SOCIAL AND ETHICAL DETERMINANTS OF THE USE OF ROUTINE ANTENATAL SCREENING TESTS

Judith Searle B.M.B.S. F.R.A.C.O.G. G.D.P.H.

Thesis submitted for Degree of Doctor of Medicine in the Faculty of Medicine, University of Adelaide, December 1996.

I declare this thesis to be original research of my own composition.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university. To the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of this thesis.

I give consent to this copy of my thesis, when deposited in the University Library, being available for loan and photocopying.

....

.....

.....16/12/96.....

LIST OF CONTENTS

LIST OF TABLES

This thesis sets out to analyse and understand some of the social and ethical determinants of the use of contemporary routine antenatal screening tests in Australia and their implications for future policy and practice.

In 1995, a cross-sectional study of 376 postnatal women at the Royal Women's Hospital in Melbourne, Victoria was conducted. In addition, 21 semi-structured interviews were performed. Consumers' beliefs and values related to pregnancy, birthing outcomes and antenatal screening were explored.

The findings of this study demonstrate that there is a complex interaction of social and ethical factors that determine the use of routine antenatal screening tests by pregnant women. In particular, this study identifies pregnant women's perception of risk as a dominant factor in the use of antenatal screening. The socio-cultural foundations of this risk perception are complex. In addition, the findings demonstrate that, because of women's high trust in, compliance with and reliance on medical input into their pregnancy care, medical dominance of antenatal care is often disguised as consumer demand.

This study also demonstrates that, in an 'opt out' or routine system of screening, high utilisation rates were achieved at the expense of loss of informed choice for some participants. Disturbing differences in information delivery and information perception are found between public and private patients. Other determining factors identified are pregnant women's altruism, their perception of their individual rights and the act of offering screening. These factors, in part, explain why the number and frequency of antenatal screening tests is increasing and why tests, once introduced, are difficult to remove from the repertoire of routine use.

The thesis identifies new criteria that are important for the evaluation of antenatal screening programs and for best practice in antenatal care. Failure to incorporate these criteria into current antenatal screening program evaluation has implications for the increasing medicalisation of pregnancy and childbirth, the widening of the gap in expectations between consumers and health care providers with resultant conflict and the increasing drain on health care resources.

ACKNOWLEDGMENTS

I wish to thank my supervisor, Dr. Neville Hicks, for his support and guidance and especially his belief in me and this research. Thank you also to Dr. Janet Hiller and Dr. Phil Ryan for their timely rescues and moral support. Thank you to Professor Shaun Brennecke for laying the path for a smooth entry into a new culture and for giving me somewhere to belong.

I am grateful to the Public Health Research & Development Council for seeing the value of this research and the contribution it can make to policy and provision of public health services. I thank them for their moral and financial support.

Thank you to Leena for her patience, her nurturing and her tireless support through this epic. Words are not enough.

And thank you to all of the wonderful women who gave of their time, their trust and their insights and made this research possible. This thesis is yours. These are your voices.

Chapter 1 **INTRODUCTION**

The objective of this dissertation is to analyse and understand some of the social and ethical determinants of the use of contemporary routine antenatal screening tests in Australia and their implications for future policy. Routine antenatal screening tests are integral to the current practice of antenatal care but women have concerns about birthing outcomes that exceed the limits of antenatal tests. What do pregnant women expect from the tests offered during their pregnancy?

During the past decade in antenatal clinics I have met surprisingly little questioning by pregnant women as to the role and worth of routine antenatal tests. That is, until new tests were introduced. I was frequently called upon at one public teaching hospital to counsel and reassure women who, following a phone call from the hospital telling them they had a positive result to the serum triple test that had been performed at 16 weeks gestation, believed themselves to be having a baby with Down syndrome. The definition of a positive result was a risk score equal or greater to a woman of 35 years, that is, 1 in 400.

Despite these negative experiences reported by women and despite the lack of formal evaluation, the test soon became universal in that hospital. This led me to question what factors actually determined the use of antenatal screening tests, in particular, routine antenatal screening tests. Murray Enkin, one of the editors of the 'blue bible' of evaluation of research and practice in obstetrics, had already observed that it was unfortunate that 'The nature and pattern of antenatal care has been shaped as much by political, professional and cultural factors as by purely scientific considerations'.[1] I chose to build on his views by exploring the social and ethical factors that are important in the use of antenatal screening but have been largely ignored to date.

Much of the research publication to date addresses antenatal screening tests such as alpha feto-protein,[2,3,4] ultrasound[5] and amniocentesis.[2,6,7,8] Little is known about the factors involved with the routine use of antenatal screening tests. Literature addressing women's experience

of antenatal testing raises issues of potential harm from antenatal screening and highlights some of women's negative experiences.[2,3,9,10] Two obstetric clinicians, Mohide and Grant, warn other clinicians that 'During pregnancy and childbirth, as in other situations, diagnostic and screening procedures do not necessarily lead to improved health of the women and babies to whom they are applied; indeed, they may actually pose threats to their well-being.'[11]

What has not been addressed thus far, is why women largely endure these inconveniences or bad experiences of testing and comply with antenatal screening programs. How do women perceive routine antenatal screening? What are their values and beliefs in relation to pregnancy and birthing outcomes? In what context do these beliefs and values arise? How do these impact on the utilisation of routine antenatal screening tests? This thesis addresses some of these questions and, more broadly, asks what are the implications of these potential social and ethical determinants of the use of routine antenatal screening for the future of pregnancy care and health resource allocation. In particular, it examines the role of women's fears in the use of screening and addresses the notion of consumer demand and its relationship with medicine. It also examines the notion of informed choice in an 'opt out' system of screening and its impact on the utilisation of screening.

This thesis represents a substantial original contribution to the body of knowledge on antenatal screening. I consider this thesis to advance medical knowledge and practice in the field of antenatal screening.

The Researcher

My motivation for this study has largely arisen from my experience as an obstetrician and gynaecologist within various public teaching hospitals in Adelaide and Melbourne over the last 10 years. During this period of specialty training I was enlightened by the power of research based practice in obstetrics and gynaecology. Many commented that I had been

'Chalmerised', meaning I had embraced the writings of Chalmers, the primary advocate for sound research based practice in the specialty.

My prior employment in community health centres for women and my ongoing activism as a feminist in women's health has established the grounding for interest in health issues for consumers, in particular, women. More recently, I have come to appreciate some broader principles of public health following completion of studies in the Master of Public Health degree at the University of Adelaide. During these studies I was also introduced to the constructivist paradigm* of knowing. In particular, I discovered the value of new methodologies to explore public health and consumer issues.

In the past decade, which incorporates my training in the specialty of obstetrics and gynaecology, many changes in the provision of antenatal care have occurred, in particular, routine antenatal screening. In that time antenatal screening for Human Immunodeficiency Virus (HIV), Group B streptococcal carriage, the triple test for Down Syndrome, and a 50 gram glucose challenge for glucose impaired states have become routine screens in many public teaching hospitals' antenatal screening programs. All were introduced for more specific purposes in selected populations: therefore I ask, 'What has driven this rapid growth in the routine use of many antenatal screening tests? In particular, what do the consumers of these services feel about this; might these feelings be a dynamic of routinisation and what are the broader public health implications?'

Thesis outline

The thesis is set out in the following way:

Chapter 2 lays the foundations for the research questions. It explores some of the historical, epidemiological, sociological and policy perspectives of the research questions. It also discusses further, the context in which the researcher raises these questions.

---

* Refer to chapter 3, methodology, for a definition of this paradigm.

Chapter 3 describes the underlying epistemology, assumptions and methodologies inherent in the research methods. It discusses, in detail, the methods employed in the research.

Chapter 4 details the results of the study, including both qualitative and quantitative data. It includes demographic information about the study sample.

Chapters 5 and 6 discuss the social and ethical questions raised by examination of the use of routine antenatal screening tests.

Chapter 7 discusses the implications of the findings for the consumers of pregnancy care. It highlights particular public health concerns and policy implications.

I do not address all possible determinants of the use of routine screening in pregnancy. In particular, it is beyond the scope of this study to examine in any depth the associated professional issues, medical development and political factors associated with the use of screening in pregnancy. Whilst that additional inquiry might provide a more balanced analysis of factors operating to promote the use of antenatal screening, the consumers' perceptions and beliefs about screening, pregnancy and birthing outcomes warrant examination.

Potential applications of the findings of this dissertation include the following:

. lessening the gap between society's expectations of antenatal screening and birthing outcomes and the known obstetric and perinatal outcomes by:
    .educating antenatal care providers about the context in which pregnant women form these expectations and
    .presenting more honest and realistic information about birthing outcomes to pregnant women;
. raising social and ethical considerations (in addition to the existing epidemiological criteria) when evaluating antenatal screening programs;
. providing guidelines for the development of antenatal screening policies that take account of consumer perspectives;
. planning antenatal service provision in anticipation of future expectations of antenatal care;

. looking to alternatives to litigation to address consumers' potential unmet expectations and needs.

Chapter 2. GROUNDING THE RESEARCH QUESTION

2.1 THE HISTORY OF ANTENATAL SCREENING

Antenatal screening tests are integral to contemporary antenatal care. It is hard to imagine the existence of one without the other. It is equally hard to pin point the emergence of antenatal screening, as a separate entity. Much of the historical critique of the rise of antenatal care has concentrated on its general development, rather than the particularities of antenatal screening procedures.[12,13] Examination of the historical context of the development of medical technologies, however, provides further insights into the role and development of antenatal screening tests.

The 16th century saw a departure from the previous beliefs, arising from the ancient Greeks, that medicine should 'assist nature to re-establish the proportional relationship of health among the humors (basic elements of the body)'.[14] The rise of scientific and artistic interest in the body's physical make up contributed to an examination of pathological transformations of anatomical structure and a search for sites of change of structure. By the 19th century this change in perception supported the growth of technological innovation seen initially with the use of the stethoscope in 1819. Such technologies lead doctors to give reduced significance to a patient's narrative and to believe strongly in the extension of their senses into the body.[15]

A strong trust and increasing reliance developed on scientific events rather than personal acts to make medical diagnoses. This was further enhanced in the 20th century by the development of sensing machines such as the X-ray and ward laboratories with microscopes and chemical tests.[15] Development of these technologies also moved the practice of medicine into hospitals as was also seen with antenatal care. Reiser[15] and others[16] note that history shows that technologies 'can be imperative'.[17] It was not until the mid 1970's, with the introduction of the 'new technology assessment' which evaluated technologies for

quality, effectiveness and cost, that the development of medical technologies were much questioned.[18]

Antenatal screening, like other medical technologies, is a relatively new concept. It has been the area of greatest expansion within the modern day provision of antenatal care. Enkin, a clinician and epidemiologist who has made significant contributions to the evaluation of pregnancy care, describes antenatal screening as 'a variety of investigations, procedures' superimposed on a basic structure of antenatal care that 'has remained unchanged and largely unchallenged for well over half a century'.[19] One of the fundamental changes that Enkin notes is 'a growing tendency to apply to all women measures which are of unquestionable benefit to only a minority'.[19] Thus the rise of the routine application of antenatal screening procedures over time has been insidious.

Clues as to the possible dynamics of screening within antenatal care are found within the historical critiques of antenatal care,[12,13] especially the context in which antenatal care developed. This section examines the possible factors that have influenced the development of routine antenatal screening to date. In particular, it discusses the relevance of these factors for modern pregnancy care and the impact, or lack of impact, of the recipients of antenatal care on the evolution of antenatal screening.

Mid-19th century to the early 1900s.

Much of what is known of as modern antenatal care has only existed in many industrialised countries since the early 1900s. Before that there was minimal medical care during pregnancy. Pregnant women were, however, given advice on their health as early as the 18th century. Oakley, who has comprehensively examined women's experiences of pregnancy and birth, states that pregnancy was 'regarded primarily as a state of health' where any care during that period was only aimed at relief of pregnancy symptoms.[20] Medical opinion of the time acknowledged that complications in pregnancy and childbirth did occur but at that time little could be done to correct them, even if diagnosis were possible. With the advent of

greater medical revelation of events during pregnancy came an increased popularity of medicine.

In the middle of the 19th century a number of developments in medicine were expressed in the introduction of the earliest tests in pregnancy, some of which have formed the basis for many routine antenatal tests today. Many of the developments arose from European understandings of physiology and pathophysiology. In 1843 Lever and Simpson noted the presence of albumin in urine of eclamptic women. In 1900, in a series of 6 lectures on 'Antenatal diagnosis', Ballantyne wrote that '...the maternal urine and blood should be subjected to chemical and microscopic examination as it is beginning to be revealed that the condition of the foetus in utero is to some extent reflected in the composition and character of the maternal excretions'.[21] In 1896 the first shadowy X-ray of a dead fetus in utero was performed. In 1897 Pierre Budin in France and in 1907 J.R. Riddell in Glasgow developed X-ray pelvimetry during pregnancy and labour. In 1910 the first X-rays of living fetuses were performed during pregnancy.[12]

Oakley[12] and Shearer[13] have written the most substantial histories of obstetrics by people outside the profession. Whilst Shearer discusses the rising popularity of medicine in relation to medical discoveries she also places these events in the context of greater social changes in the United States. In particular, she notes the rise in maternal and infant mortality after the 1850s that corresponded to industrialisation and urbanisation.[13] This context has relevance to the major changes that were about to occur in antenatal care.

Australia's experience at this time was similar but, because of the influx of younger, more innovative doctors, a greater number of significant advances in medical and obstetric care were made in Australia than were in Britain. The second half of the 19th century saw the development of diseases of women as a specialty.[22] Obstetrics and Gynaecology was taught to medical students for the first time in 1865 at the University of Melbourne.[23] Of special note around this period was the forced closure of the Lying-In Hospital in Melbourne for three months in 1876 due to 'the spread of an epidemic of fever and rising maternal

mortality'.[24] Medicine, in the management of pregnancy and childbirth in Australia, was also gaining increasing approval by society.

The early 1900s represented the turning point in antenatal care in industrialised countries. These events and, in particular, the determinants of these events highlight key factors that are relevant to the determinants of antenatal care and screening today. In June 1910, in Australia, Dr. T.G. Wilson opened the first antenatal clinic at the Royal Adelaide Hospital which was followed closely by a clinic at the Royal Hospital for Women in Sydney. The main purpose of these clinics was to check for the presence of a contracted pelvis, urinary tract infection and 'other major abnormalities'.[25] In particular, a contracted pelvis was thought to be a dominant cause of prolonged labour and subsequent fetal and maternal death. Mothers were also advised as to measures to prevent infant enteritis. In 1911 the first clinic in the United States was established at the Boston Lying-In Hospital for Women. Most attention, however, has been focused on Edinburgh in the United Kingdom where Dr. Haig Ferguson opened the first outpatient antenatal clinic in 1915. This was later run by J.W. Ballantyne (1862-1923) who is more well-known for his contributions to antenatal care.[12]

For the first half of the 19th century pregnancy was largely unmediated by medical care. From the middle of the 19th century two developments began: the first in the application of new physiological knowledge and related diagnostics; the second in the field of what might be called social midwifery. The question is, 'What factors lead to this change?' Three major themes emerge around these events and are carried through to the current day practice of antenatal care.

The first theme relates to the rise of largely unquestioning support and trust in the contributions of this medical knowledge and diagnostics. Advances in knowledge of diagnostics in Europe spread to Britain and Scotland. The British government of the day promoted the development of antenatal clinics and systematic antenatal care believing these to be the ways to reduce maternal and infant mortality. Shearer argues that, in the United

States, the decline in maternal and infant mortality rates in the early 1900s were also attributed to medical advancement.[13] In Australia, elements of both the British and American experience were accommodated. In 1928, following increased dissatisfaction with maternity services in Victoria, a report into maternal mortality and morbidity was released by the then Director of Obstetrical Research in Victoria, Marshall Allen. Amongst the nine recommendations was the formation of antenatal clinics at every centre where facilities for confinement and care existed and the erection of modern maternity units.[22]

The second theme relates to the development of social midwifery in the United States and the United Kingdom.[12,13] The role of social and political changes on the health of child bearing women and children were largely ignored. Where there were declines in the rates of maternal and infant mortality in the US in the early 1900s there were also significant social changes. Shearer highlights the role of the reduction in the birth rate, improved urban sanitation and a healthier, more active lifestyle for women of child bearing years as important contributors to the improvements in obstetric outcomes.[13] Similar trends were seen in the United Kingdom. Government reports on the high rate of maternal mortality in the UK at this time recommended improvement in the social conditions for child bearing women.[12] Oakley argues that the impact of social circumstance on the well-being of child bearing women in the early 1900s was largely ignored in favour of the development of antenatal care to solve Britain's poor maternity record. 'Schools for Mothers' were developed to focus on individual hygiene, housework and education of child bearing women rather than strategies to eliminate overcrowding or pollution that were recommended to the government around that time. This, she suggests, was a relatively easy solution to implement in comparison to the bigger issues of social and environmental change.[12] Instead of tackling social issues, there was a shift to an individual approach making individual women do what a social demographer would say was necessary.

In Australia, similarly, Allen recommended the establishment of a division of maternity hygiene in the Federal Department of Health. Part of this recommendation stated that the then maternity allowance be not paid to women unless a medical certificate could be

produced showing that the mother had had antenatal supervision.[22] Even today, evidence from western countries demonstrates that low socio-economic status is associated not only with the health status of the population in general[26], increased perinatal and neonatal mortality rates[27] but increased morbidity secondary to intrauterine growth retardation and preterm delivery.[28]

The third theme evident in this transition time in the provision of antenatal care is the concern by the government of the need for a strong and healthy race. Oakley argues that, in the face of declining birth rates but still high maternal and infant mortality rates, the United Kingdom government became very concerned over the quality of the population. This had particular relevance to the development of healthy volunteers for military service.[29] Whilst the concern was for a stronger 'Empire' the strategies for improvement in the health of child bearing women focused upon the individual. In 1921, in the United States, a bill to establish a federal state program for maternal and infant health was passed. Posters such as 'A Baby Saved is a Citizen Gained' appeared around this time. The bill, whilst addressing the issue of adequate resource availability also focused on improving women's understanding of what constitutes good antenatal care.[29] Children, Enkin argues, came to be perceived as a valuable national resource.[29] There was a significant shift in the focus of care being upon the individual as the foundation for a healthy population. In Australia also 'save the ones we have' became a catch-cry from early in the 20th century.[30] This change in focus forms the basis of antenatal screening programs today.

As the early suffrage movement gained momentum in industrialised countries around this time, the efforts of the suffrage supporters, whilst effective in raising awareness of the unacceptably high maternal mortality rates, were largely complicit with the strategy of antenatal care to address these issues. Enkin argues that the powerful lobby that achieved the vote for women in Britain in 1918 was then utilised in support of antenatal care.[29] Oakley suggests that this issue 'filled the void left after the women's movement had achieved the vote'.[31] Shearer, in her critique of the history of antenatal care in the United States, argues that the feminist movement in America began as a reaction against the early interventions by

doctors around childbirth in the 1820s. However she, too, describes the acceptance by 'the first patients' movement' of medical discoveries at the turn of the century.[13] She notes, 'Having begun among lay people as a reaction against the excesses of "heroic" medicine, the popular remedies became competing systems.'[32] Therefore, whilst objections to the trend toward the delivery and value of antenatal care were raised within different elements of the population the general reaction by the then consumers was of complicity and trust in the wonders of medicine. This reaction is echoed in much of the modern day consumer response to the advances in antenatal care, particularly antenatal screening.

From the 1930s to the present

Although there was a 'period of disillusionment' in the 1930s in the UK, antenatal care within a medical framework expanded.[33] Oakley argues that intra professional rivalries and poor standards of care, in the context of still high maternal mortality rates, led professional and lay groups to question the efficacy of antenatal care. By 1946, despite these concerns, 99.1% of women in Britain received some form of antenatal care.[12] Obstetrics firmly established itself, with very little opposition, as the predominant ethos for the management of pregnancy and childbirth.

Two major themes dominate antenatal care during the period since the 1940s. The first is the continuation of a process that arose in the early 1900s. As maternal mortality and stillbirth rates began to fall in Australia, the United Kingdom and the United States, their decline was again attributed to medical advancement in pregnancy and childbirth. In 1927 in New South Wales the maternal mortality rate was 6.5/1000. By 1952, it had fallen to below 1 per 1000.[34] Introduction of antiseptic agents, early antibiotics, anaesthesia and blood products were all significant advances to ensure greater safety for women around childbirth. However, reduction in maternal and stillbirth rates in the United Kingdom also coincided with major government social policies particularly in relation to dietary supplementation to expectant and nursing mothers. The maternal mortality rate decreased from 3.19/1000 live births and stillbirths in 1936 to 1.26/1000 in 1946. Corresponding decreases in stillbirth

rates were observed from 39/1000 in 1936 to 27/1000 in 1946.[12] A reduction in the size of families was also noted at this time. Shearer noted similar changes in the United States and argues that the concurrent fall in the birth rate was not considered as highly as the contribution of medicine.[13]

A second feature of antenatal care which has developed since 1940 now predominates in the delivery of modern antenatal care. With a gradual fall in maternal mortality rates attention turned to the well being of the fetus. With the concurrent advances in medical technology and research that enabled an inside picture of the pregnancy the potential to detect abnormalities in pregnancy and prevent fetal mortality and morbidity had arrived. The term 'perinatal mortality' was in common usage by the 1960s.[35] Clinical trials with ultrasound began in Australia at the Royal Hospital for Women, Sydney in 1962.[34] Antenatal screening moved beyond the parameters of routine abdominal palpation, pelvic assessment, urinalysis and measurement of blood pressure into the realm of medical technology. Antenatal testing became a growth area. At Queen Charlotte's Maternity Hospital in London the number of antenatal tests and procedures rose from an average of 1.5 per pregnancy in 1948-50 to 9.5 in 1977-78.[12] With the increase in medical technology came an increase in what Enkin describes as sophistication associated with antenatal testing.[36] With this came the demand for greater specialist involvement in antenatal care. Already doctors had begun to dominate the realm of antenatal care and the new technologies further legitimised their involvement. This strengthened the position of pregnancy and childbirth management firmly in the domain of the medical model. Antenatal care directed its attention to detection of the abnormal. As Enkin states, 'obstetrics has moved toward the concept that no pregnancy is normal, except in retrospect.'[36]

What was the role of women during these changes? Were they again largely compliant with these trends? Shearer describes a 'second maternity patients' movement' in the United States from the 1940s to the 1970s which promoted the concept of natural childbirth.[37] This concept, however, was not widely assimilated into the population and the more general acceptance of medical procedures during pregnancy and childbirth again dominated. Also

the late 1960s and early 1970s did see the rise in popularity of what Shearer calls the 'childbirth reform movement'.[37] Consumer groups in many industrialised countries began to speak up at this time and voice their dissatisfaction with current practices in the management of pregnancy and childbirth. In Cope's description of obstetrics and gynaecology over the past 80 years he states,

> 'The reaction of women's groups to increasing medical interference during deliveries in the 1960's led to a resurgence of home births, extremes like underwater birth, and the development of birth centres. Hospitals did not respond as quickly as they might have in making appropriate changes to delivery rooms, as had been done in countries like Holland.'[25]

Much of the impetus to evaluate current obstetric practices and, in particular, antenatal screening, came from these lobby groups. Whilst the movement enjoyed great popularity, media and academic interest in the early 1970s, along with the second wave of feminism, it was not sustained. The majority of women still chose the now established practices of antenatal care and confinement within a hospital setting. Why did this occur? Shearer argues that the reasons for this loss of popularity related to the increased popularity of well publicised obstetric discoveries such as microsurgery, new screening tests and infertility treatment. She goes further to suggest that middle class women, in particular, were less interested in intrusions on their pregnancies but more interested in the need to reduce obstetric risks.[13] But what is not discussed is why this view prevailed and what was the basis of these women's heightened awareness of risk. Chapter 5.2 returns to this question.

Conclusion

The ascendancy of medical dominance of pregnancy care, including the growth of antenatal screening, has coincided with a general rise and acceptance of medical technologies particularly since the 1930s. In addition, historical critique reveals a disregard of the impact of socio-political factors on the improvement in maternal, fetal and early childhood well-being, although, such advances have been attributed to advances in medicine and obstetrics. Women's reaction against medicalisation of pregnancy care has not been sustained within the broader community. These issues are relevant to the establishment, development and

prominence of modern day antenatal screening. They provide the basis for an analysis of the perceptions of obstetric interventions today.

2.2 EPIDEMIOLOGY

Introduction

Increasing epidemiological evaluation of antenatal screening fails to support the routine use of many antenatal screening tests.[38,39] Why, then, do the number and frequency of tests continue to increase? Whilst evaluation of antenatal screening tests using an epidemiological framework suggests caution when considering introducing many of the tests that are currently used routinely, epidemiological evaluation is limited in its ability to provide all the answers. This section describes what epidemiology has to offer the critique of antenatal screening. By addressing the limitations of an epidemiological framework, it also attempts to answer the question of why tests proliferate.

What is the ultimate criterion of an antenatal screening test? Many texts agree that the questions, 'is this test worthwhile?' or 'are the women tested better off as a result of being tested?' form the basis for evaluation of screening tests.[40,41] They argue that evaluation by epidemiological principles provides these answers. But the words 'worthwhile' and 'better off' are subjective and have different meanings in different contexts. They depend on the determination of cut-off points, who is conducting the evaluation, whose interests are being served by the evaluation, and many other factors. The objective tools of epidemiological evaluation are useful but have their weaknesses and are only one benchmark of a test being 'worthwhile'.

The past decade has seen a surge of epidemiological critique of antenatal screening. Proposed introduction of the triple test for Down syndrome and vaginal cultures for group B streptococcal (GBS) colonisation has provided much of the impetus for this recent rise in debate. Such critique includes not only consideration of factors such as validity, the impact of false positive and negative results, the relative prevalences of conditions amongst varied populations but issues of cost effectiveness and worth.[42] These tests have been subjected to greater epidemiological evaluation prior to introduction than many of their predecessors.

This growth in evaluation has also paralleled the increased interest in evaluation of pregnancy and childbirth care by the randomised controlled trial and the use of meta-analysis.[28,42] Whilst the principles for evaluation of screening tests have been known for some time, their application to the critique of modern day antenatal screens has been relatively recent. Application of many of these principles provides a sound foundation from which to begin to evaluate antenatal screening. Unfortunately, many antenatal screening tests have been introduced into routine practice without prior appropriate evaluation.[43]

What is a screening test?

Last, the editor of the *Dictionary of Epidemiology*,[44] uses the definition of screening given by the 1951 US Commission on Chronic Illness: screening is 'The presumptive identification of unrecognised disease or defect by the application of tests, examinations and other procedures which can be applied rapidly..'[45] In addition, Cuckle and Wald, epidemiologists and clinicians, note that screening is 'the identification, among apparently healthy individuals, of those who are sufficiently at risk of a specific disorder to justify a subsequent diagnostic test or procedure, or in certain circumstances, direct protective action'.[46] Screening may include the taking of a history, examining a patient for example fundal height or performing a test. For the purpose of this dissertation the discussion of screening is confined to conducting of specific tests such as blood or urine sampling.

At this point it is important to clarify the difference between a screening and a diagnostic test. Mohide and Grant say that screening and diagnostic tests are on a single spectrum and many of the routine antenatal screening tests performed today are both screening and diagnostic.[43] It is the purpose of the test, however, that discriminates between a screening and a diagnostic test. The inherent purpose of a screening test is the detection of a subgroup of individuals with a high risk of pathology.[40] Following the detection of this subgroup there is then no intention to offer therapeutic interventions based solely on the positive result of the test.[39] In contrast, diagnostic tests play the more critical role in determining who does and does not receive treatment.[40] Mohide and Grant[43] and Last[44] also make the point that

Table 2.1. Prerequisites of a screening program

1. The condition sought should be an important health problem.	2. The natural history of the condition, including development from latent to overt stages, should be adequately understood.
3. The condition should have an identifiable latent period or early symptomatic phase during which intervention is possible.	4. A suitable screening test should be available.
5. The test should be acceptable to those tested.	6. There should be a satisfactory diagnostic test with an agreed policy of case definition.
7. There should be an effective management for patients with the recognised condition.	8. The search for the condition should be a continuing process.
9. The resources needed for diagnosis and treatment should be available.	10. The costs incurred as a result of finding cases (which includes both identification and treatment) should be economically balanced in relation to possible expenditure on an alternative programme or on medical care as a whole.

