well not even exist because I'm not going to have an abortion anyway'.¹⁴

Garcia et al. suggested that screening was only useful for women who would choose to have an abortion:

'If you take a test you make beforehand the decision to terminate the pregnancy if you hear that you'll get a child with Downs syndrome. I think that you take a test with the purpose to terminate your pregnancy'.²²

Yet this suggestion was latterly refuted by both Garcia et al.²² and Markens et al.¹⁴ who argued that, although women who accepted screening did not exclude

abortion in the event of a confirmed diagnosis, they did not always directly associate screening with the possibility of abortion.

Perceptions of having a child with Down's syndrome

Perceptions of having a child with Down's syndrome shadowed women's decision-making about screening. Such perceptions were articulated in terms of disability; ability to mother a child with Down's syndrome; potential impact the child may have on the family and concerns about social support.

Although some women pointed to their low acceptance of disability and lack of will to mother a child with Down's syndrome,^{19,21} others believed that:

'there is a place in society for "special" children as well as "normal" children. If my baby is "special" then I'll do all I can to look after him/her, and offer him/her the best possible life'.¹⁶

Only one study referred to the role of screening in providing women with information which might enable them to prepare for having a child with Down's syndrome.²² Women agreed that a child with Down's syndrome might 'help family members to cope with adversity and to appreciate the worth of little and irrelevant things'²² yet shared concerns that the special attention required by such a child could give rise to more family worries and costs, together with lack of attention for other children.²² Women's fears of '... getting old, who will take care of the child? Will he or she become a burden on others?'¹⁹ appeared universal.

Synthesis

The three themes in this section coalesced into something that was beyond anxiety, views on abortion and perceptions of having a child with Down's syndrome. This led to the concept of 'destination unknown'. In other words, women's decisions about screening were incumbent upon a range of expectations based on current images of future psychological states and ethical dilemmas.²⁴ Thornton and Nardi consider such anticipatory expectations to be 'incomplete and ambiguous', helping women's decision-making only to the extent that they were accurate in drawing inferences about future states.²⁵

To choose or not to choose

The routine nature of screening

Screening was viewed by most women as routine. One explanation for such a viewpoint was that 'The technology is available so why not use it'.¹⁴ Chiang et al. pointed to women's acceptance of screening as an integral part of routine antenatal care.¹⁹ Indeed, women may not have been aware that they were consenting to an optional test, but rather framing their decisions to accept screening in terms of it being 'a formality'.¹⁷ Markens et al. suggested that women were more likely to accept screening when it was presented within the context of non-controversial routine antenatal care.¹⁴ A few women accepted screening because they were concerned that if they did not, they would not be able to access other maternity care services.²⁰

Expert authority

Women's decisions to accept screening were further influenced by their perception of its strong endorsement by expert or professional authority.²¹ Such expert authority was built upon trust and knowledge. The unlimited trust that some women placed in the expert was captured by one participant in Heyman et al.'s study:

'But you just ... basically trust (name of consultant), and whatever is to be done, then just do it'.²⁰

However, such a perception was challenged by a minority of women.²¹

The authority of the expert also rested upon his/her ability to interpret complex biomedical knowledge surrounding screening. Consequently, there was an asymmetrical relationship between women's information about screening and expert knowledge.²¹ Such asymmetric information may have adversely affected women's decision-making by rendering them:

'...powerless when we encounter medical science'.¹⁹

Moreover, reliance on expert knowledge tended to negate women's intuitive knowledge processes: 'see, I think we're not experts in this baby thing anyway, so it's like whatever they offer, we would just take ...'.¹⁸

Synthesis

The most striking effect of women's views

about the routine nature of screening and expert authority was the reduction, rather than the expansion, of choice. The result was deeply problematic because, without a sense of choice, women had the potential to make very poorly-considered decisions which failed to carefully examine their motivations for screening and the meaning of screening information to them. Thus, women who believed they had no choice may have found themselves unexpectedly on a screening path for which they were completely unprepared.