Mohide P,Grant A. Evaluating diagnosis and screening during pregnancy and childbirth.

screening procedures 'imply a search by professionals for problems in apparently healthy individuals.'[47] This concept is significant when examining the notion of risk as it applies to potential problems of pregnancy and childbirth. This will be discussed further in chapter 5.2.

Whilst the literature acknowledges a blurring of the distinction between screening and diagnostic tests, in practice there is little discussion as to the consequences of this confusion.[40] What is the impact of the lack of distinction between these tests on society's expectations of these tests? What value will be placed on the results of these tests? How reliable will the test results be perceived to be? These and other issues related to the perception of antenatal screening tests are examined in chapter 5.

Prerequisites of antenatal screening tests

Many authors have attempted to describe a set of guidelines, related to the problem being screened and the test itself, that should be considered before implementation of a screening procedure.[43,48,49] The most commonly used criteria are the 10 set out by Wilson and Jungner in 1968.[47] See table 2.1.

Whilst it is beyond the scope of this dissertation to assess each individual antenatal screening test used in modern antenatal care against these criteria, the application of prerequisite 2, the known natural history of the condition, alone raises questions as to the suitability of screening for conditions such as HIV, colonisation of the vagina with GBS, gestational diabetes and, to a lesser degree, cervical cancer. Intervention is, as discussed in prerequisite 3, in many instances an abortion of an affected fetus. Sometimes there are no interventions offered at this stage for conditions such as HIV diagnosed in the mother. Application of prerequisite 4, the availability of a suitable screening test, to the screening of conditions such as gestational diabetes and colonisation of the genital tract of GBS in labour show current testing methods to be lacking. Whilst these prerequisites act as guidelines for the evaluation of antenatal and other screening tests their application to the modern day

practice of antenatal screening has been minimal. A more judicious use of these principles could lead to greater caution with the introduction of screening programs.

Criteria for evaluation of a screening test

Before discussing the major principles of sensitivity, specificity, positive and negative predictive values that are the traditional measures of validity of a screening test, the notion of a 'gold standard' must be examined. A gold standard of any screening test is the objective diagnostic truth or best measure of truth. There is a paucity of these standards in antenatal screening which leads to uncertainty in assessing the validity of these tests.[43] This then leads to limitations in the interpretation of validity in practice. A useful example is a screening test for gestational diabetes. Not only is there lack of definition of what is glucose impairment in pregnancy but there is no clear cut measure of what is and what isn't an abnormal state. What can the results of the screening test be compared against when there is no clarity of the abnormal?

Whilst there can be uncertainty in relation to the cut-off point that discriminates between the normal and abnormal condition being considered, there can also be differences in cut-off points of the test attempting to detect the abnormal state. This alteration of cut-off point has impact on the validity and effectiveness of a given test. The original studies that evaluated the new triple test for Down syndrome used a risk of 1 in 250 to discern the 'screen positive' from the 'screen negative' patients.[50,51] Setting the cut-off point at this level will produce different measures of validity and effectiveness than if a cut-off point of 1 in 420 is used, as is more typical of screening programs in Australia.[52] These cut-off points are chosen as they correspond to a maternal age at which this risk occurs. Therefore, Australians have tended to use a risk corresponding to a maternal age of 35 years whilst the British have used a maternal age of 37 years. Attention is therefore necessary to both the gold standard and the test cut-off points before measures of validity can be interpreted.

Measures of validity of a screening test are best demonstrated by use of a 2 by 2 table. See table 2.2.

Table 2.2. Screening test validity measures

Test: Disease	Has disease	No disease
Test positive	**a** (True positive)	**b** (False positive)
Test negative	**c** (False negative)	**d** (True negative)

Sensitivity of a test is the proportion of affected individuals that are positively identified. Using the 2 by 2 table:

$$\text{sensitivity} = \frac{a}{a + c}$$

Specificity of a test is the proportion of unaffected individuals correctly identified as negative. Using a 2 by 2 table:

$$\text{specificity} = \frac{d}{b + d}$$

Whilst these two measures are useful in evaluating a given screening test a better measure of performance of a test in a clinical setting is the positive predictive value (PPV) of the test. The PPV of a test is the likelihood that a positive result is truly positive. Both the care giver and the woman are concerned with the meaning of a positive test result for that individual, i.e., what are the chances that a positive test result truly means I have the condition? This is represented in the 2 by 2 table by $\frac{a}{a + b}$.

The PPV of a test is dependent upon the prevalence of the condition being screened. As the prevalence of the condition increases the number of false positives (b) will decrease and therefore the PPV will improve. Reliance of the PPV on prevalence is seen by this equation.

$$PPV = \frac{\text{sensitivity x prevalence}}{(\text{sensitivity x prevalence}) + [(1\text{-specificity})x(1\text{-prevalence})]}$$

In practice, this is a key consideration when introducing a screening program to a population with a low prevalence of disease. In a condition such as neural tube defect with a prevalence of approximately 1 in 450[52] the implications of the false positive rate to the women screened are substantial. Not only will the false positive rate produce potential unnecessary anxiety in those women but may also lead to increase intervention in the form of additional ultrasound examination of the fetus or amniocentesis. Mohide and Grant discuss here the importance of examining the balance between potentially doing more net harm than good.[43] Uptake of a screening program into routine antenatal care may be influenced by a test's good performance as evaluated by its sensitivity and PPV when applied to a particular population. Caution, however, must be given to application of a test in a new population where the prevalence of the condition may be lower and the performance of the test will be worse.

The final measure of validity is the negative predictive value (NPV). The NPV is the likelihood that a negative test result is truly negative and is represented on the 2 by 2 table by $NPV = \frac{d}{c + d.}$

Screening tests with a high sensitivity and negative predictive value are most useful in practice. A low PPV is only acceptable if there is ready availability of a confirmatory test with low cost. Whilst Wald and Cuckle show detection rates of Down syndrome of 48-58%, using the triple test [50,51] calculation of PPV shows it to be only 2.3%.[53] Even using a cut off risk of 1 in 250 in these studies results showed a false positive rate of 5.7% before repeat ultrasound assessment.[51] It is difficult to assess the potential cost involved with the women who receive a false positive result. The measurement of cost is difficult when considering the emotional cost of either a false positive or false negative result.

Epidemiological evaluation can include assessment of the potential benefits and hazards of a screening test but direct comparison of the two is complex. Whilst the principles outlined

above provide some objective measures with which to evaluate screening tests, they must be considered in the broader context of the potential benefits and harms that may be created by the use of these tests in clinical practice. Few authors discuss the potential benefits and harms in any depth in their studies of antenatal screening. This is the point where greater subjectivity enters the equation. What is meant by benefit? Is it, as some would assert, the contribution of screening tests to the lowering of the 'total burden of childhood handicap?'[54] If this is the criterion, then antenatal and neonatal screening tests, apart from those which screen for Down syndrome, open spina bifida and congenital dislocation of the hip, are ineffective.[55] Or is the benefit a parent's emotional preparation for the birth of their child with Down syndrome detected after antenatal screening?

What is meant by harm? Is it the eventual cost of caring for a child with congenital syphilis whose mother screened negative for syphilis antenatally? Or is it the mother's anxiety, unnecessarily created by repeated ultrasounds, performed in an attempt to confirm the suspicion of choroid plexus cysts in her fetus, where such suspicion is subsequently proven to be false. What these questions highlight is the difficulty in measuring and, therefore, comparing the important components of benefit and harm.

Epidemiological evaluation of screening tests is limited in other ways. Whilst epidemiologists may differ in their assessment of the validity of a screening test based on a particular cut off result, condition prevalence or severity of condition, economists also differ in their cost effectiveness evaluation. Sheldon and Simpson's cost evaluation of the triple test for Down syndrome showed the test to be cost effective.[56] However, Sheldon and Simpson calculated their costs on the premise that a fetus detected with Down syndrome would be aborted and therefore not depend on society for future care. They also failed to cost the emotional anxiety of women receiving a false positive result. Nor did they factor in the cost to people in the community with Down syndrome or their carers and relatives who may view the debate about screening for Down syndrome as an attempt 'to stop people like you being born.'[57] Are these factors able to be costed?

Because of the difficulties in examining what is a fundamental ethical question of why genetic or structural abnormalities in unborn fetuses are screened for at all, many of the inherent assumptions about the value of screening are not explored. It has only been a relatively recent phenomenon that the input of consumer satisfaction to antenatal screening has been explored in the literature.[27,43] Unfortunately this has the effect of potentially blurring the evaluation even further. Whilst many authors would fail to support routine use of ultrasound in pregnancy[38,40] consumer satisfaction for routine visualisation of their fetus during pregnancy would hinder its removal from routine antenatal care.[58,59] What this literature does demonstrate, however, is the importance of not ignoring the potential harm to women who undergo routine antenatal screening tests. As Enkin notes, 'Effectiveness and satisfaction are intimately related'.[60]

Conclusion

What an epidemiological critique of antenatal screening tests contributes is the importance of asking the question, 'is this test worthwhile?' Whilst this is the right question there appear to be, even with evaluation by measures of validity, benefit and harm, no easy answers. On the surface it would appear that application of epidemiological principles for the evaluation of screening tests would emphasise caution in the incorporation of screening tests into the practice of routine antenatal care. Still, much of this caution has gone unheeded with the introduction of new antenatal screening tests. Whilst many authors fail to support the universal screening of HIV during pregnancy[61,62] and recommend screening only in populations with a prevalence greater than one in 1000, universal screening has been introduced into antenatal clinics in many public teaching hospitals in South Australia without evaluation or prior knowledge of the population prevalence.

Overall, examination of epidemiological evaluation of screening tests raises more questions and uncertainties than it answers. Such complexity and uncertainties of this evaluation may contribute to the expansion of inadequately evaluated antenatal screening tests into routine

practice. Attention to this trend is vital and the difficulties in removal of screening tests from routine antenatal care must be not be ignored.[58]

2.3 OPPOSITION TO SCREENING

Introduction

The advent of population screening for diseases or conditions that would otherwise go undetected until presentation has been largely supported by the public health movement as a positive move toward preventive medicine. However, many providers and recipients of health care have been critical of some of these advances. Advances in antenatal screening tests have now enabled the search for conditions in both the mother and the fetus. Examination of the impact of screening strategies, outside the domain of pregnancy, has been a relatively recent phenomenon. Much of the research in this area has used psychological assessment methods to examine both the uptake and impact of screening.[63,64] Similar methods have been applied by researchers in social science to examine the impact of antenatal screening tests on pregnant women.[2,3,10] By examining women's experience of antenatal screening these researchers have raised the question of the potential for such screening to have a negative impact on the psychological well being of women. This section examines three main areas of opposition to antenatal screening. They include: evidence from examination of screening strategies outside pregnancy; research findings from the social science examination of the experience of pregnant women; and an analysis of the notion of pregnancy as a physiologically normal event versus an illness. This section places the utilisation of screening tests in a particular context of potential harm that arises from screening.

Screening outside pregnancy

The impact of the screening process on an individual expectant mother sits in a wider context. This context includes not only a consideration of the process of the screening activity but a regard for which individuals present for screening generally and why they present. Are individuals who are inherently more anxious about abnormality or disease more

likely to present voluntarily for screening activities? Unfortunately few studies have sought to address this question.

Stoate examined, by means of a longitudinal controlled study, the psychological well-being of people who screened negative for coronary heart disease risk in general practice.[64] He followed 215 healthy adults who, by invitation, volunteered for a free health check and 225 age-matched controls. Participants completed both a pre-test and three month post-test psychological assessment by questionnaire. Two important findings were demonstrated. Firstly, the study group demonstrated significantly less psychological distress than the controls pre-testing. This finding contrasts the premise that more anxious individuals present for screening but supports the concept of 'the healthy volunteer' effect seen in similar epidemiological studies. The second major finding of this study relates to the impact of screening on individuals. The study demonstrated a significant increase in psychological distress in those previously healthy volunteers who had screened negative for coronary heart disease risk factors. This anxiety state, produced by the process of offering screening, is what Shickle and Chadwick call the creation of the 'worried well'.[65] They argue that the offering of screening implies to the individual that they may not be healthy after all. Thus, there is the potential to cause harm to individuals by the act of offering screening itself, even before considering the impact of a false positive or false negative test result. Offering screening to an otherwise healthy individual is not a neutral process.

The experience of antenatal screening

a) By pregnant women

In the past decade there has been an increase in the critique of the potential harm to pregnant women caused by antenatal screening procedures.[9,42,66] Whilst some unintended outcomes of antenatal screening, for example gastro-intestinal side effects of oral iron preparations for women who are found to be anaemic on routine haemoglobin measurement, can be easily measured, outcomes such as raised anxiety levels in pregnant women screened for maternal

and fetal conditions are more difficult to measure. Until recently, examination of the psychological impact of screening on pregnant women has been lacking. In particular, these recent studies have explored women's satisfaction or dissatisfaction with their pregnancy care. A new piece of the jig-saw has been added to the evaluation of pregnancy care which asks the fundamental question 'what is the impact of antenatal testing on pregnant women?' Like others who have explored the impact of screening,[63,64] Reid suggests that the very processes of routine antenatal screening that look for abnormality 'change the experience of pregnancy for the women and her family'.[67]

Examination of the literature in the area of women's experience of pregnancy and childbirth shows that the majority of the researchers are women[2,9,12,66,68,69,70] with a background in the social sciences.[9,42,66] The methodology they use to examine women's views and experiences has been both quantitative and qualitative, making use of questionnaires, interviews and, in some cases, psychological assessment methods. The majority of these studies have examined the impact of prenatal diagnostic tests such as amniocentesis or chorion villous sampling[6,7,71] or the major antenatal screens of ultrasound or alpha feto-protein (afp).[2,3,72] To date, examination of the impact of simpler routine antenatal screening tests has been lacking. Whilst some of these studies raise concerns about antenatal screening, for example its availability and accessibility for all women and inconsistencies in the amount of information about the tests given to women, a dominant focus of these studies is the anxiety[68,73] and the social costs[9] for women undergoing antenatal screening.

The impact on women of antenatal screening for fetal neural tube defects has recently been examined by a number of authors.[2,3,72,74,75] In these studies the impact of the screening program for neural tube defects has included examination of both the screening test (measurement of afp in maternal serum) and the diagnostic test (measurement of afp and acetylcholinesterase in amniotic fluid). In separate studies, using anxiety measuring scales from interviews, Robinson[72] and Farrant[3] showed increased levels of anxiety in those women who had been told they had a raised afp result. Farrant noted, further, that the increased anxiety felt by these women was compounded by a 'worrying about the effect of worrying'

on the fetus. Informing women of a negative result also influences the impact of afp screening on women.[3] Whilst Robinson found a reduction in anxiety levels to normal when these women were told of the eventual negative result following further testing, this did not occur in those women who were told they would only be notified if the subsequent test result was abnormal.[72]

However, these results have not been supported by two larger prospective studies from the United Kingdom. Marteau, using survey research and anxiety scales, studied 161 and then 372 women who were eligible for antenatal screening for neural tube defect.[2,74] In her earlier study she compared anxiety levels in women who chose to have maternal serum screening for neural tube defect with those that declined.[2] She found that women in the second trimester who had positive afp results did not show increased anxiety, but that those women who chose not to have screening for neural tube defect had higher levels of anxiety in the third trimester. In her subsequent study she compared anxiety levels in those women who had a negative afp (not elevated) result with those women who had a positive afp (elevated) result from maternal serum screening.[74] Whilst women who had a positive result demonstrated greater anxiety levels initially, and up to three weeks post partum, this was not evident at six weeks post partum. These findings are similar to those of a prospective study in the United States which also found that the initial elevation in anxiety demonstrated in those women with a false positive result was short lived and anxiety levels had reverted to normal on receipt of a subsequent negative result.[75] Whilst both the British studies are prospective, they suffer from large differences in the size of the study groups, 128 versus 33 and 346 versus 26, respectively, and poor response rates, particularly in the later study (only 37%). Such a response rate is not surprising considering the requirement of participants to complete 7 questionnaires. It is important to examine the response rate of these studies to consider the potential for selection bias. As Marteau has noted in her subsequent study,[74] the responders overall were of higher socio-economic status, older and more likely to have lower pre-existing anxiety levels. This suggests a 'healthy volunteer effect' being demonstrated amongst pregnant women in respect to the psychological impact of afp

screening. That is, the potential negative impact of screening may be less in a psychologically healthier pregnant woman.

The other antenatal screening test that has come under examination for its potential impact on pregnant women is maternal serum screening for Down syndrome, also called the 'triple test'. A small study by Statham and Green of 20 women who screened positive for Down syndrome (a risk of 1:250 or greater) showed these women demonstrated increased anxiety levels that remained elevated even after receiving a subsequent negative result following amniocentesis.[73] A similar study by Ferguson in South Australia also demonstrated high anxiety levels in women who screened positive for Down syndrome (a risk of 1:400 or greater).[76] Because of the small size of these studies and lack of a control group more research into the potential psychological impact of the triple test is required.

In the past decade there has also been an increase in the number of studies examining the impact of prenatal diagnosis, amniocentesis and chorion villous sampling, on the psychological well being of pregnant women.[6,7,71] Two small studies[6,71] looking, in particular, at the anxiety levels in women undergoing amniocentesis and chorion villous sampling have showed increased anxiety levels just prior to the procedure. Again these studies suffer from their small sample size and lack of a control group.

Many of these studies are small, lack a control group and suffer from selection bias. They limit their inquiry of women's experience of antenatal screening to psychological models of assessment of well being. Whilst they demonstrate some methodological deficiencies, they suggest the potential of antenatal screening tests to cause psychological harm to those women being tested. They raise important issues in the study of antenatal screening; that is, the impact of testing on those being tested.

b) By birthing services review

In Australia there has recently been a number of state and national reviews into birthing services.[77,78] Consumer satisfaction with all levels of pregnancy care has been examined in these reviews. Methods such as questionnaires, public meetings and discussion groups have been used to collect this data. One area of inquiry has been satisfaction with antenatal care. Whilst antenatal screening was not examined separately, Lumley[77] found that nine per cent of 1059 Victorian women surveyed expressed dissatisfaction with their antenatal care. Whilst direct questioning about women's satisfaction with antenatal care highlights some of the potential issues around antenatal screening there may also be indirect impacts on women's perception of their pregnancy care via what Lumley calls 'the intervention cascade.'[79] She notes the potential contribution, of false positive antenatal screening test results, to subsequent intervention during pregnancy and birth. Such interventions may have an impact on the psychological well being of pregnant women.[77]

Pregnancy as an illness

The third area where opposition to antenatal screening can be found is in the debate over whether pregnancy and childbirth are normal or not. Whilst some would depict the conflict as being largely a polarisation of views between the professionals providing antenatal care and the recipients of the care,[69] there is more likely to be a large diversity of views within these two groups. However, the two extremes of opinion have been well documented by authors from both groups.[80,81] Hern, a director of an abortion clinic, in his 1975 paper 'The illness parameters of pregnancy' argues, using an illness model, that pregnancy is an illness.[80] Hern defines human pregnancy as

> '...an episodic, moderately extended chronic condition with a definable mortality risk to which females are uniquely though not uniformly susceptible. It is a universally distributed biosocial adaptation resulting in species reproduction and has a changing significance for species survival.'[82]

The opposite view is well articulated by Sheila Kitzinger who views pregnancy and childbirth as a normal life process and is dismayed by the take over by medicine.[81] Whilst

the meaning of 'normal' may be controversial, protagonists of this side of debate would agree that pregnancy is not an illness.

If pregnancy is not an illness, routine antenatal screening tests that attempt to detect abnormal conditions in the mother and the fetus are in potential conflict with this view. The provision of routine antenatal screening tests may change the concept of pregnancy to a 'potential illness' and thus impact on the psychological well being of the pregnant woman. This concept is supported by Shickle and Chadwick[63] as described above. The potential for harm from antenatal screening would arise if the recipient of the screening tests believed that, prior to the testing, they, their pregnancy and their fetus were healthy. Whilst authors such as Kitzinger[81] express such beliefs, large series documenting pregnant women's beliefs about the normality of their pregnancy are lacking.

Conclusion

The discussion above points to the potential negative impact of antenatal screening on women receiving screening tests. Yet women largely endure these negative experiences and continue to utilise screening programs in pregnancy. Analysis of why pregnant women largely support these potentially harmful screening programs is deficient. As McIwaine writes, 'It amazes me that women come for antenatal care at all. They sit in these clinics for 2 hours to be seen for 2 minutes, with somebody laying on their hands, and they leave. We should be looking at why they come at all.'[83] The answer may lie partly in the further examination of the notion of the 'worried well' amongst pregnant women.

2.4 THE HAZARDS OF PREGNANCY

Introduction

Any examination of pregnancy care and birthing practices in Australia in the 1990s must include exploration of the adverse outcomes or hazards that can occur with pregnancy. In contemporary obstetric literature these outcome measures are somewhat narrow and limited. They include the measures of perinatal mortality, maternal mortality and congenital abnormalities of the fetus or newborn. Data reflecting long term physical and intellectual morbidities is increasingly available, particularly in relation to the infant, but 'softer' outcomes such as psychological well-being of the mother and infant are inadequate. Some of these have been discussed in the preceding section. It is, however, important to discuss these commonly used outcome measures as they often form the basis for measurement of the effectiveness of antenatal care. They are also the common signposts used by the providers of pregnancy care to indicate the safety of the environment in which women now give birth in Australia.

Measuring outcomes

Australia is a world leader in relation to data collection about pregnancy outcomes. The National Health and Medical Research Council (NH&MRC)[84] and the Australian Institute of Health (AIH)[85] are responsible for collection and compiling of national statistics on pregnancy outcomes. Each of the states is also responsible for collecting a large range of pregnancy statistics including perinatal mortality, maternal mortality, birth defects and termination of pregnancy.[86-90] Various public teaching hospitals also collect a range of local data related to birthing outcomes.[91]

Caution is needed when examining and comparing any statistics involving birthing outcomes. Differences both in definitions used and in the quality of data collection are found. Pregnancy statistics can be expressed for use for international comparisons using

World Health Organisation (WHO) definitions; for national comparisons using WHO definitions and/or Australian NH&MRC definitions;[84] and for state comparisons using state perinatal unit definitions.[86] For the purpose of this research, the following definitions commonly used in Australia are presented. They include a combination of WHO and NH&MRC definitions.

i) Perinatal mortality

The perinatal mortality rate (PNM) is defined as:

$$\frac{\text{number of stillbirths + neonatal deaths in a year}}{\text{number of stillbirths + live births in the year}} \times 1000$$ [86]

where a stillbirth is

a stillborn infant weighing at least 500 gram, or if the weight is not known, born after at least 22 weeks gestation

a neonatal death is

a death occurring within 28 days of birth of an infant whose birth-weight is 500 gram or at least 22 weeks gestation if the birth-weight is not known. [92]

These are WHO definitions used for national comparisons.

ii) Maternal mortality

The maternal mortality rate(MMR) is defined as:

$$\frac{\text{number of maternal deaths in a year}}{\text{number of deliveries resulting in live and stillbirths in the year}} \times 100000$$ [84]

where a maternal death is

a death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, both direct and indirect and

incidental and accidental(where pregnancy is unlikely to have contributed significantly to the death) [84]

This is an NH&MRC definition which has expanded on the WHO definition.

iii) Congenital abnormality

Accurate data related to the rates of congenital abnormalities is lacking. Only where concurrent statistics are kept on all birth defects, including those as a result of a termination of pregnancy as in South Australia, can a more complete analysis of congenital abnormality prevalence be seen.[93] In South Australia the definition of congenital abnormality rate is as follows:

$$\frac{\text{all births of 400 gram birthweight or 20weeks gestation and terminations of pregnancies with birth defects}}{\text{total number of live births and stillbirths of at least 400 gram or 20 weeks gestation}} \times 100$$

where a birth defect is

any abnormality, structural or functional, identified up to 5 years of age, provided that the condition had its origin before birth. This includes structural, chromosomal and biochemical defects. [89]

The 'hazards'

Before examining the rates of adverse pregnancy outcomes it is important to place these in the context of the numbers of births in Australia. In 1994, in Australia, there were 258,051 births, the majority resulting in well mothers and well babies.[85] The crude birth rate in Australia has fallen from 21.7/1000 people in 1971 to 14.3/1000 people in 1994.[85] Similar trends are noted in Victoria with a fall in crude birth rate of 21.0/1000 births in 1971 to 14.5/1000 births in 1994.[94] The birth rate has increased since 1988 for teenagers aged 15-19 years and for older women 30 years or greater. There has been a corresponding decrease in the birth rate for women in their 20s.[85] Less than 1% of births in Australia occur at home.[77] That is, the majority of Australian women deliver in a hospital or birthing unit.

1. Perinatal

i) Mortality

In Australia the PNM has fallen over the past 20 years.[85,86,95] In 1972 the PNM was 22.3/1000 births[95] and in 1994 it was 8.0/1000 births.[96] Beischer noted that the total number of perinatal deaths decreased by 20.3% over a 10 year period from 1981-92 whilst the total number of births increased by 12.6% .[95] Similar trends are present in Victoria where the PNM in 1984 of 12.6/1000 births fell to 7.9/1000 births in 1994.[94]

ii) Congenital abnormalities

As noted above, South Australia's mandatory reporting of data related to births, birth defects and terminations of pregnancy enables the most complete form of data evaluation on congenital abnormalities. In addition, they collect data on birth defects up to the child's age of five years and thus updates information on each birth cohort annually. In 1992 the prevalence of congenital abnormality was 4.4%. This figure was published in late 1993.[89] Allowing for further potential reporting of defects up to the age of five years, this may still be a slight under-representation. Completed data for the 1987 year birth cohort, as published also in 1993, shows a birth defect prevalence of 5.5% [89] which may represent a more accurate prevalence of abnormality in this population. Whilst Victoria also has a congenital malformations register, collection of data on malformations arising from termination of pregnancy less than 20 weeks gestation may be incomplete. Birth defect rates in Victoria for 1994 and reported in 1996 was 3.76%.[94] Australian data on congenital malformations is also incomplete due to variations in data collection between states and registration of birth defects only at time of birth.[97]

Assessment of trends in the rates of congenital abnormalities is difficult because of the limitations in the data from both incomplete data collection and differences in definitions. Chan, using data from South Australia, argues that the prevalence of neural tube defect(NTD) has been relatively constant at 1:500 pregnancies despite an 84% fall in birth prevalence from 1966 to 1991.[93] Birth prevalence is the prevalence of the condition reported

at the time of birth (>400 grams or 20 weeks gestation), therefore less babies are born with NTD and more are terminated at earlier gestations. These findings are consistent with those of the Victorian 12 year review of congenital malformations from 1983-1994 that found no decline in the total number of anencephalic or spina bifida fetuses. It is easier to demonstrate a consistent trend in developed countries of reduction in the birth prevalence of congenital abnormalities [86,89,95,98] and its subsequent contribution to the reduction in perinatal deaths secondary to major anomalies.[95] This reduction in perinatal deaths can be attributed to antenatal ultrasound screening, genetic counselling and termination of pregnancy and improvements in paediatric surgery.[95] In South Australia, in 1993, 24% of perinatal deaths were secondary to congenital abnormalities.[86] Data related to other perinatal morbidities are fragmented and often incomplete, lacking long term follow up.

iii) Associations with antenatal care

In Victoria in 1994, inadequate antenatal monitoring was described as the most frequent factor identified in stillbirth infants. Further, insufficient antenatal care and family neglect or ignorance was implicated in 14 of the 329 stillbirths that year.[94] Clearly antenatal care, which includes ultrasound and termination of pregnancy services, does reduce the birth prevalence of some congenital abnormalities.[86,93,95] This data suggests women confining in Australia in the 1990s have a high chance of delivering a healthy, normal baby. As demonstrated above, antenatal care may have some role in this outcome.

2. Maternal

i) Mortality

Whilst there remain marked differences in MMRs between developed and developing countries, [99] there has been a marked reduction in MMR in developed countries since the 1940s.[99-101] In Australia in 1948, the MMR was 200/100000 births.[100] Because of the relative infrequency of this event today, MMRs are reported over a triennium. The MMR for Australia from 1988-1990 was 12.7/100000 births.[85,95] These reductions in MMR have been attributed to safer abortions, reduction in hypertensive disease and pulmonary embolism,[100] improved education of women, blood transfusions and ergometrine.[101] Beischer argues that

pulmonary embolism, pre-eclampsia and cardiovascular disease are still problematic factors in the cause of maternal death.[99] More recently, obstetricians have been debating the ability to further reduce the MMR. Some concerns have been raised as to the potential for it to increase in the light of increasing caesarean section rates in Australia.[102]

Whilst the MMR in Australia for the 1985-1988 triennium was 11.8/100000 births, it rose to 12.7/100000 births in 1988-1990. It is too early to suggest this 'blip' in the MMR for 1988-90 will be an ongoing trend but risk factors associated with increasing maternal age during pregnancy and increasing caesarean section rates may be putting pregnant women at higher risk. However, despite this concern the data suggests that death of a woman in pregnancy is now a rare event. Data about maternal morbidity is not collected formally at a state or national level and as such is fragmented and difficult to interpret.

Associations between antenatal care and maternal mortality are difficult because of the small numbers. Whilst each death is formally reviewed to identify contributing factors, generalisations are difficult. Maternal deaths are particularly examined for potential avoidable factors. Antenatal, intra partum and post partum factors are sometimes implicated. With the difficulty in finding statistically significant differences in outcomes related to changes in practice, it is important to look to social and qualitative research methods to examine social factors that may be important in this area of maternal and perinatal mortality and morbidity.

Conclusion

Whilst not equally distributed amongst all populations in Australia,[78] particularly aboriginal Australians, the chance of adverse outcomes or 'hazards' of pregnancy and childbirth is low. Poorest outcomes from pregnancy and childbirth are found in 'some migrant groups, Aborigines, women of low socio-economic status and those who are unable to use obstetric services.'[103] The chance of these outcomes in Australia generally is decreasing but is unlikely to reach zero. As the effectiveness of antenatal care is often measured by these outcomes,

the overall decrease in these outcomes are often attributed to advances in antenatal care. Modern antenatal care is only one factor. Other potential factors such as social, environmental and economic are often ignored.

Women should feel assured and safe during pregnancy. However, the information on these outcomes forms only part of the context in which women experience pregnancy and childbirth. Using the public health definition of 'risk = hazard + outrage'[104] it is clear that exploration of the 'outrage' component of the equation is also required.

2.5 TRENDS IN ANTENATAL SCREENING

It might be thought ironic that despite the low chance of adverse outcomes in pregnancy and childbirth for mothers and babies, as demonstrated above, the number and frequency of routine antenatal screening tests has increased in developed countries over the past decade.[10,105-108] This trend was also evident earlier when Oakley reported that there had been a six-fold increase in the number of antenatal tests or procedures offered during pregnancy at Queen Charlotte's Hospital in London from 1948-1978.[12]

Systematic evaluation of antenatal screening has been performed over this decade by the Oxford Perinatal Data unit and more recently, the Cochrane Collaboration.[28] Enkins and Chalmers are two of the major protagonists of this revolution in research based practice in pregnancy and childbirth. In their review of antenatal screening, they state that 'there has been a growing tendency to apply to all women measures which are of unquestionable benefit to only a minority.'[19] Reviews of ultrasound and prenatal screening for congenital abnormalities also indicate the growth of these tests and their increased use in modern obstetric care.[106,107] Huisjes and others, following a major evaluation of prenatal screening in the European Community in 1984, state that 'the number of prenatal screening tests continued to increase throughout European countries'.[109] They state further that 'even with low-risk women the number of screening procedures applied more regularly meant that the basic routine has become more complicated'.[109] Palomaki, following a recent review of the use of the latest maternal serum antenatal screening test for Down syndrome in the United States of America States, found that screening has nearly doubled between 1988 and 1992 and that now 50% of pregnancies are screened for Down syndrome with this test.[108]

Currently in Australia, utilisation of routine antenatal screening tests is high.[77,110,111] Beischer and Mackay, authors of the major undergraduate text in obstetrics in Australia, list seven essential antenatal tests whilst recommending a further five. They justify antenatal testing by its role in reducing perinatal deaths.[111] Rushworth's study of utilisation rates of antenatal tests in New South Wales in 1990 found that 94% of pregnancies had an ultrasound at some

stage during the pregnancy. Lumley, in her review of birthing services in Victoria in 1990, noted that 92.4% of women had had at least one ultrasound and 33.9% had had two or more ultrasounds during pregnancy.[77] Further, once many of these tests are introduced into obstetric care and become routine, they are then very hard to remove from practice.[5]

The current picture of antenatal screening in Australia is of high utilisation of screening tests and a trend toward increasing routine use. What is driving these trends?

2.6 ANTENATAL SCREENING POLICIES IN AUSTRALIA

Introduction

A major component of the context in which women use routine antenatal screening tests is the availability of the tests. Whilst the determinants of availability are multi-factorial, examination of policy guidelines in relation to antenatal screening reveal the foundations for availability, practice and eventual use. Claims data from the national medical services rebate scheme, Medicare, is complex to access and not always accurate in respect of frequency of testing: therefore it has some limitations as an indicator of diagnostic testing during pregnancy.[110] Data from Medicare is also limited to information from pregnant women who obtain antenatal care and screening outside a public outpatient setting. Utilisation data from women accessing public hospital services are not collected formally at a national or state level. In view of this, I have attempted to obtain local utilisation rates of individual tests from the study hospital only.

Whilst policies for the use of routine antenatal screening tests differ in the western world,[48,112] antenatal care providers in Australia are guided by policies from three major sources. This section therefore examines screening policies relevant to antenatal care in Australia and this study. It examines policy development at three levels. At the national level, it discusses the policies of the National Health and Medical Research Council (NH&MRC) and the Royal Australian College of Obstetricians and Gynaecologists (RACOG) and at the service provider level, the policies and practice of the Royal Women's Hospital (RWH), a major public teaching hospital in Melbourne. It also examines discrepancies that arise in the translation of policy to practice. The three policies are all different. They differ in language and intent and will therefore be examined separately in detail.

National Health and Medical Research Council (NH&MRC)

The NH&MRC is Australia's peak advisory body for matters to do with scientific aspects of health and of medical work. Its policy statements generally are authoritative statements of established professional opinion. In 1988 the NH&MRC published a policy statement on antenatal care in Australia which acknowledges the importance of antenatal care and states three aims of this care.[98] Within these aims there is an obvious contrast in apparent ideological perspectives. Whilst support is given to the World Health Organisation (WHO) definition of health, where 'birth is a natural and normal process' but 'can give rise to complications', the document's aims also include the ability of antenatal care to 'ensure a mature, live healthy baby' using typical medical terms such as 'monitoring', 'detecting' and 'treating'.[113] Not only do the aims give the promise of ensuring a good outcome for the baby but they suggest that the wellness paradigm of pregnancy and birth as a normal, healthy event coexists with the medical model of pregnancy as potentially abnormal that requires monitoring, detecting and treating.

In relation to antenatal screening tests, specifically, a number of statements are made. At the initial consultation, the policy states that hepatitis B (Hep B), rubella antibodies and urine examination for sugar, nitrates and protein should be routine and that syphilis and human immunodeficiency virus (HIV) antibodies should be offered to all women who wish it performed and all women in an apparent risk group. It states that a cervical smear is recommended. It also says a mid trimester ultrasound and alpha feto-protein (afp) may be offered. Haemoglobin (Hb) and blood group and antibodies are not mentioned in relation to the first consultation but the policy states that the Hb should be repeated at 28-30 weeks and rhesus antibodies at 32, 36 weeks and term if the woman is rhesus negative (Rh -ve).[98]

The Royal Australian College of Obstetricians and Gynaecologists (RACOG)

In July 1992 the RACOG Council adopted a policy for 'Screening in Pregnancy'.[114] The policy has been distributed to all members and fellows of the college. It includes

recommendations on the majority of commonly used antenatal screening tests in Australia. The policy acknowledges the worthwhileness of screening for disorders that lend themselves to 'effective alteration in care'.[115] The policy also justifies the need for some investigations in 'normal' pregnancy as a means of reducing perinatal deaths that do not occur in high risk pregnancies. It recommends the screening of blood group and antibodies, Hb and blood film, rubella, syphilis, Hep B and cervical cytology at the first visit and the rescreen of antibodies at 28 and 36 weeks if the woman is Rh -ve. It states that midstream urine examination for infection at the booking visit, ultrasound of the fetus at 18 weeks and repeat Hb and blood film should be done at the discretion of the doctor. Routine screening for gestational diabetes, cytomegalo virus, toxoplasmosis and triple test for Down syndrome in low risk women are not recommended. There is complete absence of policy in relation to vaginal swabs for group B streptococci (GBS), serum screening for HIV, serum afp and first trimester ultrasound.[114]

The Royal Women's Hospital, Melbourne (RWH)

As the study sample is drawn from this population, the policies of this hospital in relation to antenatal screening are examined. No formal written policy on antenatal care nor antenatal screening exists. In 1979, a one page policy on how antenatal clinic should run was written. It states only that a new patient will 'have blood taken for routine screening'.[116] Due to the lack of policy statements, information on the practice of routine antenatal screening is obtained from two sources. The first is a small typed card that is pinned on the notice board of each of the antenatal examination cubicles in the outpatient department. It only lists tests that are to be performed at various stages of gestation. It states that antenatal screening blood and mid-stream urine for infection is done at the booking visit. At 28 weeks the list includes Hb, rhesus antibodies (if woman is Rh -ve), GBS swab and a glucose challenge test (GCT) to screen for gestational diabetes. In addition, it lists rhesus antibodies at 28 and 38 weeks and Hb at 34 weeks. Fetal ultrasound is not mentioned. The second guide to the practice of antenatal screening can be found in a 1991 midwives policy statement on antenatal care.[117] It advises that Hb, rubella, Hep B, blood group and antibodies, midstream

urine specimen and a pap smear are done at the booking visit. Further, it states that a scan is routine at 18-20 weeks. It states that GBS swab, GCT, Hb and rhesus antibodies are done at 28 weeks, repeat rhesus antibodies if woman is Rh -ve at 34 and 38 weeks and Hb at 38 weeks.[117]

Differences in policy

Language differences between the three policies are marked. Words such as 'may be offered' or 'at the discretion' are more commonly found in the policy documents of NH&MRC and RACOG. In contrast, words such as 'are done' or 'routine' are found in the instructions to health care providers in the antenatal outpatient department. It is not surprising that the instructions at the coal face of service delivery are more pragmatic. When translating policy into practice other issues are evident. At the policy level greater caution and flexibility is given to directions about the use of the tests. However, without clear policy guidelines from the hospital the relationship between recommendations based on evidence and common practice and what actually happens in the outpatient department is problematic. In this instance, the trend is for both an increase in the number of tests performed routinely and at a greater frequency than is recommended by the policy statements. Mid-trimester fetal ultrasound is instructed to be performed routinely rather than being 'offered' or 'at the discretion'. GCT is instructed to be performed routinely despite not being recommended by the RACOG. Midstream urine assessment is instructed to be performed routinely rather than 'at the discretion' and GBS swabs are instructed to be performed routinely in the light of no policy guidelines from any of the above mentioned bodies. This implies that, in practice, more is better.

Conclusion

Policies in relation to antenatal screening in Australia, whilst offering some caution, generally support the availability and use of a wide range of screening tests in pregnancy. Only the RACOG guidelines explicitly attempt to justify their use based on the potential to

reduce perinatal deaths. Further examination of the translation of broad policy statements into practice instructions demonstrate greater support for many antenatal tests performed more frequently. Clearly, lack of formal policy at the local service provider level offers the potential for indiscriminate and wide spread availability and use of testing. It also suggests a neglect of fundamental evaluation of the effectiveness of each of these tests in the relevant population.

2.7 THE RESEARCH QUESTION

Despite the limitations of routine antenatal screening tests that are evident from epidemiological evaluation; despite the negative experiences some women endure from antenatal screening and despite the low chances of adverse outcomes following pregnancy and childbirth, the number and frequency of antenatal screening tests is increasing. Pregnant women's compliance to antenatal screening is also high.[70,118,119] Given all the questions and cavils, why do pregnant women use routine antenatal screening?

In addressing this question, it is important to note some of the recent medical discourse about women's expectations of pregnancy and childbirth. In particular, there has been discussion by some authors concerning what they call, 'unrealistic expectations ' by pregnant women.[20,120-123] Discussion of these issues largely lacks grounding in research. Shearman, a leading Sydney clinician wrote in 1990, 'Progressive reductions in maternal mortality and to a lesser extent perinatal mortality seem now to suggest even to otherwise intelligent people that a perfect outcome for both mother and baby should be the norm, ideally achieved without any medical assistance'.[123] Enkin states that 'expectations have risen faster than achievements. Perinatal results are now excellent and there is a tendency to assume that with just a little more effort they could be perfect'.[124] MacLennan, a leading Adelaide obstetrician, and others comment on the public's 'unrealistic expectations' and remind the reader of the rates of adverse outcomes such as birth defect, miscarriage, preterm delivery and cerebral palsy. They do add that the public 'may have been given' these expectations.[121] Drife, in a commentary about antenatal care for the Medical Protection Society in Australia, also suggests that doctors have 'done little to correct such unrealistic expectations' by the public.[125] The Royal Australian College of Obstetricians and Gynaecologists recently released a series of patient information pamphlets about the health and normality of pregnancy and childbirth entitled 'realistic expectations'.[126-129] Do they assume women have unrealistic expectations? Despite the concerns raised in the literature, medical discourse lacks documentation of women's expectations of birthing outcomes from research directed at the recipients of antenatal screening.

I hypothesise that there is a complex set of social and ethical factors that in part determine the use of routine antenatal screening tests by women. Therefore, the research reported below examines these factors by exploring women's beliefs, values and expectations of routine antenatal tests and their fears during pregnancy. It also explores women's perceptions about normality, rights and the role of medicine in pregnancy and childbirth. Literature related to ethical issues and antenatal screening is largely confined to areas of genetic counselling,[130-132] abortion[131,132] and informed consent.[132-134] Exploration of the bioethical issues of individual and fetal rights, notion of person, notion of risk in relation to women's use of screening is lacking. This research seeks to address this deficiency. In addition, this study addresses the potential consequences of the findings, not only for the future delivery of antenatal care services, but the medicalisation of pregnancy and the impact on resource allocation in health. It also explores the potential medico-legal implications of these findings.

Research into the social aspects of child bearing has increased in the past 25 years.[135] With this has emerged an increasing acceptance of the use of surveys and interviews as valid methods to assess women's views and experiences. In addition to a trend for greater evaluation activity of perinatal care,[135] a number of social science researchers have begun to document women's experiences and concerns about antenatal screening. [4,66,70,73,131,133,136-138] Questionnaires and interviews have been the most common methodological approaches.[9] Social scientists such as Marteau and Robinson have been particularly successful in using these techniques to evaluate pregnancy care in Britain.[135] Marteau supports the use of questionnaires as both a valid and reliable way to obtain information about pregnant women's knowledge, or lack of it, about prenatal tests.[139] Gillot-de Vries, a social scientist from western Europe, states that 'Combining open- and closed-ended investigation techniques has often proved to be an efficient method of obtaining data on complex topic such as 'prenatal screening procedures.'[140] She goes further to suggest that combining techniques 'elicits a better understanding of the problem being studied'.[141] In addition, the literature reveals limited exploration of the impact for women of the minor or routine

prenatal tests.[9] Despite its limitations, it is justifiable to initially examine the experience of these prenatal tests by pregnant women using a descriptive study rather than a comparative study or controlled trial.

Chapter 3 METHODOLOGY

Introduction

This chapter examines not only the methods employed by the researcher but also the philosophical underpinnings of the approaches used. It raises the need for a new paradigm to encompass both the researcher's ideologies and the methods best suited to examine the questions inherent in the research topic. In examining the area of values and beliefs about antenatal screening I cross many 'traditional' boundaries of epistemology, theoretical perspective, methodology and methods. Therefore the chapter explores critically the assumptions that I make about human nature and society in conducting such research.

Epistemology

There is a growing debate between objectivists, who think that social-like-physical-facts can be known objectively and validated empirically,[142] and constructivists, who think that facts are constructed by minds influenced by their social context.[143] Recently the debate has included voices calling for accommodation between the two positions.[144-146] Constructivists cannot ignore their own context which, in my case, includes training in the objectivist tradition of medicine. In my case, also, context has included the practice of medicine in a holistic ethos. I approach this study disposed to seek an accommodation between the two. I call this accommodation position a 'political paradigm'. Like Bryman suggests I attempt to traverse ' the epistemological hiatus ... between the research traditions'.[147]

Within the objectivist paradigm the attainment of objectivity, discovery of cause and effect and validation of knowledge empirically is paramount. However, in many areas of clinical research and epidemiology great steps are taken to attempt to compensate for the effect of the researcher on the process and the potential effects of variables, that is, the effect of context on the outcome. Clinical practice can suggest that phenomena are not as stable, as independent of the process of investigation or as context free as objectivism would suggest,

even in the case of the gold standard of research methods, the randomised controlled trial which is designed to take particular account of bias and reproducibility. If even that exemplar of objectivism has some soft edges, the notion of a political paradigm can be accommodated, in which research can also empower its participant subjects and, thus, legitimate them.

My clinical experience leads me to recognise that 'understanding human behaviour from an informant's perspective ... assumes dynamic and negotiated reality'.[148] Understanding of how recipients of a service, in this case antenatal screening, perceive it, lends itself to traditional qualitative inquiry. Qualitative research accepts that these issues should be seen from the point of view of the 'actor' in context, that is, an insider's view. Such an epistemology subjects the understanding of how we know what we know to a more complex analysis than objectivism. It assumes human behaviour and reality is dynamic, is not context free and is constructed and shaped by the human mind.[149] Whilst this paradigm encourages exploration and induction more familiar in qualitative research, it can also accommodate snap-shot views of the world, quantifying of responses and the drawing of conclusions from a particular observed phenomenon. In research, as in clinical practice, there can be a successful meld of the objectivist and constructivist epistemologies and of qualitative and quantitative methodologies.

Assumptions

The task of examining theoretical perspectives and research methodologies has been made difficult by confusion in the literature. Many authors chose to use the words 'methodology', 'abstract philosophical issues of epistemology',[145] 'theoretical traditions and orientations'[150] and 'fundamental orientation of research'[151] interchangeably to describe similar perspectives on research. For the purpose of this thesis I have chosen to call the methodology and philosophical stance that lies behind it, assumptions. The methods proposed to be used in this research fall under various methodological headings and use components of many.

What are more consistent are the assumptions made prior to selection of various methods which will be examined below.

A political paradigm assumes that events or responses which can be measured as in surveys or questionnaires and are of their own useful. By quantification of responses, using survey research methods, I have not assumed stability of facts nor unvarying applicability of the results. After all, the relativists would argue that there is 'no objective yardstick by which to assess claims to the truth'.[152] Survey data of this kind must be considered in the social and historical context in which they are collected and caution taken as regards generalisability.

When examining the values and beliefs of the recipients of antenatal screening in Australia other assumptions are made. Consistent with symbolic interactionism[153] I assume that human nature is reflective, self-activating and dynamic. In attempting to understand the determinants of the use of routine antenatal screening the assumption is made that behaviour is a result of individual reflective interpretations of socially derived meanings.[153] These 'reflective interpretations' can be best examined by qualitative methods of research such as interviews and open-ended questions.

Interviews and open-ended questions may reveal uncharted waters and new directions of inquiry as encompassed by the concept of grounded theory.[154] They also provide richness and strength to previously held or demonstrated concepts.

Methods

An intermediate step toward the development of a new framework is to employ methodological triangulation.[145] I have chosen a range of methods to interpret the perceptions of women about routine antenatal screening. Each method brings differing strengths to the research and each is appropriate to part of the research question. The quantitative methods enable the perceptions of a large number of women to be measured and the subsequent statistical analysis enables summarising and comparing of the data. These methods enable

the research to be potentially repeatable at another time or with another population. The qualitative methods produce a wealth of detailed information, avoid simplification and add to the understanding of the values and beliefs underlying participant responses. Such methods have gained increased acceptability as appropriate ways to examine prenatal screening procedures.[140]

The literature review

I conducted an initial review of the literature by first accessing references from Sociofile and Medline from 1986 to 1996, using key words including *screening, antenatal screening, antenatal care, risk, medical technology* and *fetal rights.* Following identification of key references, I sought further literature by use of the references listed in these key documents.

The pilot study

In July 1994 I conducted a pilot study of 19 postnatal women at Flinders Medical Centre in South Australia. Flinders Medical Centre provides various models of antenatal care including shared care with general practitioners and is also a tertiary maternal and neonatal referral centre. The centre has approximately 2,500 deliveries per year; 1,870 of them to public patients. Antenatal screening practices at the centre differed from that of the substantive study. In addition to the screening tests available to participants of the substantive study, serum alpha feto-protein for detection of neural tube defect, serum triple test for probability scoring of the risk of Down syndrome and maternal serum Human Immunodeficiency Virus (HIV) screen was offered routinely to all women attending antenatal clinic. An initial questionnaire of 40 items, including open- and closed-ended questions (see Appendix 1) was distributed randomly to participants on postnatal wards. The questionnaire explored women's beliefs and expectations of routine antenatal screening tests. All participants were public patients. Results of the pilot study (see Appendix 2) formed the basis for calculation of the sample size for the substantive survey and allowed for modification of the questionnaire to improve its validity.

The substantive study

Subjects

The substantive survey and interviews were conducted at the Royal Women's Hospital, Melbourne, which is similar in style and practice to Flinders Medical Centre. The hospital is a maternal and neonatal tertiary referral centre but also provides a variety of models of care including a birthing unit and shared care with general practitioners. There are approximately 7,500 deliveries per year, including both public and private patients. In 1994, 24.3% of all deliveries at the hospital were to women with private health insurance. The survey population also comprises 34% of women from non English speaking backgrounds (NESB).[155]

Women who were inpatients of the postnatal wards were eligible for the study. Whilst the research was designed to examine women's perceptions of screening tests they received antenatally in their recent pregnancy, women's perceptions of screening were examined immediately after delivery for the following reasons. Firstly, the results of the pilot study (see Appendix 2) suggested that women expressed both strong fears and beliefs about pregnancy even when in a position of now knowing they had had a normal outcome. That is, even though the participants had all delivered healthy live babies, they still expressed intense feelings of fear and anxiety that they felt antenatally. This is consistent with an earlier study by the Royal College of Midwives in the United Kingdom who, in 1966, found that women were nearly four times more likely to express fear about fetal abnormality during the pregnancy after the birth than before.[156] Marteau suggests there is a reluctance by women to acknowledge this fear overtly during pregnancy.[156] Secondly, studies examining women's perceptions and knowledge of antenatal tests have shown post partum women to have reliable accounts of their antenatal period. Marteau found from her study, comparing women who had just given birth with women at their first antenatal visit and women who had never been pregnant, that women in the immediate post partum group had greater knowledge of antenatal tests than the other two groups.[139]

Results of the pilot study (see Appendix 2) were used to calculate the sample size of 365 for the survey, accepting a Type I error = 0.05. In particular, a 60% response to the question of being anxious that the test results would be abnormal and a 60% expectation that the results of tests to be very reliable or perfect were two of the responses from the pilot study used to calculate the sample size above. The sample size was calculated using a computer statistical program called Epi Info.[157] A statistical approach was not suitable to determine the sample size for the qualitative method of interviews. Therefore, one in twenty of the participants were sought for semi-structured interviews. This was believed to be adequate to enrich the quantitative data above.

Data collection

Inclusion criteria for participants in the survey consisted of the following: women who had delivered a live baby or babies, greater than 20 weeks gestation or 400 grams, within 1 week of the survey, women who were inpatients of a postnatal ward and women who were literate in English. Women who had experienced a mid-trimester fetal loss or stillborn or delivered a critically ill infant were excluded : first of all by the sensitive nature of some of my questions that would be unfair to those women; secondly because the central interest of the study was in examining the views of the vast majority of women who have normal outcomes. In addition, participants in the semi structured interviews remained inpatients of a postnatal ward and had responded positively to a question in the survey regarding willingness to participate in further examination.

Randomisation of eligible participants for the survey was performed using computer proportional random number tables. This technique also allowed the sample to include 25% of women with private health insurance. This was performed to include the same proportions of private patients as found in the study population. Following observation of women's interaction with health care providers during their antenatal care, I believed health insurance status to be a significant variable in participant access to information and

appropriate informed consent. In addition, health insurance status has been shown by other Australian studies to be a significant factor in the utilisation of other prenatal interventions such as prenatal diagnosis[158] and caesarean section.[159] On the Monday of every week during the study period, randomisation of all eligible patients was performed and 20 to 40 women were approached to participate in the study. Duplication of response was avoided by recording participant names in the researcher's field diary and/or by participants' self-notification of previous participation. Participants were recruited weekly during the study period until the calculated proportional sample size was reached. Participants were recruited evenly across the research period.

Participants were approached by the researcher on the postnatal ward. A five to ten minute explanation of the research was given to the women and written consent sought (see Appendix 3). The explanation page, consent form and questionnaire was left with each participant to read and complete in her own time. They were free to discuss the questions with their family or friends. The researcher returned daily to the wards to collect completed questionnaires and answer any questions. Participants had access to the hospital researcher co-ordinator via contact details on the consent form if they encountered any problems with the research.

Participants who had agreed to further examination by interview, as indicated by their response to question 45 of the questionnaire (see Appendix 4), were selected by their availability and were approached again individually by the researcher. I conducted all interviews at a time convenient with the participant. Interviews were held in a private room adjacent to the ward or the participant's room if maintenance of privacy was possible. All interviews were taped following consent by the participant and later transcribed by a typist in South Australia who was independent to the research.

The survey and interviews were conducted over a five month period from April to August 1995. All questionnaires are stored in a locked filing cabinet and identified only by an

identification number. In accordance with the hospital research guidelines the questionnaires will be stored for a minimum of five years.

Research design

My principle research technique was a survey of the recipients of antenatal screening making use of a 45-item self-administered questionnaire (see Appendix 4). Both closed and open-ended questions were employed. The questionnaire sought information about participants' demographic characteristics, their use and perceptions of routine antenatal screening tests and their fears and anxieties during pregnancy. Closed questions used both dichotomous responses and a range of four and five point scales such as 'strongly agree' to 'strongly disagree'. This method presupposed some expected responses from the recipients of antenatal screening. Whilst responses to closed questions by survey are both quantitative and largely deductive, the questions have been generated by my ten years experience in this area. My experience working with health care providers and mingling with pregnant women during the time they received antenatal care services added a rich inductive texture to the study. I was able to bring to it both my training in the professional discipline and my feminist sensitivity to the situation of the women. Quantification of both closed questions and themes arising from open-ended questions and interviews is valuable when addressing an area of potential reform. It allows greater generalisation and applicability of the results if sampling occurs broadly and randomly. Making 'the numbers count' has historically been a strong motivation for debate and change within the health care system.