Risk is rarely pure and never simple

Information about risk

In some studies, women either declined screening because of inconclusive risk information¹⁶ or accepted screening because they felt intimidated²¹: 'Who do they think I am – an MD or a scientist? I don't know every other word in this flyer; what's the point in reading it? It only gets scarier ...'.²¹

Although some women grasped the significance of risk statistics quoting the probability of a pregnancy being affected by Down's syndrome – 'So 1 in 174, or whatever it was, I just imagined 174 women, and I could be that one person'²⁰ – others did not.¹⁷

In some instances, more descriptive categories such as 'high risk' or 'low risk' also proved problematic.¹⁷ In consequence, some women placed their trust in the expert rather than engage with the complex process of interpreting risk.²⁰

Nevertheless, some women challenged the inconclusive nature of screening results:

'... and sometimes the test is inaccurate and the chances of the test being inaccurate are higher than the chances that, something could be wrong, most likely'.¹⁴

Contextualising risk

Women's unique and subjective life experiences led to different perceptions of risk and different decisions about screening. Some women declined screening because they saw themselves as 'fit and healthy' with 'no problems in earlier pregnancies'.¹⁶ Other women had experienced difficulties in conceiving and did not wish to risk harming the foetus by

being screened.¹⁶ Moreover, women's contextualised perceptions of risk may or may not have conflicted with biomedical interpretations of risk.^{14,17}

Risk and diagnostic testing

Some women found it difficult to differentiate between the results from screening and diagnostic testing.¹⁷ High risk screening results were interpreted by some women as a definitive diagnosis.¹⁵ Yet for other women the unsatisfactory nature of screening results predisposed to the need for more definitive information from diagnostic testing.¹⁷ However, decisions about diagnostic testing further exacerbated women's anxiety: anxiety related to the risk of miscarriage associated with such invasive testing.^{14,17} Despite such risks, some women perceived that there was no point in having screening if they then did not wish to proceed to diagnostic testing.^{16,20} Hence, women did not view screening decisions as discrete but rather as one stage of a progressive decision-making journey.

Synthesis

From a biomedical perspective, risks are presented as objective, neutral probability statistics that are correct, precise and unambiguous.²⁶ On this basis, women should have made rational decisions based on the magnitude of the risk. However, screening results, presented as risk probabilities, were not indisputable facts, but rather a social product that were constantly constructed, reconstructed and negotiated. The concept of risk was therefore unstable. At one level, risk figures were constructed by an expert authority who retained the power to define and interpret them. Yet women were sceptical about the usefulness of risk categories and tended to simplify risks into meaningful contextual statements, that is, summaries that were meaningful for them, embedded as they were, in their own particular life experiences.

Treading on dreams

Imaging the foetus

Nuchal translucency ultrasound screening focused women on images of the foetus. The power of such screening technology to 'personify the foetus' by '...actually seeing the outline of the nose

and everything ...'¹⁸ also had the potential to present women with further decision-making dilemmas in the event of adverse screening results:

'... but when you see that baby on the screen, you don't care what it's got wrong with it, you just see that it's there and you know it's inside you ... it must be a horrible decision once you've actually seen that this is a baby inside you, to suddenly say "no, I don't want to carry on with it".'¹⁸

Indeed, Garcia et al. reported that, despite differing views about when the foetus may be considered a person, women defined abortion in terms of loss.²² Considering termination for Down's syndrome in the first few months of pregnancy was seen as the loss of an anticipated child.

Just in case

Some women's growing awareness of the foetus was reshaped by their need to maintain a distance from it 'just in case' Down's syndrome should be discovered, and they should be confronted with the necessity to choose to end or continue the pregnancy:

'And she just said, keep looking at the screen, just concentrate on the screen, but I just looked away ... because I didn't want to get attached to this thing (foetus) that was moving, you know (tearful).'¹⁸

Thus, the status of the foetus was suspended in time until fully screened and proved 'normal'.²¹ For other women, the shadow cast by screening over their adaptation to pregnancy and emotional involvement with the foetus continued for longer periods of time:²⁰

'And it probably took me about another month after having the results to actually finally think to myself, I am pregnant. I want to have this child.'

Responsible motherhood

Women's perceptions of motherhood appeared to be based on responsibility for ensuring fetal health and well-being, with such perceptions impacting upon their decision-making about screening.^{21,22}

Some women accepted screening as they wished to live up to perceived expectations of a caring and enlightened mother as early in the pregnancy as possible.