Critical examination of the above methods reveals a lack of consideration of the complexity of the issues being considered and the voice of the participants. I have addressed this deficiency in two ways: firstly, the questionnaires included some open-ended questions particularly related to participants' experiences and perceptions of antenatal screening tests; secondly, arising from the response to a questionnaire item number 45, asking whether the participant would be willing to be involved further in the research, semi-structured interviews were also conducted with some of the participants. These interviews followed

similar themes to the questionnaire but examined in more depth the participant's experience and in particular, the socio-cultural context in which it occurred. They included standard questions that explored why participants had screening and their understanding of the role of screening (see Appendix 5). They also allowed for exploration of other matters of importance to the interviewee. The aim with these approaches was to enrich the findings and provide a description of the context in which these issues arise. These methods allowed a greater exploration of the participants and their place within society. I also explored issues of power differences and the role of medical expertise and technology in antenatal care. Without hearing the voices of the participants in this way the findings would lack depth and potency.

Analysis

The quantitative survey data were analysed by computer statistical package, Epi Info, Version 5.0.[157] Descriptive analysis using standard univariate calculations were performed. Each variable was analysed separately to elicit the frequency of the response categories and reported as percentages. Frequency calculations allowed for the inclusion or exclusion of 'not sure' categories when used. Identification of frequency responses allowed for summarising of the data and comparison with previous similar study findings. Many four-scaled variables such as those with 'yes a lot', 'yes sometimes', 'no mostly' and 'no never' were recoded to two categories such as 'yes' and 'no' to allow for bivariate analysis using odds ratios. Inferential analysis using cross tabulations were also performed and allowed for comparison of responses between sub groups within the sample. Two variables were examined to calculate significant associations. As this is a cross sectional study with categorical data, odds ratios were calculated for dichotomous variables and Chi-squared coefficients (χ^2) were calculated for non dichotomous independent variables. Fisher exact results were used with tables where less than or equal to 33% of the total cells were made up of cells less than five or when expected values were less than five. Outcome variables such as perceived anxiety and perceived information have been compared with demographic variables such as health insurance status, age and parity. A p value of less than 0.05 was

considered significant. That is, a type I error of 0.05 was chosen as the level of probability at which the null hypothesis may be falsely rejected.

Responses to the open ended questions were coded manually and analysed by the researcher. The first reading of the responses to the open ended questions identified emerging themes that were raised by participants. Interpretations of underlying meanings were also made. On the second reading significant categories of data were labelled. Patterns and recurring themes were identified and quantified. Themes from open-ended responses were linked to related closed responses. Some responses generated new themes not covered by the closed questions. Detailed examination of those responses that were deviant from the common themes and trends was performed to attempt to refute explanations arising from the other data.

The textual information from the interview transcripts was coded manually and analysed by the researcher. Recurrent themes were again identified. Responses consistent with the coded items of the survey were examined together with the quantitative data. New themes identified by the qualitative data were examined separately as they related to the research objectives.

Logistics*

Formal written consent was sought from all participants prior to recruitment to the pilot and substantive study. This was included on specific forms as dictated by the individual hospital

---

* Approval for the commencement of the pilot study was granted by the Committee on Clinical Investigations at Flinders Medical Centre, South Australia in June 1994. (see Appendix 6a) I submitted the research proposal for consideration of a Public Health Research and Development Council (PHRDC) Scholarship in June 1994. The research proposal was approved for a degree by research for a Doctor of Medicine by the Faculty of Medicine, University of Adelaide in September 1994. The research was approved for a PHRDC Scholarship for 1995 and 1996 in November 1994 .
Approval for the commencement of the substantive survey and interviews was granted by the Research and Ethics committees and the hospital board of the Royal Women's Hospital, Victoria in March 1995 (see Appendix 6b). Obstetricians with admitting rights for private patients at the Royal Women's Hospital were approached individually by detailed letter and follow up phone calls requesting consent from them for the researcher to approach their private patients to participate in the study. Permission was granted by April 1995.

committees (see Appendices 7 and 3). Explanation sheets were separately distributed to participants in the pilot study (see Appendix 1) but incorporated in the consent form for participants of the substantive study (see Appendix 3). Both consent forms included additional compulsory clauses deemed necessary by the hospital committees.

Validity and reliability

Academic rigour of both quantitative and qualitative methods is best assessed by examination of the research's validity and reliability. Triangulation of methods and methodology has been the principal way in which I have addressed validity. Use of quantitative methods including closed questions requiring statistical analysis and quantification of qualitative responses has improved the reliability of the research. Completion of a pilot study has also improved the reliability of the research. Proportional random sampling of the survey participants attempted to maximise the representativeness of the study population and improve the study's validity. My experience in the area of study informed a thorough examination of the deviant responses which also contributed to improved validity of the qualitative methods used.

Limitations of the methods include the following: cross-sectional and qualitative research methods lack comparison with a control group and are most relevant to a particular point in time. This research is unable to demonstrate if women's perceptions of antenatal screening tests and their fears about pregnancy change over time or are different to a population of non-pregnant women. Women's utilisation of routine antenatal screening tests were not formally validated as the researcher was principally concerned with women's perceptions of what they had had. As the semi-structured interviews were not the only method employed in the study, I chose not to provide feed back about the responses to the interview participants, not to use computer coding of the responses and did not employ an independent analyst. These measures would be added validity components of a solely qualitative researcher's methodology.

Table 4.1. Characteristics of Sample

	All		Public	Private	RWH‡ (1994)	Victoria[94] (1994)
	n*	%	%	%	%	%
Characteristics						
Age at confinement						
18 or less	8	2.1	2.8	0	4.2	3.5
19-26	96	25.5	33.6	3.0	(<20y)	(<20y)
27-34	201	53.5	50.9	60.6	-	-
35 or more	71	18.9	12.6	36.4	-	-
Median age group	27-34 years					
Parity						
Primip	171	45.5	45.5	45.4	42.6	40.1
Multip	205	54.5	54.5	54.6	57.4	59.9
Insurance Status						
Public	277	73.7			75.7	
Private	99	26.3			24.3	
Educational level n=370						
Completed primary	4	1.1				
Left during high	108	29.2				
Completed high	91	24.6				
Completed TAFE	46	12.4				
Completed Uni/College	121	32.7				
(High education)	258	69.7	65.3	81.8		
In paid employment	204	55.0	48.2	73.7		
Occupation † n=155						
Managerial/Admin	28	18.1				
Professional	45	29.0				
Para professional	7	4.5				
Trade	8	5.2				
Clerical	37	23.9				
Sales	25	16.1				
Plant/Machine	4	2.6				
Labourer	1	0.6				
(High occupation)	83	25.5	15.3	52.2		
Gestational age at confinement						
Preterm	50	13.3	13.4	13.1		5.9
Term	326	86.7	86.6	86.9		84.1
Congenital abnormalities	17	4.5	4.3	5.1		3.8
Mild		16.0		94.1		
Mod		1.0		5.9		
Severe		0		0		

* n=376 unless otherwise stated

† Australian Standard Classification of Occupations (ASCO) 1986

‡ supplied by Medical Records at the Royal Woman's Hospital (RWH) [163]

Chapter 4 RESULTS

4.1 Response

During the study period 492 women were approached to enter the study. Twenty-three women (4.67%) declined to participate. Of 469 questionnaires distributed, 94 (20.0%) were returned incomplete or were lost. Therefore, responses from 376 women (80.0%) are examined in this study. One hundred and fifty-four (41%) of these respondents also agreed to participate in a further interview. Twenty-one semi-structured interviews were conducted from this sample. Of the 24 obstetricians contacted to participate in this study, 19 replied (79%). All agreed to participation of their private patients but due to cessation of private obstetric practice by four, the private patients of 15 obstetricians only are included in this study.

4.2 Sample Characteristics

Consistent with the inclusion criteria all respondents delivered a live baby(ies) greater than 20 weeks gestation within one week of the study questionnaire and interview. Table 4.1 illustrates the characteristics of the sample, both public and private. It compares the sample to the survey population and Victorian data. Characteristics of age, parity, gestational age at confinement and rate of congenital abnormalities are commonly noted features of pregnant women and as such have been collected to critique the representativeness of the sample. Information on participants' health insurance status, education level and paid workforce participation has been collected also to examine potential differences in experience and expectations based on women's socio-economic status. These factors have been selected to represent features of socio-economic status in contrast to the traditional examination of marital status.

1) Age at confinement

As illustrated in Table 4.1 the median age group is 27-34 years. Victorian Perinatal Data Unit statistics from 1983 to 1994[88] and the Australian Bureau of Statistics reports from 1971 to 1993[160,161] show the percentage of women giving birth under the age of 20 years to be decreasing whilst the percentage giving birth aged 35 years or more to be increasing. This study, however, under-represents younger women, consisting of only 2.1% of women less than 19 years compared with 3.5.% less than 20 years giving birth in Victoria in 1994[94] Whilst this study is consistent with women having babies at older ages, it over-represents older women with 18.9% of women 35 years or more compared with 14.0%[94] in this age group giving birth in Victoria in 1994. Reasons for this difference can be explained by potential participant bias. Younger women may have been more likely not to complete the questionnaire or be discharged early and the questionnaire be lost. This is consistent with Brown's early discharge study[162] that showed an under-representation of young women respondents, in particular, young women with low income and low education who were more likely to go home early. In addition, women giving birth over the age of 35 years are more likely to be classified as high risk and therefore deliver in a major public teaching hospital. These results are consistent with the Royal Women's Hospital statistics for age of confinement for 1994 where 4.2% of deliveries were to women less than 20 years of age and 17.2% were to women 35 years or more.[163]

2) Parity

Table 4.1 illustrates parity expressed as primiparous and multiparous and parity number. The study sample over-represents primiparous women, 45.5% compared with 40.1% primiparous women who delivered in Victoria in 1994[94] and 38.1% primiparous women who delivered in Australia in 1992.[160] This is consistent with the tendency to manage and confine more primiparous women in hospitals that provide higher risk care.[91] In 1994, primiparous women represented 42.6% of all births at the Royal Women's Hospital.[163] In line with Victorian[94] and Australian data, [160] the majority (75.3%) of participants studied have families that consist of two or less children. There has been no change in parity in Victoria over the last 10 years.[88]

Table 4.1. Characteristics of Sample

	All		Public	Private	RWH‡ (1994)	Victoria[94] (1994)
	n*	%	%	%	%	%
Characteristics						
Age at confinement						
18 or less	8	2.1	2.8	0	4.2	3.5
19-26	96	25.5	33.6	3.0	(<20y)	(<20y)
27-34	201	53.5	50.9	60.6	-	-
35 or more	71	18.9	12.6	36.4	-	-
Median age group	27-34 years					
Parity						
Primip	171	45.5	45.5	45.4	42.6	40.1
Multip	205	54.5	54.5	54.6	57.4	59.9
Insurance Status						
Public	277	73.7			75.7	
Private	99	26.3			24.3	
Educational level n=370						
Completed primary	4	1.1				
Left during high	108	29.2				
Completed high	91	24.6				
Completed TAFE	46	12.4				
Completed Uni/College		121	32.7			
(High education)	258	69.7	65.3	81.8		
In paid employment	204	55.0	48.2	73.7		
Occupation † n=155						
Managerial/Admin	28	18.1				
Professional		45	29.0			
Para professional	7	4.5				
Trade	8	5.2				
Clerical	37	23.9				
Sales		25	16.1			
Plant/Machine		4	2.6			
Labourer		1	0.6			
(High occupation)	83	25.5	15.3	52.2		
Gestational age at confinement						
Preterm	50	13.3	13.4	13.1		5.9
Term	326	86.7	86.6	86.9		84.1
Congenital abnormalities	17	4.5	4.3	5.1		3.8
Mild		16.0		94.1		
Mod		1.0		5.9		
Severe		0		0		

* n=376 unless otherwise stated

† Australian Standard Classification of Occupations (ASCO) 1986

‡ supplied by Medical Records at the Royal Woman's Hospital (RWH)

3) Health Insurance Status

Table 4.1 illustrates the health insurance status of the study sample. As previous Australian studies, examining participants' utilisation of other perinatal interventions such as prenatal diagnosis[158] and caesarean section[159] have shown health insurance status to be a significant factor, this research includes an examination of health insurance status. Of the respondents, 26.3% were privately insured and cared for by a private obstetrician during their recent pregnancy and delivery. This is consistent with current Royal Women's Hospital privately insured rates of 24.3% in 1994 for obstetric patients. This rate is also consistent with the gradual decline observed over the past decade of obstetric patients with private health cover in Australia.[91,163] In Lumley's review of birthing services in Victoria in 1988, 45% of women had private specialist obstetric care, 11% were managed by a general practitioner and 40% were managed in a public hospital.[77] Whilst the study sample is representative of the rate of private obstetric patients in the population, selection of these patients from a major public teaching hospital may show bias toward a higher risk group of patients.

As expected the private patients were significantly older (χ^2 = 52.54 p=0.0000 3df), were more highly educated (OR = 2.39(1.3-4.4) and three times more likely to be in paid employment (OR = 3.02 (1.76-5.21) than the public patients in the study. Whilst privately insured participants were 2.4 times more likely to be more highly educated, 18% of privately insured women were of low education and 65.3% of public patients were of higher education. There were no significant differences, however, in parity, gestational age at confinement or number of babies born with abnormalities between public and private patients.

4) Educational level

Whilst education level can be a feature of a woman's socio-economic status, it may also be a factor in women's perceptions about information received during the antenatal period and as such is examined separately. Table 4.1 illustrates the highest educational level achieved by the study participants, 69.7% of whom attended fifth year high school or higher compared

Table 4.1. Characteristics of Sample

Characteristics	All n*	All %	Public %	Private %	RWH‡ (1994) %	Victoria[94] (1994) %
Age at confinement						
18 or less	8	2.1	2.8	0	4.2	3.5
19-26	96	25.5	33.6	3.0	(<20y)	(<20y)
27-34	201	53.5	50.9	60.6	-	-
35 or more	71	18.9	12.6	36.4	-	-
Median age group	27-34 years					
Parity						
Primip	171	45.5	45.5	45.4	42.6	40.1
Multip	205	54.5	54.5	54.6	57.4	59.9
Insurance Status						
Public	277	73.7			75.7	
Private	99	26.3			24.3	
Educational level n=370						
Completed primary	4	1.1				
Left during high	108	29.2				
Completed high	91	24.6				
Completed TAFE	46	12.4				
Completed Uni/College		121	32.7			
(High education)	258	69.7	65.3	81.8		
In paid employment	204	55.0	48.2	73.7		
Occupation † n=155						
Managerial/Admin	28	18.1				
Professional		45	29.0			
Para professional	7	4.5				
Trade	8	5.2				
Clerical	37	23.9				
Sales		25	16.1			
Plant/Machine		4	2.6			
Labourer		1	0.6			
(High occupation)	83	25.5	15.3	52.2		
Gestational age at confinement						
Preterm	50	13.3	13.4	13.1		5.9
Term	326	86.7	86.6	86.9		84.1
Congenital abnormalities	17	4.5	4.3	5.1		3.8
Mild		16.0		94.1		
Mod		1.0		5.9		
Severe		0		0		

* n=376 unless otherwise stated

† Australian Standard Classification of Occupations (ASCO) 1986

‡ supplied by Medical Records at the Royal Woman's Hospital (RWH) [163]

with 53.0% of women in Australia in 1994,[160] and 32.7% of these had completed a University or College course. Whilst these results are consistent with a trend for girls to stay in school longer and generally increasing educational levels for women in Australia, [160,161] they do represent a more highly educated sample. This may reflect the exclusion of women from Non English Speaking Backgrounds (NESB) and English speaking women not literate in English from the study. Whilst the catchment population for the study hospital is mixed, proximity of the hospital to a university may lead to a higher representation of women with higher education. In addition, this age cohort of women in their child bearing years may also be more educated than a larger sample of women from age 15 to 69 years.

5) Paid employment

Table 4.1 illustrates that 55.0% of the study participants were currently, or recently had been, in paid employment. These results are higher than work force participation figures for women in Australia. The female labour force participation rate for 1995 in Australia was 53.2% which included an 8.7% unemployment rate.[161] That is, 44.5% of women aged 15 to 69 years were in paid employment. This difference reflects the higher level of employment observed in women in child bearing years,[164] the exclusion of non literate NESB and English speaking women in the study and the observation of a relatively higher education level amongst the study participants. These findings are, however, consistent with an observed increase in women's labour force participation rate with a projected rate in the year 2000 of 58.8%.[160]

6) Occupation

Table 4.1 illustrates the occupational status of the study participants coded to the Australian Standard Classification of Occupations (ASCO) 1986. [164] Whilst a high rate of professional positions is consistent with the growth of women into such occupations in Australia over the past 10 years,[160,161] professional, managerial and administrative occupations are over- represented by the study participants, 18.1 and 29.0% respectively compared with Australian statistics for women of 6.1 and 14.2% respectively in 1995.[160,161] Movement of nursing training into the tertiary sector has contributed to this observed Australian trend and

Table 4.1. Characteristics of Sample

	All		Public	Private	RWH‡ (1994)	Victoria[94] (1994)
	n*	%	%	%	%	%
Characteristics						
Age at confinement						
18 or less	8	2.1	2.8	0	4.2	3.5
19-26	96	25.5	33.6	3.0	(<20y)	(<20y)
27-34	201	53.5	50.9	60.6	-	-
35 or more	71	18.9	12.6	36.4	-	-
Median age group	27-34 years					
Parity						
Primip	171	45.5	45.5	45.4	42.6	40.1
Multip	205	54.5	54.5	54.6	57.4	59.9
Insurance Status						
Public	277	73.7			75.7	
Private	99	26.3			24.3	
Educational level n=370						
Completed primary	4	1.1				
Left during high	108	29.2				
Completed high	91	24.6				
Completed TAFE	46	12.4				
Completed Uni/College		121	32.7			
(High education)	258	69.7	65.3	81.8		
In paid employment	204	55.0	48.2	73.7		
Occupation † n=155						
Managerial/Admin	28	18.1				
Professional		45	29.0			
Para professional	7	4.5				
Trade	8	5.2				
Clerical	37	23.9				
Sales		25	16.1			
Plant/Machine		4	2.6			
Labourer		1	0.6			
(High occupation)	83	25.5	15.3	52.2		
Gestational age at confinement						
Preterm	50	13.3	13.4	13.1		5.9
Term	326	86.7	86.6	86.9		84.1
Congenital abnormalities	17	4.5	4.3	5.1		3.8
Mild		16.0		94.1		
Mod		1.0		5.9		
Severe		0		0		

* n=376 unless otherwise stated

† Australian Standard Classification of Occupations (ASCO) 1986

‡ supplied by Medical Records at the Royal Woman's Hospital (RWH) [163]

within the study sample nurses and teachers made up the greatest proportion of occupations in the professional category. Clerical and sales positions are also under-represented in the study sample. Whilst less than half of respondents in this study reported their occupation, differences in these representations may be explained by the selection of only women in their child bearing years into the study and non inclusion of NEBS and English speaking women not literate in English. The occupations represented are consistent, however, with a older, more educated sample as discussed above.

7) Gestational age at confinement

Table 4.1 illustrates a preterm (less than 37 completed weeks) rate of the study participants of 13.3%. This is higher than the Victorian rate of 5.9% in 1994,[94] a figure that has remained constant over the past 10 years. This finding is consistent, however, with rates of preterm deliveries in major public teaching hospitals providing tertiary neonatal facilities.[91]

8) Congenital Abnormalities

Table 4.1 illustrates a congenital abnormality rate in the study sample of 4.5%, 94.1% of which were categorised as mild. Whilst this rate is consistent with overall birth defect rates in Australia where accurate statistics are kept[89] this study sample is not representative of the diversity of birth defects notified in the broader population. Only women delivering a live baby greater than 20 weeks gestation have been included in this study and women with severely sick infants were not approached to participate due to the sensitivity around many of the survey questions. Participants in the study also recorded their responses within one week of the birth such that some birth defects may, at that stage, have been undetected.

As discussed above, the study sample may under-represent women of NESB, especially those not literate in English. Statistics for Australia in 1992 show that 16% of women were born in NESB countries.[160] This is consistent with Victorian Perinatal statistics showing 16.9% of women giving birth in 1992 were born in NESB countries. Whilst study participants were drawn from a number of models of care including shared care with general practitioners, birth centre management, and management in the high risk perinatal unit,

selection of study participants from a major tertiary care teaching hospital will under-represent low risk obstetric patients. Lumley's review, in 1988, reported that deliveries in tertiary hospitals accounted for only 32% of births in Victoria.[77] In addition, women living in rural Victoria, except those transferred to the Royal Women's Hospital for management of high risk pregnancies, are not represented by this study. Whilst the sample characteristics are consistent with the demographic profile of women giving birth in a large tertiary metropolitan public teaching hospital, because of the sample's limitations demonstrated above, the results from this study may lack greater generalisability to women giving birth in other settings in Australia.

4.3 Perceived utilisation of Routine Antenatal Screening Tests

The focus of this section of the study is women's perception of what tests were performed. No validation procedure was performed on these responses except to examine the Royal Women's Hospital policies on the performing of antenatal screening tests on public patients attending this hospital.

Policy and practice

Whilst no formal policy on routine antenatal screening exists at the Royal Women's Hospital, formal and informal rules of practice exist. A policy statement from December 1979 on Antenatal clinic states, 'A new patient upon arrival at the Outpatient Department....then have blood taken for routine screening'.[165] Each cubicle in the outpatient department contains a small card on the notice board outlining the routine antenatal investigations to be performed and at what gestation. These include examination of urine at each visit for urinalysis and microscopy at booking, haemoglobin at booking, 28 and 38 weeks, rubella and hepatitis B status at booking, blood group and antibodies at booking and repeat antibodies at 28, 34 and 38 weeks if patient is Rh negative, pap smear at booking, mid-trimester ultrasound of the fetus preferably at 18-20 weeks, low vaginal swab for group

B streptococcus (GBS) at 28 weeks and a 50 gram glucose challenge test (GCT) at 28-32 weeks.

The women attending antenatal clinic are routinely given a pamphlet called, *Having a baby at the Royal Women's Hospital* that contains only limited, bland information on antenatal screening[166] and another called *Being Pregnant*. This latter pamphlet states that at the booking visit, 'You will also be asked for a urine sample, have some blood taken, as well as have a smear test done. These tests are to make sure that your pregnancy is progressing normally'.[167] Further to this it states;

> At different visits, various tests are recommended to make sure your pregnancy is progressing well and to avoid some known complications... Around 26 to 28 weeks you will be tested for diabetes. This involves having a sugar drink and an hour later having a blood test. At about 28 and 38 weeks, blood will be taken from a finger prick to check your blood count. At 28 weeks, another test is done to check for a germ so that a rare postnatal (after-birth) infection can be prevented.

Separate pamphlets are available on ultrasound and some complications of pregnancy.[168,169] Little information is supplied about the reliability or limitations of these investigations in pamphlets available to women using this service. No mention is made in these pamphlets about women having a choice to have the tests or not. The practice of screening in the antenatal outpatient clinic is of an 'opt out' mode. That is, pregnant women must decline to have a test rather than request it be done.

Maternal Human Immunodeficiency Virus (HIV), serum alpha feto-protein (afp) and the triple test for Down syndrome are not offered routinely to public patients attending the hospital's antenatal clinic.

Performance of screening tests on private patients is dependent on the antenatal screening practices of the relevant private obstetrician. The Royal Australian College of Obstetricians and Gynaecologists has developed a policy on 'Screening in Pregnancy' July 1992 that has been distributed to all members and fellows of the College for their use.[114] Whilst the policy recommends that many of the screening tests are 'left to the discretion of the doctor after

discussion with the woman', a formal statement on informed consent in relation to these tests is lacking.

Perceived utilisation

Table 4.2 shows that 375 (99.7%) of respondents perceived they had had some form of routine antenatal screening investigations during that recent pregnancy.

Table 4.2. Perceived utilisation of routine antenatal screening tests

	Yes %	Didn't know %
Blood test for infection	73.2	3.7
Blood test for diabetes	86.4	1.3
Vaginal swab for infection	75.6	1.3
Ultrasound	96.5	0.0
*afp	10.4	6.6
*Down syndrome screen	12.0	5.1
Any routine antenatal screening test	97.0	

* Tests have been included as potentially used routinely in private practice

The one respondent who perceived she had not had any form of screening was a public patient, aged 27-34 years, having her third baby, who had completed tertiary level education but was currently unemployed. The reason she gave for not having screening investigations was, *'Due to the way I was treated with my last birth.'* A total of 96.5% of participants perceived that they had had at least one ultrasound of the fetus during the recent pregnancy. This utilisation rate is consistent with Lumley's study of antenatal fetal ultrasound rate in Victoria of 96.9%.[170] In addition, participants were more likely to report not knowing whether they had had afp or Down syndrome screening.

Differences in the availability of screening tests and practice methods of the antenatal care provider are reflected in table 4.3.

Table 4.3. Differences in utilisation of routine antenatal screening tests

	Public		Private		OR	(CI)
Screening test	n	%	n	%		
Blood test for infection	213	77.2	62	62.6	0.5	(0.29-0.87)
Ultrasound	264	95.7	99	100.0	-	
Blood glucose	247	89.5	78	78.8	0.49	(0.25-0.90)
Vaginal swab	221	80.1	63	63.4	0.42	(0.24-0.73)
afp	29	10.5	10	10.1	-	
Triple test for Down syndrome	23	8.3	20	20.2	2.68	(1.32-5.43)

Private patients were half as likely to report they had had blood tests for infection, glucose challenge test or vaginal swabs for infection. However, they were 2 ½ times more likely to have serum screening for Down syndrome. In addition, only 89.8% of public patients perceived having had screening for diabetes. This is less than the utilisation rate of the glucose challenge test of 95.1% for public patients at the hospital in 1994.[171] Nineteen per cent of public patients also perceived not undergoing a vaginal swab despite the hospital's utilisation rate for vaginal swabs for GBS to be 93.8% in 1994.[171] Despite a practice of not offering afp routinely to public antenatal patients and the laboratory only performing one to two tests per year on public patients,[172] 29 public patients perceived they had had serum afp screening for neural tube defect. Twenty-three public patients also perceived they had had serum screening for Down syndrome that is not provided by the hospital laboratory. Public patients may have been able to access these screens outside the public hospital via private practitioners and private laboratories. However, this difference in women's perception and hospital utilisation rates may reflect some deficiencies in the information given to these

women. Greater perceived serum screening for Down syndrome by private patients may reflect greater availability and perhaps greater demand.

By examining participants' perception of what routine antenatal screening tests they had performed during their recent pregnancy and comparing that with current policies and practice standards, two issues are demonstrated. Firstly, that the amount of information about routine antenatal screening pregnant women receive varies and may impact on women's use of these tests. The amount or type of information received is associated with the issue of whether women have a choice to have these tests or not. Secondly, participants' perceived utilisation of these tests demonstrate a high level of compliance and acceptance of testing. This acceptance of testing as a routine, raises issues about the role of medicine in the utilisation of screening tests. Both these factors may be determinants of the use of routine antenatal screening and will be discussed in following chapters.

4.4 Information about routine antenatal screening tests

Table 4.4 shows results of women's perception of information given to them about routine antenatal screening tests during their recent pregnancy.

Table 4.4. Perception of information received about routine antenatal screening tests

	All %	Public %	Private %	OR	(CI)
Not enough information	15.5	21.1	5.3	4.8	(1.74-14.24)
Not told what tests would be done	8.3	9.8	5.1	ns *	
Not told why the tests would be done	7.5	8.8	5.4	ns *	
Not told the results of the tests	8.1	10.3	2.0	5.54	(1.24-34.79)
If not told, didn't ask for the results	43.3	42.9	50.0	ns *	
Not told the reliability of the tests	37.1	40.8	27.6	1.81	(1.01-3.24)

* not significant

Of the study participants, 15.5% reported not having enough information about the tests, while 8.3% reported not being told what tests were being done and 7.5% reported not being

told why the tests were being done. Public patients were nearly five times more likely to report not having enough information (see table 4.4). The lower the participant's occupational level the more likely she was also to report not having enough information (OR = 2.62 (1.06-6.74) However, the participant's education level was not associated with her perception of being told what tests were being done, why the tests were being done or whether she was given enough information.

A total of 8.1% of participants reported not being told the results of their tests during the recent pregnancy. Public patients were five times more likely to perceive they had not been told the results of their tests (see table 4.4). Of those participants who perceived not being told the results only 17 out of 30 (56.7%) then asked staff for the results. In response to the question about why participants didn't ask for the results if not given five women expressed feelings of 'no news is good news'. *'If anything was wrong I would have been told (hope).' 'I presumed I would be told if anything was wrong.'* A further two women responded by expressing a lack of information on which to ask questions. *'I wasn't even sure what some of the tests were.' 'Because I didn't know what they were testing me for.'*

In the study, 30.7% of participants reported not being told the reliability of the screening tests during the pregnancy and 17.3% were not sure. Again, public patients were nearly two times more likely to perceive not being given this information (see table 4.4). Younger women were also less likely to perceive not being given information on the reliability of the screening tests ($\chi^2 = 11.46$ 3df p=0.00946).

Women who perceived they were not given enough information about screening tests in pregnancy were also likely to report not being told what tests were being done or why the tests were being done or the results or the reliability of the tests ($\chi^2 = 91.51$ 1df p=0.00000, 113.6 1df p=0.00000, 31.92 1df p=0.00000, 60.34 1df p=0.0000000).

To enrich and increase the depth of understanding of participants' experiences and perceptions of pregnancy, responses from interviews with participants are included

extensively throughout the results.* Additional themes, not previously explored in the survey, are revealed in this qualitative data. When participants were asked during the interviews whether their usage of an antenatal screening test would change if they knew it was not 100% reliable and may give a 10% false positive or false negative result, many were either then unsure or would choose not to have the test:

> *I wouldn't feel as secure as I would otherwise. See, I haven't had enough knowledge of ultrasounds to know of this, so I presumed that ultrasounds are really the way to go.*
>
> *I think I'd worry. I suppose, not knowing makes you worry a lot just throughout the whole pregnancy. Not knowing is really bad but, then you* (the doctors and the tests) *could be wrong and I would be really devastated and then there's nothing wrong.*
>
> *I don't know. I don't think I could choose to terminate either. But that's my feelings. But then I've never had to be placed in that position.*
>
> *No, I don't think I would, because it wasn't 100% accurate and it might cause more concerns giving you a wrong answer. And you would have that stress through the pregnancy, worrying about it. Although, I would imagine there would be follow up tests that they would carry out in order to determine if that was the case.*
>
> *No, I don't think so. I don't think you should go through the expense of having them if they're not reliable. It's better to have something you know for sure, not just wasting time.*

Others felt they would have the test even if it had only a slight chance of detecting an abnormality.*'I would probably still take it because I'd still think that I was better off than not having had it done - there was still like, a 50% chance that it would let you know.'*

When participants, who reported not having had enough information about the screening tests, were asked how more information would have made a difference they responded as follows. Nineteen out of 52 (36%) expressed the value of knowing what to expect.

> *It's just good to know what is being done to your body.*
>
> *You would know what to expect.*
>
> *If the tests had been positive to anything, what did it mean to the baby's health and development.*

---

* It was not relevant to this study to examine the interviewees individually throughout the results. Therefore, responses from participants in the interviews have not been identified separately by pseudonym or number. All responses are included together to illustrate the study findings.

Twenty three per cent of women wrote about the reassurance associated with having information.

> *It would have assured me that they are looking after me and my baby.*
>
> *I wouldn't have had the fear of being different to others.*
>
> *I felt like a nobody and I think if medical people explained and took time in telling parents what the test was for it would have eased and made the pregnancy a lot smoother.*
>
> *Knowledge of what is being done to you and for you and your baby to me is very important for your confidence throughout the pregnacy...*

Other women expressed the value of information in knowing what questions to ask. *'Only more knowledgable - and maybe then able to ask more questions.' 'I would have read more information about the tests and asked more questions.'* Others expressed the value of being given prior information about the tests so that they could make an informed choice as to whether to have the tests or not i.e. the right to refuse. *'I could have made a personal, somewhat informed decision, about whether to have all tests knowing the possible implications. I would have felt more of a participant.'* Many respondents used the question to express concerns about and remedies to perceived barriers to pregnant women obtaining information about antenatal screening tests.

> *I had to ask what they were for!! Drs often don't give enough information- you shouldn't have to ask your G.P. very much. They should render the information as they are doing the tests/prescribing medication etc.*
>
> *Before coming in hospital a leaflet should be given about tests.(why, when, and how the tests are given)*

In interviews with participants the issue of the quality and source of information given during pregnancy was also raised. Not all information was perceived as being of value and in some cases was perceived as leading to increased fears during pregnancy.

> *...I've had bad experiences in the past from non medical people giving, I believe, a bit of gossip. It might be a harsh word but I think you can get the wrong ideas....I have a real loathe - irritation, I don't know how they (magazines) are allowed to print what they do about all sorts of things...I think alot of the stories are incorrect, alot of the information is incorrect and they've created sensationalism for the sake of sales...*
>
> *...but my greatest fear was because I'm a smoker. So everybody sort of scared me and all the things you hear and you read - you know - am I putting my baby that much at risk?*

The issue of lack of informed choice and the impact of this was also raised. One participant, when asked whether she chose to have a vaginal swab for GBS in the recent pregnancy responded:

> *Well, it was recommended. I suppose it wasn't really a choice - my understanding was that the hospital would not let me go any longer* (past the expected date of confinement) *or I would need to sign something...*
>
> *First of all I had them* (routine antenatal screening tests) *because the doctor ordered them...*
>
> *Well I think information is the key basically. Women should have as much information as they can get and then they can choose whether they want to have these tests. But there is certainly a discriminatory element there at a certain age....Once they get past a certain age they're making all these women completely paranoid.*
>
> *I don't feel that they give you enough information. In fact, they say these tests have to be done. If you don't ask that's as far as they go.....even if they say to people that aren't that interested, I think they're not interested because they're intimidated by the fact that oh it's a doctor.....they know what they're doing.*
>
> *There wasn't enough information given. If there had been more information given I wouldn't have been at all stressed and I wouldn't have been worried.*

Another woman described her experience of trying to obtain information in an antenatal clinic as follows:

> *I found him* (the senior obstetrician) *a bit brusque but I can't understand why that would be and felt a little bit intimidated about asking questions...I think that literature could be handed out if there is visits saying what you're being tested for...like what sort of things medically you can expect to have happen and I think if it was written down, I mean it's good to be informed all the way through of what's happening and advanced information is really useful...*

The issue of compliance and trust in the pregnancy care women received was raised by many participants.

> *The doctor just said this is the procedure, go and have this done or go and have that done, so I just did it. I just figured he's the professional, he should know. I guess I'm one of those people that just believes that he knows what he's doing and absolutely trust him 100% - I don't know whether that's a good thing or not....Perhaps the other ones (excluding the ultrasound) I didn't really get a good understanding of what they were for, but again I sort of felt that well it probably didn't really matter if I didn't know. I mean, I was told if there was something wrong with the tests I would find out.*
>
> *...I actually don't know what they were simply testing for when I put in my urine sample every visit...*
>
> *...I would just sort of say well it's like immunisation. It's the accepted thing at the moment. I have to do it unless I'm really well read and I actually know*

> *my facts. I can't argue with you people like you who are doing doctorates and know all the information.*
>
> *I didn't know what they were testing for in my blood and still don't know...and I thought they would tell me if I needed to know.*
>
> *I would have trusted those tests to tell me that everything was going okay....So I don't find them intrusive at all....It didn't bother me at all.*
>
> *You've got to rely on your doctor alot. I mean, even the so called experts. You've got to rely on whether they think you should have it, because they're the ones with the knowledge of whether tests are going to benefit you or the baby.*
>
> *I just take it for granted that that's the way it's done and it's fine. It suits me.*

Some participants with private health insurance who had chosen their pregnancy care provider expressed high levels of trust in their carers having made that choice.

> *I think more knowledge can be a dangerous thing. I spent a lot of time choosing my gynaecologist and obstetrician and I chose him for specific reasons and handed over my faith on the first visit....*

Compliance with antenatal screening appeared enhanced by the view that the tests were 'just routine'.

> *I don't mind doing tests like that* (urine). *It's not really inconvenient....If it was more like I had to go into hospital and they were actually operating, I would like to know a lot more but if all they wanted was a bit of urine you can have it and do what they want with it. It keeps them happy too. Like I said, if it's just a blood test and urine test then it's not really putting me out too much.*

As previously demonstrated, in the utilisation of screening tests, many public patients perceived having had serum screening tests for neural tube defect and Down syndrome when neither of these tests were offered routinely at the Royal Women's Hospital.

Participants' perceptions about the amount of information they received about antenatal screening tests, the process of seeking it and the impact of such information, or lack of it, on their pregnancy raise three important questions related to the potential usage of screening during pregnancy. Firstly, many women refer to the lack of information about the tests, including their reliability and the results. A participant's health insurance status is an important factor in the receipt of information. Therefore, a question arises about how having or not having this information and choice impact on participants' use of screening. Secondly, how is participants' trust in, and compliance with, the antenatal care they receive, including

screening, important in their use of routine antenatal screening tests? Lastly, does the act of offering screening tests as 'routine' in pregnancy make them more acceptable, and therefore more likely to be taken up than other non-routine screening tests? These questions are addressed in the following discussion chapters.

4.5 Perceived value of routine antenatal screening tests

a) How routine antenatal screening tests are valued

Table 4.5 illustrates the perceived value of routine antenatal screening tests as demonstrated by women's responses to a number of questions about screening tests and their use.

Table 4.5. Indicators of how women perceive routine antenatal screening tests to be of value.

Indicator	No.	Percentage
1. Maternal routine antenatal screening tests are valuable or very valuable (n=370)	368	99.5
2. Fetal routine antenatal screening tests are valuable or very valuable (n=371)	365	98.4
3. Routine antenatal screening tests benefit all pregnant women, agree and strongly agree (n=367)	355	96.7
4. Routine antenatal screening tests should be available to all pregnant women agree and strongly agree (n=315)	300	95.2
5. All pregnant women should have routine antenatal screening tests, agree and strongly agree (n=358)	336	93.9
6. The cost of routine antenatal screening tests should not influence whether they are done or not, agree and strongly agree (n=335)	318	94.9
7. More routine antenatal screening tests should be developed, agree and strongly agree (n=370)	182	49.2
8. Would have routine antenatal screening tests in a future pregnancy (n=376)	356	94.7
9. Routine antenatal screening tests helped reduce anxiety during pregnancy, yes mostly and yes completely (n=368)	333	90.5

The majority of participants (99.5%) perceived routine maternal antenatal screening tests to be valuable or very valuable whilst a similar percentage (98.4%) also perceived fetal screening tests including ultrasound, and in some cases serum afp and serum triple test, to be valuable or very valuable. Greater than 90% of participants believed that routine antenatal screening tests benefited all pregnant women, should be available to all pregnant women and that all women should have these tests during pregnancy. Table 4.6

demonstrates that public patients were four times more likely than private patients to believe routine antenatal screening tests benefit all pregnant women and 3.5 times more likely to believe all pregnant women should have routine antenatal screening in their pregnancy.

Table 4.6 Variable associations of perceived value of routine antenatal screening tests (RANST)

Variable	Crude OR	(C.I)	Variable adjusted	Adjusted OR	(C.I)
RANST benefit all pregnant women					
Private	1.0			1.0	
Public	4.12	(1.13-15.56)	Education	3.22	(0.99-10.49)
All pregnant women should have RANST					
Private	1.0			1.0	
Public	3.54	(1.36-9.31)	Education	2.88	(1.18-7.02)
Cost should not influence test use					
Private	1.0				
Public	5.55	(1.8-17.66)			
High occupation	1.0				
Low occupation	3.99	(1.29-12.56)			
More RANST should be developed					
Private	1.0			1.0	
Public	3.95	(1.69-9.28)	Education	3.0	(1.34-6.74)
High education	1.0				
Low education	5.98	(1.64-25.92)			
In paid employment	1.0				
Not in paid employment	3.2	(1.28-8.25)			
High occupation	1.0				
Low occupation	4.2	(1.74-10.16)			
RANST reduce anxiety					
Not told results	1.0				
Told results	7.94	(3.07-20.46)			
Not enough information	1.0				
Enough information	3.39	(1.44-7.92)			
Shouldn't assure	1.0				
Should assure	3.56	(1.42-8.77)			
Maternal RANST are done for benefit of baby					
Private	1.0				
Public	3.35	(1.13-9.99)			

Lower educational levels of women were also associated with these two outcomes (χ^2= 5.30 1df p=0.0129588, χ^2 = 7.5 1df p=0.00617791). Lower educational levels of women and lower age were also associated with the belief that routine antenatal screening tests should be available to all pregnant women (χ^2=22.71 4df p=0.0014, χ^2= 9.61 3df p=0.0221).

Of those participants who believed that all pregnant women should have routine antenatal screening tests, 88% reported the reasons for this belief as being similar to beliefs about the value of these screens to them as individuals (see below). *'If tests are available they should be used rather than leaving "nature" take care.' 'To avoid ignorance and heartache.'* Of those who did not believe or were not sure that all pregnant women should have routine antenatal screening tests, many expressed views about women's right to refuse based on individual or cultural beliefs.

> *Routine tests should be made available to all pregnant women. They should have the right to refuse.*
>
> *I believe it should be the women's choice after they have had the reasons for the tests well explained to them.*
>
> *Tend to disagree because they might create different and sometimes unnecessary anxieties depending on the person; also everyone has different personal/cultural/religious/ethical perspectives.*
>
> *...some women find them invasive and unnecessary and this should be respected.*

A few participants wrote of their concern about the use of antenatal screening tests routinely in all instances.

> *I am concerned about overtesting, as it can suggest that something is wrong. I am sure the need for testing varies according to the age of the woman and the number of pregnancies it is.*
>
> *Testing should be done if indicated ie. if woman or baby is 'at risk'. Some tests are of questionable benefit/limited value.*
>
> *...routine tests keep increasing and there is a duplication and lots of resources which may be more use elsewhere - perhaps there's a conspiracy by pathology labs and companys to create more demand!*
>
> *I am a bit concerned about tests becoming 'routine' because society 'expects' them rather than a genuine medical need. There sometimes appears a spectra of overservicing and a offering of false guarantees.*
>
> *Not all tests are required all the time...*
>
> *I dont think they should be routine - only when symptoms appear.*

In response to a question about how much they thought routine antenatal screens for a pregnant woman cost, 33.7% of participants reported close to the correct amount of between $300-500.[173] 26.9% of women believed the tests per pregnant woman exceeded $500. In

addition, table 4.5 illustrates that the majority (94.9%) of participants believed that how much the tests cost should not influence whether they are done or not. Whilst perception of how much tests cost was not associated with health insurance status, educational level or occupation, public patients were five times more likely than private patients and women of lower occupational level were four times more likely to believe that how much the tests cost should not influence whether they are done or not (see table 4.6).

Whilst 41.9% of respondents were not sure, the majority (49.2%) agreed that more routine antenatal screening tests should be developed. Only 8.9% disagreed with this statement. As table 4.6 demonstrates, public patients were four times and women with low education levels were six times more likely to support the development of more routine antenatal screening tests. Younger age was also associated with the support for more tests (χ^2 = 9.77 2df p=0.02). Not being in paid employment and low occupation level were also associated with the support for the development of more tests (see table 4.6). In addition, 94.7% of respondents said they would have routine antenatal screening tests again in a future pregnancy.

Participants who highly valued maternal and fetal antenatal screening tests were also more likely to believe routine antenatal screening tests benefit all pregnant women, should be available to all pregnant women, all pregnant women should have these tests, that the cost of the tests should not influence the use of the tests and that more routine antenatal screening tests should be developed (χ^2=16.27 2df p=0.000293, χ^2=14.75 2df p=0.000636, χ^2=20.14 2df p=0.000042, χ^2=19.48 2df p=0.00005, χ^2=17.57 2df p=0.00015). How women valued routine antenatal screening tests was not associated with their perception of whether they had received enough information about the tests.

b) Why are routine antenatal screening tests valued

Women's perception of why routine antenatal screening tests are valued was then explored. Table 4.5 shows that 90.5% of participants felt that routine antenatal screening tests helped to reduce anxiety during pregnancy. When asked to list the things that helped to reduce

anxiety during pregnancy, 53.4% of responses included antenatal screening tests. Importantly, women who were told the results of their tests were eight times more likely (see table 4.6) than those not told the results to perceive routine antenatal screening tests to be helpful in reducing anxiety. Women who reported they had received enough information about the tests were also three times more likely to feel that the tests helped in the reduction of anxiety during pregnancy. The ability of routine antenatal screening tests to reduce anxiety was also associated with women's faith or belief in the tests. Women who believed routine antenatal screening tests should assure a normal pregnancy and baby were three times more likely to feel the tests reduced anxiety during pregnancy and women's perception of the reliability of the tests was also associated with this outcome (χ^2 = 21.24 2df p=0.00002445)(see table 4.6). However, ability of routine antenatal screening tests to reduce anxiety during pregnancy was not associated with women's anxiety levels about pregnancy, having an abnormal baby or receiving an abnormal test result.

When women were asked in open-ended questions how routine antenatal screening tests were of value or not a number of themes emerged. The ability of the tests to provide reassurance was a major factor. The responses to the question of how the antenatal screening tests reduced anxiety or not showed that 85.3% expressed some notion of the tests' ability to provide reassurance or peace of mind.

> *...having tests and good results gives you a safe feeling.*
>
> *You are reassured that at least most things are progressing normally.*
>
> *...confirmation that all was going great made such a difference.*
>
> *Although I was never really anxious the tests were a reassurance.*
>
> *With the knowledge that the pregnancy and baby were normal, time flew by and I felt good always.*
>
> *Assured and safe knowing nothing was wrong.*
>
> *...to be reassured that things were progressing normally and I was healthy, so I could relax and enjoy my pregnancy.*

Although the tests' ability to provide reassurance to the pregnancy as a whole was commonly reported, many respondents reported reassurance provided about the health and well being of their unborn baby as being most important.

> *Emotional reassurance for me that the baby was being cared for before he arrived.*
>
> *Absolutely invaluable to myself* (antenatal screening tests) *to be assured I was carrying a healthy baby.*
>
> *I felt peace in mind knowing that my baby was healthy. I would have felt better if I had had all of the tests in section B* (fetal screens).

Some women also reported the positive benefits to their unborn baby of themselves being reassured.

> *If peace of mind can be given, then the mother is less tense, more relaxed. I feel that this must aid baby and the pregnancy.*
>
> *Relaxed pregnancies make happier babies.*
>
> *Relieved - any anxiety that I may had passed onto baby.*

Interviews with participants demonstrated similar perceptions about the value of routine antenatal screening tests.

> *...I felt them reassuring and not a worry. If anything I would have been worse, I would have worried more if I hadn't had those tests.*
>
> *...I'm a real worry wart so it's nice to know, I mean, I kept thinking thing can happen... so it (having the screening tests) was sort of a nice bench mark that when people would say how are things going... The scan was reassuring once I had that, I sort of thought, well you know it's got two arms, two legs and you can sort of see that things look pretty okay and everything is growing, like it's right length. Probably like I said, the results that came back I felt a bit more reassured things were going how they should.*

When one participant was asked her view about the development of more antenatal screening tests she responded:

> *The more they can do the better. I mean, as long as they're 100% sure it doesn't affect the baby, that's great. Just as long as they're sure that these tests are going to provide better and more information and at the same time not affecting the child, that's great.*

Not only did having routine antenatal screening tests provide reassurance but many participants (28.5%) reported feelings of actual relief on receiving the results of their tests. *'Relieved, knowing there was nothing wrong.' 'The results were normal which was a great relief.' 'Relieved, happy - a weight off one's mind.'* In one interview one participant expressed the following:

I mean, while you're going through all these tests you get a bit annoyed and think, 'oh no, not again' but when you get clear results you're quite relieved that you have had those tests.

Many respondents also reported feeling safe and protected as a result of having their antenatal screening tests.

Reassurance for mother and ultimately protection for child.

For the safety and well being of mum and baby.

Protection of fetus during pregnancy.

Protection/indication for active management to protect me, baby and (in case of HIV) medical and nursing staff.

For the safety of your baby these tests should be a must.

Some wrote as if their baby was in danger or peril. *'...they could mean life or death for your child.' 'Mother and child health can be jeopardised if none of these tests are carried out.' 'They allow you to treat a problem or possible problem before the baby is in any danger.'*

Many respondents valued having antenatal screening tests as they gave them information about and a greater insight into what was happening to them during pregnancy.

In a way you know where you stand.

Doctor and mother should have understanding of total/overall condition of pregnancy depending on each individual case.

Gives a general picture of my condition...

If you don't have tests, then you wont know.

So you know what's happening.

It would be terrible to have something wrong and you didn't know about it.

To see what's going on inside.

Because I knew what I had to worry about and what I didn't.

By being informed I felt a little more in control and able to manage.

Others perceived information from the tests as a way of relieving uncertainty or fear of the unknown. *'Knowledge makes me less ignorant, therefore less fearful.' 'Not having to worry about the uncertain.' 'Relieved the "not knowing"feeling.'*

Having information from the screening tests also enabled women to perceive they had choices during the pregnancy, including termination of pregnancy.

> *If a patient is at risk of testing positive in any of these groups then they can make informed decisions about their pregnancy when they get the result.*
>
> *Knowledge is power. The test enables parents to make informed decisions about their impending parenthood.*
>
> *It gives you the choice on whether you would bring a child into the world if you knew it was severely retarded etc.*
>
> *Prewarning of handicap means the option not to continue the pregnancy - or at least the knowledge of what's to come.*
>
> *...Allows you to review your options if something is wrong.*

Some women described the benefit for themselves and their families of being prepared for negative outcomes by having screening tests being performed antenatally.

> *....It allows parents to prepare questions and accept possible problems they may need to confront. Decisions need to be made early.*
>
> *The mother and the family would benefit with early detection of untreatable problems in coming to terms before the birth or considering termination if it was an option.*
>
> *To enable you to prepare for possible future problems.*
>
> *Allow mental adjustment if results are bad.*
>
> *If the baby is found to have either spina bifida or Down's* [sic] *syndrome through mother having an ultrasound I think it can prepare the whole family for any obstacles that arise in the future.*
>
> *...forewarned is forearmed.*
>
> *To prepare parents for the worse.*

Many respondents described the value of antenatal screening tests, in particular a first or second trimester ultrasound performed before fetal movements were identified, in making the pregnancy a reality and in some cases being able to bond with their unborn child.

> *...the ultrasound makes the whole thing very real.*
>
> *...it mentally 'confirms' the pregnancy as resulting in a baby.*
>
> *Ultrasound may be too much guess work but does help mother realise the life inside her.*
>
> *Until then, I didn't believe I was pregnant.*
>
> *I felt I knew baby.*

Ultrasounds (are of value) *as you can see yourself everything is OK.*

Peace of mind, bonding process.

Only two women mentioned the ability to know the baby's sex antenatally as valuable. *'Assessing sex of the child....'*(wanted to know because of family history of haemophilia.) *'Knowing it was a girl.'*

c) Who influenced participants in their beliefs about routine antenatal screening test

After self, the majority of participants (39%) believed doctors and midwives were most influential in their beliefs about antenatal screening tests. The media was reported as being most influential in 4.9% of responses. Many participants wrote about the importance of medical technology and professional skills in the area of antenatal screening. Many felt the findings of the testing to be more reliable than self.

It confirmed that fears were just thoughts in my head.

While there were never outward signs that there was anything wrong the tests seemed to be positive and physical evidence that things were OK.

...was being monitored by experts.

Medicine is advancing everyday, more babies and mothers are surviving childbirth and if testing continues, advances in controlling abnormalities will occur.

A sense of professional assurance that everything was OK.

I was aware of the results, not guessing or imagining them.

These issues were also raised in interviews with participants.

Because the technology is there to detect it (fetal abnormalities) *and because the option is there to have an abortion the yes, the more tests the better.*

One participant acknowledged the role of technology in an otherwise normal pregnancy.

...once all the investigations are done, like, all the testing is done and then finally the baby is born, it's like that doesn't exist anymore - the technology doesn't - the baby's here now.

However, one participant felt she had been let down by 'medicine' during pregnancy.

...there's only a certain point that medicine can go. It astounded me, particularly last year when we lost the baby, nobody could tell us why and everything was perfectly normal. And then it went wrong and no one could tell us why...I felt all through this pregnancy and the last that people have said the doctors have retreated from their medical knowledge, hid behind it, that's to say, it's you we can't fathom, it's not that we don't know these things. It's just that you are an individual and don't react as the normal. I guess that's true to some extent but it's not my fault, it's just the way things are.

And if they had a greater medical knowledge or, I don't know, technology was better, perhaps they would have the answers in general rather than just in my case.

d) Who benefits from routine antenatal screening tests

Of the respondents, 95.2% believed maternal antenatal screening tests are done for the benefit of the baby. Public patients were three times more likely than private patients to hold this belief (see table 4.6). Many respondents expressed the importance of antenatal screening to uphold the rights of the fetus, sometimes over and above the rights of the mother.

All unborn babies should have the same fair chances to rectify any problems.

Tests still should be carried out even when a healthy pregnancy - it's the baby that counts.

...because I think it is the right of the baby to have a good chance at a healthy life.

It is the best care for the baby (having routine antenatal screening tests)*- almost a form of child abuse not to test.*

I believe people should take a more proactive attitude to all health care issues - but especially during pregnancy where you have a responsibility also to another life to give it the best chance possible.

In the interviews, women further explored their beliefs and feelings about their unborn child.

I wanted to stop taking prescribed medication but kept saying to myself, 'just think of the baby

I was always concerned about her. I was much more concerned about her than me. In fact, the weekend before last when I was really sick, I thought if anything happened to me could they save her not me? ...When the first lot of tests came through they said she's not at risk, you are. You are at risk now and we have to deliver her for your safety. And I said, 'oh can't we wait just a little bit longer, can't we go for another one or two weeks?', and they said no - it's just not safe for you any more.

Well I mean, any woman if you ask them truthfully, if there's a choice between their husband and their child, saving one or the other from a wreck - which would they save? I think you'd probably find 99% would save the child. It's that protecting. I don't think there's anything you could get closer to.

Yes I probably feel different (when pregnant)- probably feel proud of myself. I mean I shouldn't.

Whilst the majority of respondents reported routine antenatal screening tests to be of value to themselves and the fetus a few also raised the question of the value of such testing to others.

> *Seems to be done more for the hospital data bases than for benefit of parents.*
>
> *Protection/indication for active management to protect me, baby and (in case of HIV) medical and nursing staff.*
>
> *To help other women in pregnancy.*
>
> *So the doctor can have a clear view on how the pregnancy is getting on.*

Only a few participants raised questions of conflict between their individual rights and benefits and the rights of others in the society. *'Some tests should be compulsory, especially to make sure mothers health is good. But how can I have my rights if I expect to take away another mothers?'*

e) Impact of the results of routine antenatal screening tests

When participants were asked how the results of the antenatal screening tests made them feel only 12 out of 344 respondents (3.4%) expressed any negative feelings about being tested. The majority expressed positive feelings including relief and reassurance. Of those who expressed negative feelings the commonest factor was anxiety.