'This is my first baby and I want to do all that I can to ensure its good health'.²¹

Other women argued that they were doing all that is necessary to ensure the birth of a healthy baby by avoiding the risks posed by screening – risks posed by information, false positives and amniocentesis.^{14,16} Importantly, women linked their responsibility for ensuring fetal health and well-being with healthy pregnancy behaviours. Indeed there was limited recognition that chromosomal abnormalities such as Down's syndrome are unaffected by such behaviours.²¹

Moreover, responsible motherhood meant preventing the perceived suffering and misery that a child's disability might entail:

'... I will never stop blaming myself for not doing the tests, all that are available at the moment. It is just so hard to raise a child with disability; I am not prepared for that'.²¹

There was also recognition that responsibility for raising a child with a disability would fall to the mother, contrasting sharply with notions of responsible fatherhood.²¹

Synthesis

The concept of 'treading on dreams' related to how technological advances in screening together with expectations of responsible motherhood impacted upon the quest for a 'perfect' baby.²¹ Such a quest was integral to women's decision-making processes about screening. Technological advances served to hasten women's sense of relatedness to the foetus as a 'perfect person' from its earliest stage. Whilst screening invoked the 'perfect personness' of the foetus it also contributed to the stress and uncertainty which women experienced when trying to make decisions following adverse screening findings. Consequently, for some women the status of the foetus became provisional or tentative,²⁷ precluding maternal-fetal relatedness. Importantly, women perceived themselves as ultimately responsible for the production of a 'perfect baby'.

Betwixt and between

Women's decision-making about screening was etched with perceptions about the 'right to know' versus the 'right not to know'. In other words, women existed in a state of betwixt and between. The right to know was associated with

women's desire to have sufficient information in order to attain control over their future motherhood by ruling out Down's syndrome.²¹ On the other hand, the right not to know was associated with the risk that information obtained from screening results could cause emotional distress and lead to further difficult decisions.^{14,16} The interplay of women's 'right to know' versus 'right not to know' was highlighted by one participant in Liamputtong et al.'s study:

'I would like to have had the reassurance that chances of Down's syndrome were low – but decided against the risk of finding out that things were not ok'.¹⁶

Taking the five core concepts together, it is argued that women's decision-making processes about antenatal screening for Down's syndrome were not only complex in that they were influenced by a number of factors but also that such factors acted both independently and inter-dependently. For example, women trying to grapple with the risks associated with diagnostic testing were also engaged in anticipating how they might cope with a child with Down's syndrome. In addition, such deliberations cannot be easily disentangled from views on abortion. So rather than locating women on a particular decision-making trajectory, a conceptual framework is proposed which recognises the intersecting and interwoven nature of women's decision-making about screening for Down's syndrome).

Conclusion

The meta-synthesis presented in this paper has sought to realise the important contribution of qualitative studies in generating more comprehensive understandings of pregnant women's decision-making processes about screening for Down's syndrome. The development of such understandings into a conceptual framework constitutes a new and insightful level of conceptual development. This framework reflects a synthesis of nine selected studies with the core concepts of destination unknown; to choose or not to choose; risk is rarely pure and never simple; treading on dreams and betwixt and between, which emerge as integral to women's decision-making processes. These core concepts have not previously been identified and further

research is proposed to verify such concepts. If such research verifies that the framework is indeed reflective of women's decision-making, midwives and other healthcare professionals may need to reconsider the support they provide in order to empower women in making choices about screening.

Key messages

1. Antenatal screening for Down's syndrome has the potential to enhance pregnant women's reproductive choices. Yet concerns remain that such screening may contribute to complex ethical, legal and social dilemmas for women.
2. An examination of pregnant women's experiences and decision-making about screening for Down's syndrome is therefore important.
3. Twelve themes were identified from this meta-synthesis of nine qualitative studies and then merged into five core concepts. These core concepts were destination unknown, to choose or not to choose, risk is rarely pure and never simple, treading on dreams and betwixt and between.
4. The authors propose that a more sophisticated conceptual framework, which acknowledges these multiple and complex aspects of perception and decision making about screening for Down's syndrome, would provide a more comprehensive understanding of women's perspectives and behaviour.
5. This, combined with further research, might make midwives and other healthcare professionals better equipped to meet the needs of pregnant women for support and information to assist them in making their screening decisions.

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Dr Bernie Reid, lecturer in nursing, and most of the research group are based at the University of Ulster.

The authors and research editor have aimed to make the paper accessible while at the same time retaining sufficient detail of the theoretical and methodological processes to introduce the reader to meta-synthesis of qualitative research studies. The terms 'Down's syndrome' and 'Down syndrome' have the same meaning. NCT uses the former; the original paper on which this article is based uses the latter.