> *Some worried me ie. the ultrasound because it looked strange and they can't say everything is OK. Also they tried offering extra tests eg.urine - you start to think you should have them 'just in case'.*
>
> *Nervous because of previous experiences, although very worthwhile.*
>
> *Finding out I was Rh neg scared me a little as I didn't fully understand what it meant...*
>
> *Results made me concerned at times, as baby was smaller than she should have been for the term.*
>
> *..Some results created anxiety.*

Other negative responses included:

> *I became depressed only when I was told the sex of the child during the ultrasound.*
>
> *Fine except Gestational Diabetes - had to leave the Birthing Centre etc.*
>
> *...mildly annoyed at positive vaginal swab for GBS since this increased likelihood of having to have an induction again.*

Interviews with participants further highlighted some of these negative feelings and experiences with antenatal screening tests.

> *...But the one thing in the whole pregnancy that made me very very angry was that I was admitted and discharged and then sent downstairs to have my glucose test because it was around the right time, about 28 weeks, to have it. And the doctor came down, "you know I'm really glad I found you, (this is in the waiting room) Oh, we've just had your results back and you've got an infection and we need to do this and that". It was all very quick. It was done in front of a whole lot of people. Everyone could have heard in the waiting room and I was absolutely mortified. Normally I'm usually pretty assertive and can speak up for myself but like, she didn't give me enough information and I was very angry about that....I think that's been my only negative experience throughout the whole of this pregnancy. That was very disappointing and that should not happen. I think if you're going to be given test results you need them in confidence.*

> *...I came here and had the glucose tolerance test done and it was positive, it was just over - I don't know - I think the cut off point is 8 and mine was 8.7. So then I was classified as gestational diabetic which I query because every test that I did after that was well within the limits and as a result, of course, my baby had to get pricked in his heel. And he had to be pricked every 3 hours to find out his blood glucose level. So I'm dubious, I'm not sure about that test being done.... So I query that test being done and it seems to me that a lot of people have just been in the ward here - a lot of women are gestational diabetics.*

> *I think it is a myth that we all have about, oh yes you'll be fixed. Everything's right or wrong, there's no grey area so you don't think you'll get a test back and find out that a mistake has been made. You feel personally that you have been neglected. It's a strange sensation - you almost want to go and blame someone for making a mistake, which is silly. ...It was the weirdest feeling (having a screen for HIV) and you did feel a bit unclean... I do get concerned about overtesting I've known of other women who I think have had a test every second or third week for what I don't know. And they're almost convinced something's wrong because they're having all these tests.*

Another participant expressed concerns about the impact of being offered antenatal screening tests during pregnancy.

> *He said that there was a certain miscarriage that can be associated with it (maternal age greater than 35 years) but it was possibly at that point that I started thinking maybe he thinks there's something not right that made me feel along those lines, maybe. It was only after I'd been to the doctor that I spent the rest of the time concerned that something might be going to go wrong.*

Less than half of one per cent of participants expressed doubt about the value of routine antenatal screening tests.

> *I only had the ultrasound but it didn't tell me anything I didn't already know.*

> *If nothing can be done I'd rather allow nature to take its course.*

If there is anything wrong with the baby during your ultrasound you have to carry the worry all throughout your pregnancy.

...doesn't seem very valuable but I was made to feel it was important to check things out generally and if I said no, I was taking a risk. It may give people pressure to be tested/terminate when they are not happy.

They only diagnose things which can't be prevented - only as good as the person interpreting the material.

..I think to place too much emphasis on tests is giving people a false sense of certainty in an uncertain life.

Participants' perceptions about the value and utilisation of routine antenatal screening tests demonstrate that these tests are valued highly by the majority of pregnant women who receive them. These results suggest that use of these tests is closely related to their perceived value. Indeed, greater use of routine antenatal screening tests is supported by participants' desire for more tests. Why are public patients and women of lower education more likely to value these tests and support the development of more tests with broad availability? Examination of participants' responses to why the tests are valued, who benefits from the tests, and who influenced them in their perceptions about testing offers a more complex representation of the issues and values that underlie the use of antenatal screening is apparent. In particular, issues such as the ability of the tests to reduce anxiety, provide reassurance and relief and provide safety and protection are related to pregnant women's perception of risk. The ability of the tests to provide bonding for some participants with their fetus and the lack of expressed negative experiences of testing by these results raise issues about the role of medicine and technology in antenatal care. Participants demonstrated a high reliance on medical technology in antenatal care to provide reassurance and safety during pregnancy. Similarly, participants perceived medical professionals to play an important role in the formulation of their values in relation to antenatal screening.

The belief that the fetus is a major beneficiary of antenatal screening tests, including the maternal screens, and the ability of women to endure negative experiences of testing raises questions of how the fetus is perceived by pregnant women. Is it a person? Does its existence come into conflict with the pregnant women? In addition, participants' strong support for antenatal tests and more antenatal tests and their availability to all pregnant women regardless of the cost raises issues of the rights of the individual and the community

to such medical technologies. How then do these underlying issues impact on participants' use of routine antenatal screening tests? These issues and the role they play in the utilisation of antenatal screening tests will be discussed in chapters 5 and 6.

4.6 Expectations of routine antenatal screening tests

Table 4.7 illustrates participants' expectations of routine antenatal screening tests. A total of 98.1% of respondents believed routine antenatal screening tests to be mostly reliable, very reliable or perfect, while 3.8% perceived the tests were perfect.

Table 4.7. Women's expectations of routine antenatal screening tests

Expectation	No.	Percentage
1. Reliability of routine antenatal screening tests		
(n=370) Perfect	14	3.8
Very reliable	178	48.1
Mostly reliable	171	46.2
Minimally reliable	6	1.6
Not at all reliable	1	0.3
2. Routine antenatal screening tests should assure a normal pregnancy and a normal baby, agree and strongly agree (n= 342)	298	87.1
3. Routine antenatal screening tests are a necessary part of a normal pregnancy (n=370)	332	93.8

Belief about the reliability of the tests was associated with women's perception about the amount of information they were given about the tests (χ^2 = 7.87 3df p= 0.04868), in particular being told what tests would be done (χ^2 = 10.23 3df p=0.01672), and being told the reliability or not of the tests (χ^2 = 12.18 3df p = 0.00678). There was no association with health insurance status or educational level.

Interviews with participants also demonstrated that routine antenatal screening tests are perceived as being highly reliable.

> *I just automatically thought that they were reliable.*
>
> *I suppose because they've always come back normal or around that range that I assume that they were an accurate test because nothings gone wrong with them.*
>
> *I didn't doubt that they were reliable at all. I trusted them completely.*

When participants were asked if they would have an antenatal test that wasn't 100% reliable many felt that may alter their choices.

> *No, I don't think I would. Because it wasn't 100% accurate it might cause more concerns giving you a wrong answer and you would have that stress through the pregnancy worrying about it...*

> *No, I don't think so. I don't think you should go through the expense of having them if they're not reliable. It's better to have something you know for sure, not just wasting time....We should be 100% sure that what we are testing is accurate. Not just taking a chance. I want to know 100%. I don't want to take chances or guesses.*

Table 4.7 also shows that 87.1% of participants believed that routine antenatal screening tests should assure a normal pregnancy and a normal baby. Table 4.8 shows that public patients were four times more likely and women of lower education level were three times more likely to believe antenatal screening tests should give this assurity. Age of the respondent was also associated ($\chi^2 = 22.32$ 3df p=0.00005) with this belief. One participant, when asked what she thought antenatal care might be in 50 years time responded:

> *In 50 years we'll be able to stand on something and it will go 'zip' and tell us everything. They should be able to have everything perfect.*

Table 4.8 Variable associations of expectations of routine antenatal screening tests (RANST)

Variable	Crude OR (C.I)	Variable adjusted	Adjusted OR (C.I)
RANST should assure a normal pregnancy and baby			
Private	1.0		1.0
Public	4.06 (2.0-8.25)	Education	3.57 (1.84-6.93)
High education	1.0		
Low education	3.10 (1.19-8.55)		
RANST are a necessary part of normal pregnancy			
Private	1.0		1.0
Public	2.95 (1.13-7.7)	Education	2.4 (0.99-5.84)
High education	1.0		
Low education	10.26 (1.42-211.08)		

The majority of participants (93.8%) also believed that routine antenatal screening tests are a necessary part of normal pregnancy (see table 4.7). Again, public patients and women of lower educational level were three times and 10 times respectively more likely to accept this view(see table 4.8). Women who perceive routine antenatal screening tests as a necessary

part of normal pregnancy are also likely to believe these tests should assure a normal pregnancy and baby (χ^2 = 25.08 1df p = 0.0000577). Interviews with participants also demonstrated the widespread acceptance of antenatal screening tests as part of a normal pregnancy.

> *Yes, I accept them as part of the course.*
>
> *Well I don't know if you ever really have a normal pregnancy...I mean, you can't really. I would sort of say, well it's like immunisation, it's the accepted thing at the moment. I have to do it unless I'm really well read and I know my facts...*

Two recurrent themes that arose from participant responses about expectations of routine antenatal screening tests were firstly, the ability of the tests to confirm or even determine health and well being of the pregnancy, mother and baby and secondly, the ability of the tests to detect abnormality with the view, in many cases, to be then offered appropriate treatment. When participants were asked how they thought the tests did or did not benefit themselves or their baby, 53% of the responses included positive comments about the ability of the tests to confirm normality whilst 57% of responses included negative comments about the ability of tests to detect abnormality. Participants expressed positive expectations as follows:

> *Make sure baby is growing and coming along as it should.*
>
> *Establish normality of the fetus.*
>
> *Establishing my baby's health.*
>
> *That things were normal for myself and baby.*
>
> *All was within normal limits.*
>
> *That everything was how it should.*
>
> *That I was healthy and would produce a healthy child.*
>
> *Everything will turn out fine.*
>
> *...that my baby was coping with pregnancy...*
>
> *Just that my baby is safe and healthy - so it can enjoy its life.*
>
> *Health and well being of my child/growth and development. Not knowing hurts.*
>
> *That the child would be healthy and 'normal' to give it the best start in life.*

They (the antenatal screening tests) *benefit me by letting me know what is going on and that way I know everything is well.*

In the interviews, one woman, whilst expressing positive outcomes, also raised the notion of 'blind faith' in these outcomes when antenatal screening is not available.

You can assume that if you become pregnant that your baby will be alright. With our first, scans weren't around or they were just coming in. That pregnancy was a blind faith and in some regards that's easier and in another regard it is nice to see the picture of the healthy growing baby and having the specialist tell you everything was fine and everything was developing the way it should.

Not only were the tests perceived valuable in confirming normality or health but the tests were also expected to ensure or determine a normal outcome. Participants wrote:

Determine mothers and baby's health during pregnancy.

They are necessary for the health of myself and the baby.

Ensure mother/baby's health.

...they'd determine the condition of the baby and how well the pregnancy is progressing.

They ensure the baby's health is well and its progress is normal.

To determine baby's future.

To ensure that the aim of delivering a healthy baby is achieved.

Am I healthy - is the fetus healthy - what can I do with the information gained from the test to ensure the best possible outcome for everyone?

...and I felt satisfied that eveything has been done to have a normal pregnancy.

Gives mother and baby maximum chance of a healthy pregnancy.

Few women expected the tests available currently would confirm a 'perfect' baby. *'That everything was perfect.' '...that she was perfectly healthy...' 'That all was perfect with me and my baby.'* However, when asked what they would like a test to be able to tell them in the future, 30 out of 311 respondents (9.6%) expressed some desire for a perfect outcome.

100% good health in full body functions.

Baby was going to be 100% OK.

That would be a good test! The ideal crystal ball would, I guess, tell me I had a perfectly normal child.

A test to give a guarantee of brain function.

That the baby would be perfectly healthy.(Rich, good looking and successful!)

That everything is perfect in every way about the baby.

That my baby was perfectly normal (internally and externally)

A guarantee that your baby would be born perfectly.

Participants expressed negative expectations of the tests as follows:

Pick up problems that may be overlooked/not detectable by a doctor.

If my baby was under any risk of abnormality or other health problem.

Any abnormalities or danger to baby...

To make sure my baby was in no danger before the birth.

Disorders, deficiencies, safety/health of baby.

...whether my health was affecting baby's development.

To detect any abnormalities/deficiencies that could effect mother or baby during pregnancy and when baby is born.

They cover every possible problem that may occur in pregnancy.

...they allow early detection of any abnormalities in the fetus and the mother.

Detecting any problems that may harm you or your baby.

Every parent wants/needs to know if any possible complications or illnesses that may effect their unborn child....

....the implications are serious ,if not done....

Interviews with participants demonstrated similar expectations.

Well you have to be told in the beginning don't you? If they didn't do screens on your blood and stuff like that, and urine or whatever, then they wouldn't be able to detect early in the pregnancy if there was a problem.

Inherent in many expectations that the tests could detect potential problems or abnormalities, were also expectations that related treatment options are available.

If mum's not well she can take appropriate measures to improve her condition and therefore baby will be better off.

I think having tests done and as many problems/complications eliminated as possible would ensure everything has been done for mother and baby.

...if any or all tests come up negative appropriate treatment can be taken.

To treat problems before they get out of hand.

If for example either showed HIV, I would like to know so I could deal with it and decide on treatment.

If tests are positive appropriate treatment can be administered so to help both mother and baby.

To allow prevention of complications.

Prevention of abnormalities in babies.

...and if anything was wrong it would have to get fixed.

In some instances, participants recognised that such solutions may include termination of the pregnancy.

You can find out if anything is abnormal early enough in your pregnancy to opt for termination if required.

It gives you the choice on whether you would bring a child into the world, if you knew it was severely retarded etc.

They help to show any abnormalities in the baby so you can be better prepared at birth or if you believe in abortion - to abort an abnormal fetus.

...giving parents time for a termination if things are abnormal.

To give prior knowledge of a problem is good - then it can be decided whether or not to keep the baby.

Whilst the tests were expected to confirm normality or detect abnormality in the pregnancy, mother and baby the majority of responses directed their concerns at the well being of the baby. When participants were asked, if there was one safe test in pregnancy that could tell them anything they wanted to know about their pregnancy, only 7% of responses expressed wanting knowledge about the mother's health. *'To check overall well being of mother.' 'A test that would specifically state that mother and baby would be totally healthy by the end of the pregnancy.' '...the mother maintains well being.'*

Other expectations of routine antenatal screening tests from the participants included ability of the tests to provide information about the pregnancy, reassurance, relief, safety and protection, choices and preparation for potential abnormal outcomes. These issues are demonstrated in 'why routine antenatal screening tests are valued' above.

One participant believed the process of partaking in antenatal screening to be a way of removing some of the responsibility for maintaining a healthy pregnancy from herself, and thus avoid blame in the event of adverse outcomes. *'Confirmation that things were probably*

OK and to some extent an alleviation of responsibility. ie I did everything asked so if any problems, I can't be blamed for refusing tests.' Few participants had minimal or no expectations of routine antenatal screening tests.

> *I didn't expect to find out anything really. It was more that they're routine.*
>
> *Nothing!*
>
> *Personally they make little difference unless knowing ahead of time of problems helps in acceptance or treatment. If nothing can be done, I'd rather allow nature to take it's course.*

Participants' expectations that antenatal tests are reliable, assure and ensure a normal pregnancy and baby and are a necessary part of a normal pregnancy raise issues of the extent of trust in, compliance with, and reliance on medical technologies and expertise. In addition, what is the impact of offering antenatal screening tests to these largely healthy women who demonstrate fears and even expectations that the tests will detect abnormality? Many participants demonstrated a belief that a termination of pregnancy would be available in the event of an adverse finding. Does the perceived availability of this process affect participants' utilisation of screening? Chapters 5 and 6 explore these issues and their impact on the utilisation of screening more closely. Chapter 7 also discusses potential implications of mismatch in expectations between consumers and providers of antenatal care.

4.7 Perceived fears and anxieties about pregnancy and outcomes

a) Risk perception

Tables 4.9,4.10 and 4.11 illustrate participants' perception of the risk of adverse pregnancy and birthing outcomes, and their own anxieties in relation to these. The majority of participants (34.5%) believed the risk of giving birth to an abnormal baby in Australia to be as low as one in 1000. Of all the participants, 87.1% perceived the risk to be one in 100 or less. Participants of lower educational level were nearly three times more likely, and those of lower occupational level were 3.5 times more likely than women of higher education and occupational level to perceive the risk of having a abnormal baby as being 5% or greater (see table 4.10). Lower age of participants was also associated with perceived risk of this outcome. Perception of the risk of having an abnormal baby was not associated with health

insurance status, parity, whether or not the participant knew anyone who has had an abnormal baby or their anxiety about having an abnormal baby themselves.

Table 4.9. Women's perception of the risk of having a baby with an abnormality

		No.	Percentage
Risk of having a baby with an abnormality			
(n=333)	1 in 1000	115	34.5
	1 in 500	82	24.6
	1 in 100	93	27.9
	1 in 20	27	8.1
	1 in 10	16	4.8
Felt anxious about having a baby with an abnormality, sometimes and a lot (n=367)		242	65.9

In contrast to this, 65.9% of participants reported being sometimes or a lot anxious themselves of having an abnormal baby. Participants most commonly described 'abnormal' as disability or handicap (53.4%) (177 of 331).*

Intellectual or physical disability.

Physical defects, long term diseases, mental defects...

They fill me with terror - I would consider the words to mean either mental or physical disability.

...someone who can't function it's own body properly and needs assistance.

A baby who cannot, once grown, totally look after themselves whether dependent on other humans or mechanisms eg hearing aids etc.

Gross physical/mental retardation preventing social interaction in later life.

Physically or mentally handicapped.

Another 22.6% of participants described general, non specific states of illness, disease, or 'something wrong' as conditions brought to mind by the word 'abnormal': *'Baby that has physiological/medical problems.' 'Any sort of illness that needs special attention and care.' 'A baby who will not be born healthy.' 'Something wrong.' 'Diseased requiring treatment after birth....'* Another 22.4% of participants described 'abnormal' in relation to a deformity

* The following per centages are described in text form.

or developmental problem. *'Not formed properly.' 'Any deformities such as hair lip, spina bifida etc.' 'When a baby has failed to mature completely ie in one way or another.'* Many made particular reference to missing limbs. *'No hands, retardation, missing limbs, heart malformations...' 'A baby that hasn't developed properly before being born. ie. missing limb.'* A further 14.8% of participants described abnormal as meaning genetic abnormalities of which Down syndrome was most commonly reported. *'Genetic or chromosomal disorders which disallow for normal functioning.' '...or the genes are out of wack.' 'Something wrong with it like Down's* [sic] *syndrome etc."*

Only 17 respondents expressed concern about a possible abnormality in relation to its impact on the life of the child or the carers.

> *One which has extreme special needs which means restriction/exclusion from main stream school structures eg. school. Socially imposed exclusion in a society that over glorifies the 'norm' and low burden, 'achieving' individuals that 'pay their own way'.*
>
> *Abnormal means to me physical/mental problems of a serious nature in that they will impede or disrupt a child's life greatly.*
>
> *When a child has a disability which is going to hold it back in some major way from doing the things that other children can do, or stop it from leading a 'normal' lifestyle. Lack of independence.*
>
> *Having disability that effects quality of life.*
>
> *A baby born with a disease or condition making it more dependent on its carer.*

A few participants responded to the question with feelings that the words 'abnormal baby' provoked. *'Fear' 'Hard work!' 'Distress'.* A few participants raised concerns about the words 'abnormal' or 'normal'.

> *I don't believe that there is such a word as abnormal used to describe a baby.*
>
> *...something that I didn't expect.(because abnormal to me could be normal for someone else. It depends on you - the mother.)*
>
> *What is normal?*
>
> *I'm not sure. I had my first baby at 30 weeks which was 2 pound with a bowel obstruction but I wouldn't call that abnormal. (it's not normal though)*

Primiparous participants were 1½ times more likely, and those that knew of someone who had had an abnormal baby were two times more likely, to have expressed anxiety about the chance of having an abnormal baby during their recent pregnancy (see table 4.10).

Table 4.10 Variable association with risk perception

Variable	Crude OR (C.I)	Variable adjusted	Adjusted OR (C.I)
Risk of having an abnormal baby is 5% or greater			
High education	1.0		
Low education	2.75 (1.35-5.62)		
High occupation	1.0		
Low occupation	3.72 (1.2-12.88)		
Anxious about having an abnormal baby			
Multiparous	1.0		
Primiparous	1.63 (1.03-2.6)		
Doesn't know someone	1.0		
Knows someone	2.21 (1.36-3.59)		
Anxious about having an abnormal test result			
Believe to be common	1.0		
Believe not common	2.6 (1.64-4.33)		
Know someone with abnormal baby			
Public	1.0		1.0
Private	2.46 (1.44-4.21)	Age	1.85 (1.07-3.19)
High occupation	1.0		
Low occupation	0.4 (0.22-0.71)		

One participant expressed the following.

> *I suppose I was worried more about will it* (the baby) *be okay, is it going to survive? Then everything went okay with the first pregnancy so I was more reassured the second and third time round. I think the second time around I was concerned a bit but the third time round even less.*

Anxiety about having an abnormal baby was not associated with health insurance status, educational level, occupational level or age of the participants.

More than half (52.5%)* of the participants also reported feeling anxious sometimes or a lot that their pregnancy would be abnormal. Anxiety about having an abnormal pregnancy was not associated with the health insurance status, age, parity, educational level or occupation

* The following per centages are described in text form.

of the participants. The majority of participants (47%) (130 of 277) reported 'abnormal pregnancy' as meaning a pregnancy with complications.

> *A pregnancy that doesn't run to the 'text book' and may include problems such as excessive bleeding, pre-eclampsia, preterm labour.*
>
> *Any condition that induces risk to maternal or fetal health.*
>
> *Pregnancy with disease of some sort, alot of physical troubles.*
>
> *Not to term or complicated by my health.*

Many women, in particular, mentioned complications that would place the fetus at risk. *'A pregnancy which can result in or cause abnormalities in the baby.' 'Survival of the baby is at risk, death of baby.' 'Problems with my health which jeopardise outcome for baby.'* Thirty per cent of participants reported non specific differences in pregnancy as representing an 'abnormal pregnancy'. *'...a pregnancy that is difficult and things go wrong.' 'Strange, not same as others.' 'Sick and unhealthy.' 'Not within the range of a normal pregnancy...'*

Thirteen per cent of participants reported the need for medical intervention or hospitalisation during pregnancy as representing an 'abnormal pregnancy'.

> *Lots of drugs and treatment are needed to keep you going.*
>
> *...antenatal stay at hospital.*
>
> *Requiring medical intervention.*
>
> *Requiring extra tests, examinations, drugs.*
>
> *A pregnancy where outside intervention is required for safety of mother and baby.*
>
> *In hospital for the 9 months and not carrying on normal duties.*

One participant expressed an abnormal pregnancy as being one in which she could no longer use the birthing centre. Another reported, *'Dying through it.'* Only a few participants reported not being conscious of the potential for abnormalities in pregnancy or non- acceptance of the term.

> *I never thought about that because I had such a text book pregnancy.*
>
> *There is no such thing as abnormal pregnancy or baby.*
>
> *I have never considered the term 'abnormal pregnancy'. I have only ever thought of the baby as the result.*

Every pregnancy is different...

I don't think there is a 'normal' pregnancy but hopefully a safe and healthy pregnancy.

Table 4.11 illustrates that 53.3% (185 of 347) of women perceived the incidence of receiving an abnormal test result during pregnancy to be not common or rare.

Table 4.11. Women's perception of the risk of having an abnormal test result

		No.	Percentage
Risk of having an abnormal test result (n=347)	Rare	20	5.8
	Not common	165	47.6
	Common	154	44.4
	Very common	8	2.3
Felt anxious of having an abnormal test result, sometimes and a lot (n=366)		223	60.9

Perception of the incidence of receiving an abnormal test result was not associated with the health insurance status, age, parity, educational level or occupation of the participants. Despite this finding, 60.9% (223 of 366) of participants reported being sometimes or a lot anxious they would receive an abnormal test result. Anxiety about receiving an abnormal test result was not associated with the health insurance status, age, parity, educational or occupational level of the participants. Nor was this outcome associated with the perception of how much information was given about routine antenatal screening tests, being told what tests and why the tests would be done, or being told the results and the reliability of the tests. Participants who perceived the likelihood of receiving an abnormal test result to be common were two times more likely to be also anxious about this outcome for themselves (see table 4.10).

Participants who reported feeling anxious that they would have an abnormal baby were also more likely to be anxious about having an abnormal pregnancy ($\chi^2 = 264.04$ 9df p=0.00000) and receiving an abnormal test result during pregnancy ($\chi^2 = 265.82$ 9df p=0.0000).

b) Range of fears

Responses to open-ended questions and interviews further demonstrated that the participants experienced a wide range of fears and anxieties during pregnancy. Participants, as expected, generally expressed similar fears and anxieties of their own as those they believed pregnant women in general would have. More participants, however, were likely to comment on issues such as alteration to body image and effects on lifestyle, relationships and work from pregnancy effecting them individually rather than them being perceived as generalised concerns for all pregnant women. Such responses included:

> *...weight gain, unattractiveness to husband, emotional changes.*
>
> *How to manage work with fatigue and sickness. Discrimination in the workplace.*
>
> *How we'd be as a family...*
>
> *That the child could have some handicap that would make life for the child, siblings and parents difficult.*
>
> *...change of life. What sort of parent will I be?*
>
> *The dynamics within my immediate family. Being able to cope. Loose weight afterwards.*
>
> *Leaving my son and husband.*
>
> *Stretch marks.*
>
> *...my changing shape.*
>
> *...what will happen to my body - would I be OK afterwards. How will I cope if anything is/goes wrong?*

As illustrated in table 4.12 the most commonly reported response (55%) raised concern

Table 4.12. Pregnant women's most common fears *

(n=354)	Percentage
Health, normality, well-being of the baby	55.0
Disability, abnormality of the baby	26.0
Labour and delivery	21.1
Loss of the pregnancy/ baby	14.4
Inability to cope post delivery	3.3
Effects of maternal behaviour on the pregnancy	1.9

* Responses were to an open-ended question. Many women gave more than one response

about the health, well being or normality of the baby, using positive expressions.

That the baby is well and developing normally.

The safe delivery of a live healthy baby.

That everything is right with the baby.

That the baby is alive and OK.

Whether their baby will be born healthy and normal.

I did worry about everything being right with the baby.

Whether she would be alright and normal like my other children.

Twenty-six per cent of responses expressed concerns about the likelihood of disability or abnormality of the baby, using negative expressions.

Abnormalities in the baby.

Baby with disability, handicap, abnormal build.

Born 'less than healthy'.

Undetected abnormality.

That she'd be brain damaged or something like that, or spina bifida or things like that. I couldn't wait to get to the 18 weeks so that they could detect it. I couldn't wait for them to do the ultrasound.

The third most common fear was related to labour and delivery (expressed in 21.1% of responses) and involved concerns about:

...complications ie cord tied around neck, emergency caesarian.

Epidural, stitches.....contractions.

...If I could handle the pain and the experience of the labour and birth.

Labour - how long it's going to be and how much pain they'll suffer.

Delivery complications.

The pain of labour and it's effects - excess weight, stitches etc.

Of the respondents, 14.4% perceived that pregnant women were fearful of losing the baby during pregnancy and after. *'Everything - cot death, stillborn.' 'Of losing their child.' 'Threat of miscarriage.' '...will it be stillborn, will it survive labour?' 'Doing too much and losing it.'* Many participants expressed fears about the effects of maternal behaviour during pregnancy on the fetus.

That they (pregnant women) *will do damage to their baby if they do or don't do certain things.*

Will the baby be healthy -eg. the time you took medication, had a fall, got drunk etc. before you knew.

If they (pregnant women) *are doing the right things, eating properly.*

Making sure you do everything possible for your baby eg.eating (diet)

That she not hang out on methadone.

That I may have done something/not done something which would harm my baby.

Some participants expressed fears for their child's future. *'The child's future health and welfare.' 'Coming into the world.'* Others expressed fears about uncertainty and the unknown. *'...Not knowing what to expect.' '...the unknown too.' 'The "fear of the unknown".' 'I probably stopped worrying for about three hours after the birth and then I start worrying again.'* Other fears included the possibility of the baby being born prematurely, whether or not they would be good parents, being sick or incapacitated during pregnancy or what sex would the baby be and what would it look like.

c) Origins of fears

Table 4.13 demonstrates that the origins of and bases for participants' fears in pregnancy are varied.

Table 4.13. Perceived origins of fears *

(n=299)	Percentage
'Word of mouth'	19.0
Previous experience	16.7
Normal or 'human nature'	15.0
Knowledge/information	15.0
Exposure	11.7
Reading material	9.0
Media	9.0
Lack of knowledge	7.6
Health care professionals	5.0
Imagination	3.6
Technology	2.5

* responses were to an open-ended question. Many women gave more than one response

The most commonly identified origin was 'word of mouth' (57 of 299). Participants wrote:

> *Lots of people telling horror pregnancy/labour stories. In society, it's as though women are vocal to tell you their bad experiences rather than their good.*
>
> *Things you read and hear in everyday life.*
>
> *By speaking to other women.*
>
> *Stories and research ie labour is painful from friends and family.*
>
> *Horror stories from other people with babies complaining about things going wrong.*
>
> *Listening to people.*
>
> *Hearing tales of other deliveries and complications.*

Two participants at interview described the following:

> *Yes, I've had bad experiences in the past from non medical people giving, I believe, a bit of gossip (might be harsh), but I think you can get the wrong ideas. That either you're not being looked after because this doctor's doing the tests every two months or that maybe your doctor doesn't know what they're doing because they're not doing the tests every two months...*
>
> *...but my greatest fear was because I'm a smoker. So everyone sort of scared me. And all the things you hear and you read, you know, "am I putting my baby that much at risk?"*

In addition, 53.4%* of participants, on direct questioning, reported knowing someone who has had an abnormal baby. Private patients were two times more likely to know someone who has had an abnormal baby (see table 4.10). Increasing maternal age was also associated with this outcome (χ^2 = 22.48 3df p=0.000518). Participants of lower occupational level were half as likely to know someone who has had an abnormal baby (see table 4.10). When participants were asked generally how they thought their fears had come about, 11.7% reported having had some exposure to children with abnormalities through the community, family or friends.

> *People seem to be having abnormal babies fairly frequently, so often in back of your mind.*
>
> *I have a brother with a mental disability so am acutely aware of problems of raising such a child.*
>
> *...from working with physically and intellectually disabled people.*
>
> *Through seeing mothers not cope, and abnormal babies.*

---

* The following per centages are desribed in text form.

Close friend had a Down's[sic] *child.*

I am 36 yrs old and work in genetics, molecular biology and immunology.

Knowing two of my friends had lost their babies because of problems.

Previous midwife in type 3 hospital, hence exposure to at risk patients.

There are a lot of people out there who are not able bodied. No parent wants that for their child/children.

...seeing disadvantaged children.

Two participants at interview expressed the origins of their fears as follows:

> *These days we hear more about the babies born with problems. In the old days these babies were kept out of sight. Whilst I think integration of these children into schools etc. is fantastic I feel people are more aware of just how many babies are born with problems. I know that with the tests we now have, fewer children are actually born with problems.*
>
> *So I guess it's what you've been exposed to in your jobs or your life with what you worry about.*

In addition, 22.6% of participants demonstrated the role of having both 'too much' information and also not enough information in the generation of their fears and anxieties during pregnancy. Some participants expressed the following about the role of knowledge.

> *Just knowledge of what can go wrong in the womb and with children with chronic problems.*
>
> *Being aware that abnormalities and complications do happen and it's God's grace to have a healthy and normal baby.*
>
> *Increased education and knowledge...*
>
> *Because I was on methadone and there is a chance that the baby may hang out.*
>
> *Through my own selfishness, never again. (on methadone)*
>
> *From awareness of risks.*
>
> *Knowledge of fetal abnormalities...*
>
> *Because it's fairly common knowledge that if you use drugs they could effect the unborn child.*

Sources of acquired knowledge about pregnancy and birthing outcomes, demonstrated by respondents, were varied. Whilst reading material was the most commonly reported of these, media influence and information from health care professionals were also reported as origins of their fears during pregnancy. *'Too much reading.' 'So much information and a lot of scare tactics on what you should and shouldn't do.' 'Reading about all different problems*

that can happen during pregnancy.' '...developed through reading of popular and professional literature.' The media was also noted to have played a role.

> *...exposure to media 'horror' stories over the years.*
>
> *Hearing and reading things in the media about families who have had difficulties with unhealthy children.*
>
> *Media talk...*
>
> *We hear lots of diseases (unknown) in TV and media.*
>
> *Media coverage of severe abnormalities.*
>
> *Media influence about smoking, drugs, alcohol. Media hype...*
>
> *...media stories that highlight particular conditions.*

One participant at interview described her experience of the media:

> *...it had been in the press and it had been in the Woman's Day. You know, great big front page at the newsagency. So I knew from the media that IVF programs would be strictly scrutinised because of the chances of HIV...I thought the question about magazines was a good one. I have a real loathe, irritation. I don't know how they legally are allowed to print what they do about all sorts of things. I mean, I know women who actually rely on these magazines to fix their marriage, or how to garden by the astrology or something like that. They say, 'oh, it's just a bit of fun'. I think, 'no', it's dangerous fun because what happens if it doesn't work or you've put a lot of emphasis on it? And I think a lot of the stories are incorrect. A lot of the information is incorrect and they've created sensationalism for the sake of sales and that really gets me angry and therefore, on principle, I won't buy one.*

Participants wrote that advice from health care professionals was also effective in the generation of fears.

> *For me doctors have been very pushy about the more serious tests and the implications of having or not having them.*
>
> *...Talking to different doctors.*
>
> *Doctors not explaining or taking the time. Just generally putting you in the same category as everyone else.*
>
> *Seeing different doctors and getting different information.*
>
> *Staff of hospital always talking about 'big' diabetic babies.*
>
> *From being asked to keep a check on fetal movements.*
>
> *Doctors saying things about you.*

Previous pregnancy experiences were included as the basis for their fears in 16% of responses. *'I had a baby die at 11 months due to an accident at home and lost all my self*

esteem.' 'From previous poor obstetric history.' 'First hand experience.' 'Losing a child at 17 months.' ' Feeling that I have tested my luck too far by having an 8th child.' One interview participant commented that:

> *I'm a lot more anxious. I expected this pregnancy to go the same as the last and I waited the entire pregnancy for things to go wrong. And it did go wrong but I thought it would go wrong a little bit later. I thought I would probably get to about 35 weeks and it wouldn't be the drama that it was. I expected my body to give up somewhere along the line.*

Fifteen per cent of written responses to an open-ended question about the origin of participant's fears expressed fears as a natural component of a pregnancy.

> *Just normal fears about doing something you've never done before and something so amazing and special.*
>
> *I think some concern about it is natural and unavoidable despite best testing possible.*
>
> *It is part of having a normal healthy fear to question. Having a baby means not knowing, not being in total control, given environmental, age and modern day pressures most mothers to be experience some fear.*
>
> *Normal maternal instincts.*
>
> *Normal mothers reaction for the care and love of her child.*
>
> *I think it is only natural to have certain fears about the mystery of nature and our expectations of the perfect.*
>
> *...and generally being realistic that life and circumstances aren't always 'rosy' and complications can occur.*

Others expressed concerns about their lack of knowledge and fear of the unknown.

> *That was my first child and I didn't know what to expect.*
>
> *Not enough knowledge.*
>
> *We do not really know how the baby is developing inside and whether there will be any problems after birth.*
>
> *Ignorance of experience of not having a child or any children around whilst growing up. 1st baby.*
>
> *Because we can never tell what will happen.*
>
> *...Not knowing what may lay ahead.*

For a few participants the use of medical technologies in pregnancy, especially related to infertility treatment, generated particular fears.

> *...but we got pregnant by micro injection (IVF) and I constantly worried the baby would not be normal.*

From not being able to conceive naturally and from already having a previous miscarriage.

Generally more knowledge from technology, learning more every day.

In addition, a few participants discussed the generation of fears arising from facets or failures of their own character, and in doing so, attempted to dismiss such features as not legitimate.

Over - active imagination.

Not sure - maybe I'm just a general worrier.

Because I worry about things for no apparant reason.

Just irrational fear of the worse...

You behave differently when you are not pregnant to when you are.

Family superstition on cravings resulting in birth marks.

General anxiety from making such a major decision to have a child. For me it was the biggest decision I have ever made.

My obsession with being normal...

Finally, a few participants discussed the role of society and its expectations on the generation of fears during pregnancy. Women expressed fear at being 'blamed'.

Pressure from society to be perfect. ie don't be a burden or irresponsible. Special needs babies seem (by my interpretation of general society) considered preventable and undesirable and often the 'fault' of the mother to a significant extent.

...our expectations of the perfect.

...general public opinion that if the baby is not perfect it's the mother's fault entirely.

...peer pressure in relation to 'cute' babies.

Participants perspectives about disability demonstrate values that may give rise to some fears and anxieties during pregnancy about having a baby with an abnormality. Many respondents struggled with their positive views of the acceptance of and integration by society of people with disability with their individual unwillingness to have and rear a child with a disability. Many recognised their own inability to manage with a disabled child, as these three examples show:

...Because I'm a teacher I have integrated children like that (Down syndrome). *And there were a couple at my school when I left to have this baby. And though I had a lot to do with these kids and I think they're gorgeous and they're fantastic for other kids in schools..... I guess I would prefer not to have had one. I probably would have had something done. It's hard to know....Integration is good. I think it's fantastic for what needs to be done with their progress. When integration first started in schools I must admit, I was a bit dodgy because I thought these kids probably get a better go in a situation where there's only three children in a grade to one teacher and they're probably getting more specific skills that they need. But after working in schools for about 10 years with kids with different disabilities, I've seen the toughest kid in the school play baseball or cricket or something with the Down's kids and they are just so wonderful and so encouraging. The whole school has sports day and the whole school is just barracking for this child. And so I think a lot of kids now, could see someone with half a body and they wouldn't sort of flicker an eye at them. So I think society is fantastic.*

We tend to try and push those people in a corner and not recognise that they are people. People are uncomfortable with them and just sort of try to push them away. I like the idea now where disabled children are integrated into primary schools. a lot of people don't like that and they think it's a drawback because of the resources going to that child, that it's a drawback on the other children. But I think we have to look at it as a community, that our children are learning to accept these people with disabilities and can cope with it. And as they become adults, they will have grown up understanding people with disabilities. I'm sure it's not easy for the child with the disability either, to try and integrate into a school with more children but, I think in the long run society will benefit....But as I said previously, I think it's important for women's health and the health of the child to know and to be prepared if there is a problem... Only towards the end, the thoughts of Down syndrome kept popping into my mind.""I still think everyone thinks, "I'm glad it's not me". I mean, I know it's nice to think you know everyone's equal and they've got as many rights....if you see a lady pushing a little girl in a wheelchair you think, "I'm glad my kids are healthy at this stage"... It would still be awful to cope with. I don't know if things have changed. We don't institutionalise them now which is good for the rights of the actual person but I don't think we give enough help to the parents that have to cope with that. So in a way, you sort of help one and make it a lifetime of hardship for the other.

You would feel so bad about making that decision anyway (to have a termination). *Because everybody I know that's got a Down syndrome child, it has altered their lives in quite a special way - they're wonderful children. Having said that, you know I don't have that, so it's easy for me to say that...Well I think if it happens to people anywhere, their friends and families have a new acceptance of something they were ignorant about before. It isn't necessarily a bad thing....Yes, we should be working on making these things accepted, not trying to avoid them. Yes, it doesn't make things very pleasant - things we don't like we just abort.*

Many felt that society was not yet accepting of people with disability and feared the impact of that on them as carers and the child. In particular, many were concerned about the continuity of care to the child following the death of the carers.

(as a society) *We're lousy. We're basically really lousy. I look at my views. I'd rather terminate than bring an abnormal or deformed baby in. Basically it's because I know me and myself. I don't know whether I could institutionalise and institutionalise these days doesn't mean much anyway because they're de*

institutionalising everything anyway. But I, for me, it would disturb our family unit and the fact that once Russell and I are gone the sibling would have to be taken care of by his brothers and sisters, and that's not fair on them. It's something you two have created and you're putting this burden on the brothers and sisters for later life...It shouldn't be that way, it shouldn't be a burden....It shouldn't be that way and they are being integrated more but I would still see it as a burden.

If I had a child that was not formed, malformed, I wouldn't want him. Not because it wasn't a perfect child but it's a myth that it's my life. When I go, whose going to take care of it? I'm not looking for the perfect child. I'm looking at the child's future. It's a burden on me and a burden on society. It won't be able to do anything if it's deformed. What use is it to itself?

Society doesn't give a damn about disabled people. Society is so callus and cruel. I've nursed people with no life. They should have a say. I do feel guilty though. I couldn't do that to a child. I wouldn't cope with a disabled child myself.

I don't think there has been a lot of education in this society and community at large. If this little girl hadn't been put into a school environment where basically everybody's consent was sought, not just teachers, but parents, what reaction would it have had on the rest of the class? They were just lucky it was positive feedback.

Society is very cruel. You watch people shudder and ignore it and not want to ever discuss that that child is still alive.

Many respondents were concerned with the level of pain and suffering and difficulties that they saw associated with the rearing of a disabled child, for the child and the carers. Some women expressed a desire to be able to prevent such situations.

I think, no matter what, there will still be people who have had a child who is disabled and society will accept them anyway. I think having testing is essential because I know in my own eyes, if I could prevent pain and suffering for a child of my own, I would do it....I mean, the nurturing mother instinct, I suppose, is so strong you just want to envelope or prevent anything happening.

My uncle has three kids, two of whom have severe autism. I look at how difficult their life is coping with just the kids, now in their 20's. And as their parents are getting older there are real concerns now about who's going to look after the kids when their parents have gone....I don't know what we would have done.

I wouldn't like to have an abnormal baby. I think it's a bit selfish of me and it's a lot of care, worry and a lot of expense and you can't enjoy that person 100% because of their abnormality. I feel that personally I wouldn't have it if I knew something was wrong with my baby. I think I would abort it.

I know a few women that have had handicapped children and it's really tough on them. It's not only tough on the parents, it's tough on the whole family. We've become a society that's really prone to be selfish. So I don't know that's something that is easy to talk about if you are not in the situation...

d) Factors that reduce fear

Routine antenatal screening tests were identified by participants as being the most effective factor in reducing the levels of fear and anxiety experienced throughout pregnancy. Table 4.14 demonstrates other factors identified, including 37.7% of responses (127 of 320) which expressed the importance of advice and support from health care professionals during pregnancy to reduce anxiety.

Table 4.14. Factors identified by women that reduce anxiety during pregnancy *

(n=320)	Percentage
Routine antenatal screening tests (ultrasound identified in 55%)	53.4
Support/advice from health care professional	39.7
Support from partner/friends/family/work	17.1
Antenatal visits	12.8
Contact with the baby ie. FH, FM,CTG,US	11.3
Reading pamphlets and books	11.0
Positive attitude	9.0
Antenatal classes	3.7

* Responses were to an open-ended question. Many women gave more than one response
FH = fetal heart; FM = fetal movements;
CTG = cardiotocography; US = ultrasound

An open relationship with my doctor.(A woman, which made me more relaxed)

Special (and free) care available to me.

...Having phone access to professional medical help.

...Having doctors and midwives tell you everything is all right.

The doctors and midwives and the pamphlets that I read at the hospital, besides being able to talk easily to the hospital staff.

The midwives expertise, knowledge and reassurance.

That I had a wonderful doctor in the shared care program.

Confidence in obstetrician, answered all questions patiently and clearly.

The special clinic staff were excellent - knowing the field - always being positive and listening to me. Also the never exaggerated or alarmist.

An excellent, honest obstetrician who encouraged discussion at all stages.

...Also seemingly unflappable doctor helped.

A further 17.1% (55 of 320) of participants reported support from their partner, family, friends and work as being valuable in reducing anxiety.

My partner helped me believe everything was fine.

Encouragement/positive thinking of partner and friends/family.

Support was essential - from parents, friends, relatives, doctors, tests.

My husband was very supportive, loving, caring, and helping.

Just talking it out with people that have experienced birth.

Support of husband, employer.

Husband support, workplace support.

The value of having some contact with the baby, through fetal movements, fetal heart beat detection or ultrasound in reducing anxiety was reported by 11.3% (36 of 320) of participants.

Being in touch with my baby and listening to it.

A strong healthy heart beat of the baby.

Movement and kicking from 18 - 20 weeks onwards.

(the doctor) *doing regular ultrasounds and ECGs.*

...feeling the baby move, having my ultrasound.

In addition, 9% (29 of 320) of participants perceived having a positive attitude during pregnancy as being effective in allaying fears.

Relaxation - constant reminders to myself that everything would be OK.

I think I am basically usually an optimist and therefore I don't think I was really anxious. I didn't have any feelings that anything was wrong.

...positive images that an unexpected outcome is not necessarily a disaster.

Keeping an open mind - listening to your body.

Working to maintain normality rather than thinking about the expected date of delivery.

Positive frame of mind. Not trying to think too much about events and let them take own course.

To keep working like normal and think healthy all the time.

Not to pick up other people's pressure.

Positive mental attitude and shopping.

Thinking to myself, I'll be different.

Whilst some participants perceived having positive thoughts to be beneficial, others reported using denial as a way of reducing anxiety. *'Tried not to think about it.' 'Closing my eyes, wishing I was not there. Having a smoke.' 'Pretending I wasn't pregnant.' 'By just not thinking about these things and just getting on with life and focusing on other things.'* A few participants only, relied on their religious faith to reduce anxiety during pregnancy. *'Faith in religion.' '...strong faith in God.' 'My spiritual/religious views.'* Only 3.7% (19 of 320) of participants perceived antenatal classes to be effective in reducing anxiety during pregnancy. Other factors reported to reduce anxiety during pregnancy were clinic or doctor visits, reading pamphlets and books and experiencing, over time, that all was progressing normally.

Participants demonstrate that they feel 'at risk', have many fears, particularly for their baby and show differences in their perceived risk of adverse outcomes for others as opposed to themselves individually. Responses about the origins of fears and the perspectives on the role of society and disability lend understanding to the socio-cultural context in which women feel at risk. Factors that participants identified as effective in the reduction of fears are important in considering strategies in the reduction of pregnant women's risk perception. This perception of risk and its role in the utilisation of routine antenatal screening is explored in greater depth in the following discussion chapter.

4.8 Consideration of termination of pregnancy

When participants were asked, if the test results had shown a fetal abnormality would they have considered termination of the pregnancy, 33.8% (127 of 376) said yes whilst the majority (49.2%) were unsure. Only 17% (64 of 376) said that they would not consider termination of pregnancy in this instance. Older participants were more likely (χ^2 =9.4 3df p=0.02438) to consider termination of pregnancy as were professional or para-professional women (OR = 3.21(1.3-8.3). Consideration of termination of pregnancy was not associated

with health insurance status, educational level or parity. Nor was it associated with participants' perceived risk of having an abnormal baby or anxiety about having an abnormal baby.

Many participants explored the possibility of considering termination of pregnancy as demonstrated above. Underlying a consideration of choice of termination for many of these participants is an assumption that termination is available in the event of a fetal abnormality. The following discussion chapters discuss this issue and issues of risk perception, informed choice, and medical sovereignty in more depth.

INTRODUCTION

The utilisation, by pregnant women, of routine antenatal screening tests depends on many clinical, epidemiological, sociological and political factors. The following two chapters discuss some of the social and ethical questions that arise from the research findings. In particular, they examine the factors which form the basis for many of the participants' values and beliefs. In addition, they address the role of these factors in the utilisation of routine antenatal screening tests. Chapter 5 provides a sociological perspective and is divided into two sections dealing with the notion of risk and medical sovereignty. Chapter 6 provides an ethical perspective and is divided into four sections which consider issues of informed choice, rights, altruism and the act of screening.

Chapter 5. DISCUSSION - SOCIOLOGICAL ANALYSIS

5.1 NOTION OF RISK

Introduction

Whilst pregnancy and childbirth are generally regarded as joyful and exciting times in a woman's life they are also filled with fear, uncertainty, a feeling of being 'at risk' and anxieties about what the pregnancy and the future may hold. Not only do women perceive themselves to be 'at risk' but so, they think, is their unborn child. Will it be born alive, will it be 'normal'? In a society where the perinatal and maternal mortalities and morbidities are very low what prompts the rise of these fears and anxieties? Examination of pregnant women's perception of risk throughout history is limited and the study of women's perceptions of maternity services is a relatively recent phenomenon. A working class English woman commented in 1914, 'I always prepared myself to die, and I think this awful depression is common to most (pregnant women) at this time'.[174] Shorter, in his history of women's bodies states that 'There is no doubt that the typical woman in the years before 1900 faced her approaching delivery with foreboding'.[175] He argues further that women developed a collective lore about childbirth that was then repeated generation to generation and 'alerted women to the risk that womanhood entailed'.[176] Whilst dramatic reductions in maternal mortality in developed countries since 1935 may have led to a diminution in women's perception of the risk of dying, their fears may have been transferred to perceptions of risk to the fetus.

This section explores this 'notion of risk' as perceived by women giving birth. It also explores the origins of risk and the impact of this notion on the utilisation of antenatal services, in particular antenatal screening? In particular, it examines the notion of risk using a sociocultural perspective.

Fears in pregnancy

The results of this study demonstrate that pregnancy is not wholly perceived as a joyful and happy time in a women's life. Most women are fearful and feel at risk during their pregnancy. Whilst women fear losing the pregnancy, having an abnormal pregnancy, and the birth, women are most fearful of the outcome for their baby. Women express a diverse range of these fears, from the baby being abnormal to fears about what the future may hold for their child. They express a variety of emotions including anxiety, fear, feeling unsafe, uncertainty and feeling not in control in relation to the pregnancy and the birth outcomes. For some, the fears never stop: *'I probably stopped worrying for about three hours after the birth and then I started worrying again!'* Such perceived risk of having an abnormal baby is far reaching. That is, it is not associated with a woman's health insurance status, educational level or her own perception about what the actual risk of having an abnormal baby is. It is however, expressed significantly more frequently by women having their first baby.

These findings are consistent with other studies that have attempted to examine women's experience of antenatal screening and diagnosis, in particular women's fears and anxieties during pregnancy. [4,73,112,137,177,178] The Cambridge Prenatal Screening Study reported that the majority of pregnant women worry about the potential for abnormality with their baby.[73,112,137] Marteau also found that pregnant women eligible for alpha feto-protein (afp) screening were anxious about the health of their baby. [4,178] These findings are also consistent with earlier work by Farrant, whose 3-year qualitative study of 135 women's experience of afp screening and amniocentesis suggested that pregnant women fear fetal abnormalities. She also argued that such fears are linked to women's valuing of the tests.[177] The consistency of these findings suggest that fears are a significant feature of a woman's experience of pregnancy and childbirth. Therefore, further examination of the origins of these fears and the implications of them for women and antenatal service delivery is warranted.

What is 'abnormal'?

Before discussing pregnant women's fears of abnormality it is important to examine what women mean by the word 'abnormal'. Findings from this study suggest that women's understanding of the term 'abnormal' relates closely to conditions considered abnormal in obstetrics and neonatology. To this extent the notion of abnormal is constructed for women by the discourse of the professions. In addition, women expressed abnormality in a broader social context. Abnormality in a baby was expressed in terms of implications, such as a disability for the child or an additional burden on the carers, regardless of the actual condition. *'When a child has a disability which is going to hold it back in some major way from doing the things that other children can do, or stop it from leading a 'normal' lifestyle. Lack of independence.'*

Many expressed 'abnormality' as meaning a missing limb, perhaps still a residual fear following the thalidomide story. It is important to note that many of the concerns, including intellectual disability, are beyond the scope of current medical technologies offered during pregnancy. That is, many of the abnormalities women feared cannot currently be detected by antenatal screening. This broader context in which women consider what is abnormal and their concerns about abnormalities that cannot be detected by antenatal screening is an important consideration for antenatal care providers. Clearly, just offering antenatal screening tests will not address all women's fears about potential abnormality.

What do women expect?

Whilst women in this study sought confirmation of normality from these tests, their fears were expressed in their expectations that the tests might actually detect abnormality. With this expectation also came expectations of treatment options including termination of the pregnancy. These findings are in contrast to those of Farrant[177] and the Cambridge Prenatal Screening Study,[112] that pregnant women expected that prenatal tests would confirm normality. The current study shows women hope for normality to be confirmed, but

concurrently have fears and expectations that the tests will detect abnormality. This suggests that women's expectations are closely aligned with those of the antenatal health care providers who offer screening tests with the objective of detecting abnormality. Detection of abnormality is consistent with the medical model of pregnancy. This study demonstrates that this facet of the medical model of pregnancy plays a dominant role in influencing the perceptions of recipients of antenatal care. Incorporation of this model into the experience of pregnancy in women who have generally limited medical knowledge, contributes to the generation of fears in these women.

Risk perception

Few studies have compared pregnant women's epidemiological risks and their perceived risk. Marteau's large qualitative study of pregnant women undergoing screening with afp and subsequent amniocentesis found no relationship between participants' perceived risk of having a baby with an abnormality and their actual risk.[179] The results of my study demonstrate that women's perception of their own risk of having a baby with an abnormality is out of proportion to the actual risk and to their perception of what the actual risk is. Not only are the perinatal mortality rates for Victoria (7.0/1000 births in 1993) or for Australia (8.2/1000 births in 1993) low but the risk of all congenital abnormalities is approximately 4%.[86,92] * These statistics show that the majority of women underestimate the actual risk of having a baby with an abnormality. So, despite 87% of women perceiving the risk of having an abnormal baby to be 1% or less , 66% reported being sometimes or a lot anxious that their own baby would be abnormal. These findings raise the question of the role of knowing the actual risk in the formation of individual women's risk perception. Further study is required to adequately address this question. The tendancy for women to feel disproportionately at risk was also evident in women's perception of risk of receiving an abnormal test result. Despite 53% of women perceiving the actual chance of getting an abnormal test result to be uncommon or rare, 61% reported being anxious a lot or sometimes that they would get an abnormal result.

---

* World Health Organisation statistics for national comparison of birth weight of at least 500 grams or 22 weeks gestation

Why do women feel 'at risk'?

Many authors have observed the general risk discourse and the perception of risk to be increasing. [29,180,181] This is despite the low risk of adverse pregnancy outcomes in developed countries. Some authors have offered theories about the origins of the perception of risk in today's society[182-184] and as it relates to pregnancy.[29,180,181] Only a handful of studies have attempted to examine the notion of risk as perceived by pregnant women.[179,185-188] Even fewer studies have examined the notion of risk in the context of antenatal screening or diagnosis.[179,188] Most of the forgoing studies do not offer explanations for the origins of pregnant women's risk perception. In addition, no studies have examined pregnant women's notion of risk as it relates to their use of routine antenatal screening tests.

The term 'risk' has a variety of meanings. The early neutral use of the word has yielded to notions of adverse outcome.[189] Whilst this colonisation of 'risk' to denote adversity is common amongst users, there is a marked discrepancy in definition of risk between various disciplines and the public. The medical and obstetric use of the term 'risk' arises from epidemiology.[185] It assumes risk to be unambiguous, objective, measurable, monitored and quantifiable.[156,185,189] James and Stirrat define a pregnancy 'at risk' as involving 'a likelihood of an adverse outcome for the mother or baby which is greater than that for the general pregnant population.'[190] In obstetrics terms such as 'at risk' or 'high risk' are used to assign risk to a particular pregnant population. But various social sciences find this definition to be inadequate. [182,185,189,191-193] Social scientists criticise the lack of a social, cultural and political context.[185,189,191] Lupton, a sociologist, argues that risk is not 'out there waiting to be measured, monitored and dealt with, but rather is constructed through social and cultural assumptions and frameworks'.[194] Nelkin, in addition, argues that the scientific definition of risk 'ignores non quantifiable, fragile values - the emotional distress and disruption of social relationships that may be associated with risks, or the attitudes toward authority that may foster mistrust'.[195] Other authors have attempted to discuss the notion of risk as viewed by the lay person using a socio-cultural perspective.[196,197] Gifford, an anthropologist, states that

women with breast cancer perceive being at risk as 'a state somewhere between health and illness', involving 'a dynamic experience of personal uncertainty about one's future'.[198]

What are pregnant women's definitions of risk? Are they different from medical definitions? Or are they intertwined with their values and beliefs and therefore draw upon socio-cultural definitions of risk? Patterson, in a small qualitative study of black American women at a high risk antenatal clinic, found these pregnant women defined risk as 'some degree of shift from certainty to uncertainty, from expected to unexpected, which was then verified by their social network of family and friends.'[199] The literature just mentioned suggests that the reasons for the perception of risk amongst the women I studied are easier to understand when a socio-cultural definition of risk is applied rather than the epidemiological. The exploration of the context of the risk and the underlying values and beliefs reveals five probable reasons: society's values in relation to normality and abnormality, society's loss of a sense of tragedy, the role of offering screening itself, society's focus on adversity and the pressure of the 'premium baby'.

The results of my Melbourne study suggest that society's values in relation to normality and abnormality impact greatly on women's beliefs and values.* Whilst most women perceive the deinstitutionalisation of people with disability to be desirable, they are cautious about the degree to which society accepts people with disability and provides the support carers need.

> *I still think everyone thinks, 'I'm glad it's not me.' I mean, I know it's nice to think you know everyone's equal and they've got as many rights...if you see a lady pushing a little girl in a wheelchair you think, 'I'm glad my kids are healthy at this stage'...It would still be awful to cope with. I don't know if things have changed. We don't institutionalise them now which is good for the rights of the actual person but I don't think we give enough help to the parents that have to cope with that. so in a way, you sort of help one and make it a lifetime of hardship for the other.*

---

* Elkins and Brown argue that society has viewed disability, in particular Down syndrome, more positively in the last 30 years. They argue that non institutionalisation, deinstitutionalisation, socialisation and normalization of people with disability have led society to see the value of such quality of life.[200] Further reading of papers by disability lobbyists reveals the other side of the argument, where disabled people are socially constructed and suffer prejudices for being outside prescribed norms.[201,202]

Women did not raise issues of attainment of perfection but rather the wish to avoid the burden, pain and suffering they believe falls upon the child and the carers of the child with a disability. These findings are consistent with those of Sjogren's Swedish study where 73 parents-to-be undergoing prenatal diagnosis were interviewed about their beliefs about disability:[203] 50% of them believed the disabled child would suffer and 100% believed the family would suffer.[203] The Swedish study also demonstrated that parents-to-be were pessimistic about adequate support services.[203] Women in my Melbourne study largely perceived the environment to be hostile or unsupportive of a child with a disability or themselves as potential carers, thus the thought of having a baby with an abnormality was feared as a potential threat. At the same time, women in my Melbourne study expressed discomfort with these views. They felt that it was somehow 'wrong' or 'uncaring' not to accept rearing a child with a disability despite the limitations they saw in themselves and society. Sjogren noted in her study that parents-to-be also demonstrated this ambivalence. They 'may be tolerant towards handicap in general, but are not ready to take the risk of giving birth to a child with a handicap..'[204] Marteau also recognised that positive moves by society to accept people with disability whilst on the other hand providing resources to prevent births with disability, produced conflicts and pressures for pregnant women.[8] However, using a prudential judgement argument, women in my Melbourne study perceived that, given a choice, it would be better for a child not to be born with a disability.[205] As participants wrote:

> *These days we hear more about the babies born with problems. In the old days these babies were kept out of sight. Whilst I think integration of these children into schools etc. is fantastic I feel people are more aware of just how many babies are born with problems...*
>
> *There are a lot of people out there who are not able bodied. No parent wants that for their child/children.*

Further analysis is required to examine the potential impact of the trend toward deinstitutionalisation of people with disability and society's increased exposure to disability. Will the increased exposure to disability in today's culture and values augment women's desire to avoid perceived pain and suffering? These issues cannot be resolved in this study but raise questions for future research.

Death or severe abnormality in a neonate is now uncommon so such tragedies remain largely hidden from many in the community. Modern society has lost its sense of tragedy as a 'sad event, calamity, serious accident'.[206] That is, events such as death of a woman in childbirth or death of an infant soon after birth were previously more common and while still associated with a grave sense of loss and sadness, were nevertheless not unexpected in many cases. However, as the incidence of these events decreases, so does the expectation and so does the acceptance of such events by our society as part of life. When it does occur, the rare or uncommon event is exaggerated, generating uncertainty and, sometimes, irrational fears. Enkin describes these events as 'catastrophes'.[124] This study suggests that women expect tests to provide a promise of certainty to address their uncertainties in relation to pregnancy and birthing outcomes. However, epidemiological evaluation of many of these tests, as shown in chapter 2.2, reveals their limitations and, in particular, their poor reliability and inability to provide certainty.

Whilst routine antenatal screening tests are highly valued and utilised, the very act of offering screening tests or expertise to otherwise well pregnant women raises the potential for women to consider their pregnancy to be abnormal. This process of offering screening to healthy individuals is explored further in chapter 6.4.

Many women spoke of the tendency for friends, family and the media to concentrate on the negative outcomes that women may experience during pregnancy. 'Word of mouth' was the most commonly identified origin of women's fears and anxieties. *'Lots of people telling horror pregnancy/labour stories. In society, it's as though women are vocal to tell you their bad experiences rather than their good.'* This focus on adversity is not confined to pregnancy and childbirth. It is evident in human intercourse about many life events and experiences. Whilst such attentions make 'good stories' and 'good gossip' they have the ability to contribute to an individual's perceptions and fears. They contribute to women's heightened sense of individual risk.

The participants in this study demonstrate features consistent with national trends for smaller families, parenting at older ages and high paid work force participation by women.[160,161,164] Each of these characteristics has the potential to increase the stress on parents to 'get it right this time' because there may not be another opportunity. Mahowald calls this the 'premium baby mentality'.[207] That is, as parents plan to rear their families later in life, to have only one or two children and to return quickly to the paid workforce, they are faced with pressures of time - time to conceive their families and time to manage the demands of the family amidst other demands of home and work. However, these concepts are not new. As the birth rate has fallen the importance of rearing a normal child has increased.[30] Hicks, in his study of the Australian population from 1891 to 1911, notes that the decline in the birth rate during the 1890s was largely due to deliberate limitations of family size within marriage.[30] Clearly, despite the discounting of these factors by the Royal Commission into the decline in the birth rate in 1903, socio-economic factors were important. One of the remedies prescribed by the Commission to address the fall in the birth rate was to 'counteract the tendency of the increased employment of women and girls in factories'.[208] Debate in the newspapers at the time began to address the need for 'preservation of existing child life as a partial compensation for the absence of new life.'[209] Today, there is additional pressure when such plans attempt to incorporate the concept of rearing a child with special needs or extra demands, be these physical or mental. Such considerations must also be examined in the context of today's lifestyles. Pressures created by these trends in lifestyle, particularly around families, contribute to the perception of risk as expressed by the women in this study. In addition, women's perception of society's lack of adequate provision of supports for parents of children with disability add to the fear of this outcome, and the perceived risk of this outcome for themselves.

What is the role of antenatal screening?

The presence of these fears and the perception of risk during pregnancy generate a need for reassurance, safety and protection. *'Reassurance for mother and ultimately protection for child.'* One of the ways in which reassurance is sought is through the utilisation of routine

antenatal screening tests. *'...having tests and good results gives you a safe feeling.'* Enkin describes this as a form of taking out insurance.[29] Whilst the reasons for the need for reassurance were not explored, the findings of this study are supported by Hyde's study of 404 women in an antenatal clinic in England which also found that the majority of women expressed feelings of reassurance in relation to ultrasound scanning during pregnancy.[210] This need for reassurance, generated by women's perceived notion of risk, determines in part their use of routine antenatal screening tests. Utilisation of these tests is sustained by pregnant women's belief in the value of, and reliance upon, these tests as demonstrated.

Not only is reassurance sought through this avenue but more reassurance is being sought. Pregnant women support the development of more routine antenatal screening tests to take out more 'insurance', regardless of the monetary cost. Not only do routine antenatal screening tests provide reassurance but such technology and expertise in antenatal care offers perceived certainties, in a context of fear and uncertainty. The consequence of this behaviour is the development of a reliance on technology and expertise to ensure a safe pregnancy and normal baby. Ironically, their insurance may not deliver. Not only can routine antenatal screening tests fail to deliver this desired outcome but they may offer as their only 'dividend', termination of the pregnancy. This notion of high reliance on routine antenatal screening tests as a form of insurance may also help to explain the observed increases in the numbers and frequency of routine antenatal screening tests being offered in developed nations. [29]

Much ethical debate concerns itself with the question of whether the act of offering screening and/or diagnostic tests for fetal abnormality brings a negative bias toward people with disability.[8,200-202,205] Whilst many lobbyists for the rights of the disabled argue that prenatal screening campaigns can potentiate public prejudice and non-acceptance of people with disability ,[201,202] others argue prudential judgements made by parents about disability do not represent moral injustices to disabled people.[205] Gillam argues that, by parents making a value judgement that a future child would be better off with no life than a life with a severe disability, this is not discrimination against disabled people. Therefore, given a choice, they

may prefer not to allow a life with a disability.[205] In addition, Borthwick argues that parents terminating a fetus with a disability because they feel the public provision of services is inadequate won't necessarily lead to increase prejudice to those already disabled in the community.[202]

What are the implications?

Is risk perception harmful? Many women spoke of their fears and anxieties as a natural and welcome component of their pregnancy. *'It is part of having a normal healthy fear to question. Having a baby means not knowing, not being in total control, given environmental, age and modern day pressures most mothers to be experience some fear.'* For some, fear formed the basis of a special 'instinct' that comes with motherhood. *'Normal maternal instincts.'* Heightened perception of risk as a dominant feature of women's pregnancy and, as a determinant for their utilisation of routine antenatal screening has a number of worrying implications. If women's risk perception leads to use of routine antenatal screening tests it may also influence the use of other perinatal interventions. This has further implications for the potential increase in the medicalisation of birth and its impact on health resource allocation. Women now accept testing as a necessary part of normal pregnancy.

Secondly, if the providers of antenatal service perceive the risk of adverse outcomes to be congruent with the epidemiological risk, then there is a mismatch between the risk perception of the health care provider and that of the patient. This is supported by Handwerker, who performed a qualitative study examining the interactions of pregnant women and health care professionals at a prenatal clinic and argues that pregnant women's perception of risk differs from medical professionals' and that these perceptions are dependent on values, education and class.[185] Such a mismatch raises the potential for misunderstandings, unmet needs and disappointed expectations. A small qualitative study from the Netherlands found that ambiguities and misunderstandings could arise when women were unexpectedly confronted with a screening for Down syndrome that identified

them as 'higher risk'.[188] Discontent and disappointment leads to the search for compensation through the legal system. Medicalisation of birth and the medico-legal environment of obstetric care are considered further in chapter 7.

What can be done?

Opportunity exists to take account of women's fears and perception of their risks in the provision of clinical antenatal services. Identification of these perceptions may be effective in the reduction of the mismatch in expectations. As identified by women in the study, advice and support from health care professionals, support from family and friends or contact with their unborn baby (listening to the fetal heart with sonicaid, being aware of movements and ultrasound) can be utilised to reduce pregnant women's perception of risk.

Whilst antenatal screening tests are also identified as important in reducing anxiety, they appear most effective when women perceive that they have sufficient knowledge about the tests, that they are told the results of the tests and they believe the tests to be reliable. That is, despite concerns raised by women in this study about testing, if testing is to be of value in reducing fears, the delivery of information about the tests is vital to the process. This is particularly important for women who are receiving antenatal care in the public system and who were demonstrated in this study to be significantly less likely to receive adequate information about the tests and their results. The role of antenatal classes in relation to risk perception must also be addressed. Antenatal classes could be utilised better to overcome the anomaly that reassurance is sought but fear is raised. Studies have found that attendance at antenatal classes produce '...no discernible impact on prenatal attachment, father's involvement during labour, childbirth satisfaction, or early parenting'. [211] But as Simkin and Enkin argue, the outcome of the classes depends partly on the underlying objectives.[212] Therefore, one objective of these classes could be to address women's fears not only about pregnancy and childbirth but about their outcomes.

The results of this study also demonstrate that providing actual risk figures in the antenatal period has limited value as these figures do not alter an individual woman's perception of her risk. Not only does knowing the real risks appear not to alter an individual woman's perception of her risk but it also raises the potential for complacency by the providers of antenatal counselling. The counsellor may perceive the simple transference of epidemiological risk figures to the parent to be the end of the provider's responsibility in relation to addressing risk perception. Clearly, dealing with an individual's risk perception is far more complex. Therefore, the messages given to women in this period need to be addressed.

Although fears and anxieties were expressed from women of all parities, women having their first baby were significantly more anxious. Whilst this is not surprising, more time and support given to primigravida women in the antenatal period is clearly indicated. Whilst there is limited scope for the providers of antenatal services to effect many of the origins of women's fears during pregnancy that arise from broader societal values in relation to normality and disability, identification of the context in which pregnant women perceive these risks is important.

Conclusion

Whilst pregnant women hope for a positive experience, they are at the same time highly fearful of adverse outcomes, disproportionate to their actual epidemiological risks. Understanding of the socio-cultural context in which pregnant women perceive their risk is paramount to addressing their concerns and to avoiding a conflict of expectations and subsequent discontent. Reassurance, in part, is provided by the utilisation of routine antenatal screening tests. But is fear a legitimate determinant of the use of routine antenatal screening tests? To enable a more complete evaluation of current obstetric and perinatal interventions, the issue of risk perception must also be considered alongside other more traditional measures of effectiveness and value.

5.2 TRUST, COMPLIANCE AND MEDICAL SOVEREIGNTY

Introduction

What is the role of medicine in the use of medical services, in particular, antenatal care? Willis's concept of medical sovereignty describes a broad sustained social deference to technical knowledge and medicine.[213] Using both overseas and Australian sources he argues that medical sovereignty is expressed through patronage by society of medical dominance. In this study society is represented by the consumers of the predominantly medical services of antenatal care and screening. Patronage of these services is supported by women's compliance with, trust in, and reliance on medicine and technologies within antenatal care. This section, by a careful delineation of terms such as trust, compliance, reliance, and uncertainty, examines women's use of the medical system in the provision of antenatal care, in particular, antenatal screening. Through this analysis I examine the role of medicine as a determinant for the use of routine antenatal screening. A closer examination of the role of medicine in the act of offering screening and promotion of the illness model of pregnancy is offered in chapter 6.4.

Trust

The predominant form of antenatal care provided to the participants of this study is embedded in the medical model of pregnancy that is concerned with the detection of potential abnormalities and disease during pregnancy. This includes the provision of antenatal screening tests. The results of this study illustrate three forms of support by the participants of this antenatal care. The first form is a high level of trust which the participants place in both the care givers and the care itself. Trust in the care giver is illustrated by the following response. *'I think more knowledge can be a dangerous thing. I spent alot of time choosing my gynaecologist and obstetrician and I chose him for specific reasons and handed over my faith on the first visit...'* In addition, approximately half of the women who did not ask for the results of their screening tests when not offered them,

expressed trust that they would be told things if they needed to know. *'I presumed I would be told if anything was wrong.'* Not only were participants trusting that 'doctors knew best' but that doctors would be beneficent, non-malevolent and, when appropriate, paternalistic. *'You've got to rely on your doctor alot. I mean, even the so called experts. You've got to rely on whether they think you should have it, because they're the ones with the knowledge of whether tests are going to benefit you or the baby.'* Put simply, women trusted doctors to do the best for them and their baby, to avoid harm and to do make judgements about necessary measures to ensure this. In particular, women demonstrated a high level of trust in medical professionals to provide beneficence to their unborn baby. Lumley argues that medicine is able to exercise control over pregnancy care under the guise of doing best for the fetus/infant.[214] In addition, Millikin argues that 'our increasing ability to act on behalf of the fetus has made its claims to our care more compelling'. [215] Potential exploitation of pregnant women's concerns for their unborn baby and their trust in the medical system is further explored in chapter 6.3.

Compliance

The second form of support for antenatal screening services is demonstrated by participants' high compliance with the performing of antenatal screening tests as part of their pregnancy care. All but one of the participants had some form of routine antenatal screening tests. More than 90% of participants believed all pregnant women should have routine antenatal screening tests, that these tests are now a necessary part of a normal pregnancy and that they would have the tests again in another pregnancy. Further, only 3.4% of participants expressed any negative feelings about these tests. Sociologists, Porter and MacIntyre, following interviews of 232 women in antenatal clinic in Scotland in 1980, argue that pregnant women are conservative and uncritical and 'assume that whatever system of care they are receiving has been well thought out and is probably the best one.' [216] Pregnant women are also highly motivated. As Millikin argues, 'women have a strong interest in giving birth to healthy children and go to great lengths to increase the likelihood that they will do so'.[217] Sociologists, who have examined women's responses to antenatal tests in

particular, have found similar levels of compliance.[70,118,119] Green, in the Cambridge Prenatal Screening Study, commented that 'this test (alpha feto-protein) has now become a non-event for many women in the United Kingdom'.[218] An Australian study by Shapiro, examining 'power in the obstetric encounter' made similar observations of high compliance by pregnant women. She argues that obstetricians have used newer technologies as 'an argument for absolute and unquestioning compliance by their patients'.[219] That is, newer technologies have contributed to the 'increased perceived importance' of antenatal care and thus to compliance with their use. In addition, she argues that the 'obstetric encounter involves two unequal participants' and this has implications for women using antenatal services.[220] In particular, Shapiro suggests that women, as a result of this power difference and high compliance, are 'apparently unaware that their interests have been set aside'.[221]

Reliance

A third example of support for antenatal screening services is demonstrated by participants' reliance and, in some cases, dependence on antenatal screening tests to ensure positive outcomes from their pregnancy. Over 80% of participants believed that routine antenatal screening tests should assure a normal pregnancy and a normal baby. Words such as 'ensure' or 'determine' were often used by women to describe their expectations of these tests. Many participants were also reliant on their care to then provide adequate treatments should disease or abnormality be found. There was also a high reliance upon antenatal tests to relieve participants' fears and anxieties during pregnancy. This is examined more closely in section 5.1.

Medical sovereignty

So why are medicine and medical technologies, inherent in antenatal care, seemingly so alluring? Why do they receive such high support and use? Part of the answer lies in the sociological exploration of medical dominance set out most recently by the Australian sociologist, Evan Willis.[213,222] Willis describes medical sovereignty as the component of

medical dominance that is sustained by the wider societal arena. In that arena doctors are 'the institutionalised experts on all matters relating to health in the wider society'. [223] In the context of antenatal care, medical professionals are the experts on all matters related to pregnancy and birth and are supported by the consumers of antenatal services. Willis argues that medical sovereignty is legitimised by the ideology of professionalism and expertise and the ideology of technological determinism.[213,222] He describes the former ideology as that which 'only those who have expert knowledge are competent to judge'.[224] The logic of that proposition is circular: legitimacy is based on the notion of 'science as truth' and the expertise claiming to be effective.[213] Participants of this study used words such as 'experts', 'professional', 'not guessing', and 'physical evidence' to describe why they valued routine antenatal screening. Willis's analysis suggests that the invention of a new technology then determines the division of labour in the service provision and also the societal response.[213] That is, the development of antenatal screening tests requires experts to supervise and takes on primacy within the provision of antenatal care. As Willis suggests, it is easily incorporated into the hierarchy of dominance.[213]

This is not to suggest that medical technology has not had a significant role in modern pregnancy care. The advent of surgery, anaesthesia, blood transfusion and antibiotics have all made important contributions to the improved safety of pregnancy and birth for women. Despite less significant advances beyond these developments, medical technology in pregnancy care has continued to be well accepted. Medical sovereignty continues to be successful in the provision of antenatal care. More than 90% of participants believed routine antenatal screening tests are now a necessary part of normal pregnancy. In addition, after self, participants recognised doctors and midwives as being the ones who most influenced their beliefs about the value of these tests. This acceptance by women of medical technology, as a necessary component of antenatal care, has contributed to a diminution of trust and reliance on self as a competent custodian of pregnancy. The modern day position of 'wise women' or 'cunning women' is threatened.[225] Historically, wise women represented the highly valued community healers that all people turned to, including pregnant women. Traditionally, these women trusted 'the evidence of their senses.'[226] Loss of trust means loss

of this valued position in society. In addition, participants in this study looked to medical technology to provide an insight into their pregnancy, to ensure well being of themselves and their baby and, in some cases, to enable bonding with their unborn child to occur. Routine antenatal screening tests were attributed with *'Peace of mind, bonding process'* and *'I felt I knew baby.'*

The presence of medical sovereignty in pregnancy care is not new. As is discussed in chapter 2.1, the rise of largely unquestioned support and trust in the contribution of medicine has been a dominant feature of antenatal care in industrialised countries since the early 1900s.

Uncertainty

The notion of uncertainty is also relevant to the exploration of the high support for medicine and technologies in the provision of antenatal care. In addition to medicine offering a level of expertise to antenatal care, it also offers a promise of certainty to a time of uncertainty. In particular, antenatal screening tests attempt to measure specific parameters in pregnancy. An assumption is made that those parameters are definable, accurately measurable and offer certainty. The advent of the ability to see the fetus and 'know more' about the pregnancy has contributed to this promise of certainty but has bred uncertainty. Also, whereas the fetus was once 'assumed to be healthy, unless there is evidence to the contrary', it is now viewed as potentially unhealthy, with an uncertain destiny.[227]

With this shift in perception comes an expectation and reliance on testing to provide the certainty. Marteau argues that 'The presence of prenatal testing and monitoring shifts the balance toward having to prove the health or normality of the fetus'.[227] Participants in this study expressed concerns about the uncertainty that came with pregnancy but they also recognised antenatal testing as a valuable way of addressing these uncertainties. *'It would be terrible to have something wrong and you didn't know about it.' 'Not having to worry about the uncertain.'* For some, the promise of certainty also included the presumption that

treatment would be possible in the event of detection of abnormality or disease. This feeling of certainty offers benefits to pregnant women. Lumley argues that this sense of certainty has additional benefit to the antenatal care provider. 'Considerable psychological gains stem from feeling certain about something, particularly when something is viewed as a means of saving lives. Certainty reduces apprehension, ambivalence, and anxiety in both doctor and patient.'[228] But for some women, certainty may mean terminating lives rather than saving lives, as one option in the event of detecting a major fetal abnormality. Enkin, an important participant in the documentation and dissemination of effective care in pregnancy and childbirth, also believes that 'The complexity and pervasiveness of the screening procedures that characterise antenatal care today are manifestations of our unwillingness to tolerate these uncertainties.'[124] Feeling in a position of certainty will further enhance the perception that the areas of uncertainty are intolerable.

Feelings of certainty gained by women from antenatal screening are strengthened by a strong belief in the reliability of the tests. In this study, almost all of the participants believed routine antenatal screening tests to be mostly reliable, very reliable or perfect. Indeed 4% of women perceived the screening tests to be perfect. This supports research by Marteau which found that perceived reliability of antenatal screening for neural tube defects was a determinant of its use.[8] Much of this perception about the reliability of the tests arises from the fact that most tests are reported as normal and the majority of women have normal outcomes. On the face of it, it would appear that this is a result of the tests' low false positive and false negative results. In a healthy western population of women receiving antenatal care however, the incidence of major illness in pregnancy is now low and the rate of fetal abnormality low. The perception that antenatal screening is solely responsible for this outcome, and must therefore be reliable, merely confuses the fact with artefact! The belief that, if it is reliable for a particular individual it must be reliable and necessary for all, merely compounds the confusion. Perception of tests as being reliable and necessary will clearly lead to greater utilisation of these tests. When the Melbourne participants were asked about whether they would have a hypothetical test that had up to a 10% false positive and false negative rate, many expressed uncertainty and greater caution about utilisation of such

a test. This is relevant when considering the routine introduction of the triple test for Down syndrome. Currently, depending on the risk cut-off level used and whether or not ultrasound is used concurrently, the test has a false positive rate of approximately 5% and a false negative rate of 40%.[50] Screening for diabetes, using a glucose load and blood sugar level, currently have false positive and false negative rates of 5-10%.[38]

The apparent promise of certainty amidst uncertainties is clearly a dominant feature in the patronage of antenatal screening tests. Further examination of the origins of women's uncertainties, fears and anxieties is described in section 5.1.

Medical mystique

In addition to the offer of science to consumers of antenatal care, medicine also offers a particular mystique or magic.[29,214,229] Willis describes this as the ideological side of medicine.[213] Daly, another Australian sociologist of medical work, argues that developing medical technology has aided in the rise of what she describes as the 'medical mystique'.[230] She argues that this mystique is promoted by the associated proportion of indeterminate aspects in addition to the technical elements within the practice of medicine. That is, medical practice also contains 'rules of thumb, clinical judgement, flair or knack' that 'cannot easily be taught to others'.[230] She further argues that with the introduction of new technologies 'the medical profession extends its own expertise in the indeterminate aspects of use'.[230] Lumley, in her critique of antenatal care, suggests that women may see the ritual of examining women's bodily fluids 'as mystifying or magical a process as consulting the entrails'.[231] Antenatal care, which is intimately involved with the maintenance of 'the wonder of pregnancy and birth', is especially vulnerable to features of the care that are perceived to be of mystical quality. Such features, including antenatal tests are therefore likely to well supported.

Notion of 'routine'

Finally the examination of the reasons why routine antenatal screening tests enjoy such patronage, is helped by an exploration of the notion of 'routine'. The Cambridge Prenatal Screening Study concluded that compliance in testing was greatest if the test was viewed as benign and routine and that women react differently to tests that are new compared to those that are accepted as routine.[119,232] In my Melbourne study one respondent said:

> *I don't mind doing tests like that* (urine). *It's not really inconvenient....If it was more like I had to go into hospital and they were actually operating, I would like to know a lot more but if all they wanted was a bit of urine you can have it and do what you want with it. It keeps them happy too. Like I said, if it's just a blood and urine test then it's not really putting me out too much.*

The finding of such high compliance and acceptance was not surprising in this study that examined, in particular, women's perceptions to routine as opposed to non-routine tests. The fact that a test is perceived as harmless, however, does not justify universal use. Comparison of women's perceptions of established antenatal tests with newly introduced tests would be required to address adequately this notion of routine.

The role of social background

What is the role of social background in the acceptance of tests? Findings from this study demonstrated significant differences in expectations and subsequent utilisation of routine antenatal tests between women of different education level and, independently, health insurance status. In particular, women with higher education levels and women with private health insurance were less likely to believe in universal compliance with routine antenatal screening. They were also significantly less likely to express reliance on testing to assure a normal pregnancy and normal baby and to support the development of further tests. In addition, participants with private health insurance were half as likely to utilise blood tests for infection, serum screening for diabetes and vaginal swabs for infection.

There are two possible explanations for the differences noted in expectations and utilisation between these groups. Firstly, how routine antenatal tests are delivered might influence women's compliance. That is, differences in how women receive information and the environment in which women choose to have antenatal screening differ markedly depending on the health insurance status of the woman. Participants who attended the public hospital antenatal clinic for all or part of their antenatal care were subject to a culture of 'routine' and 'normal procedure' that was heavily dependent on high compliance to run efficiently. Pamphlets about pregnancy failed to give detailed explanations of antenatal screening tests and their reliability and offered no suggestion of choice to have or not have such tests. Antenatal clinics are by nature busy and women are aware of the pressure of using up time. The message in antenatal clinics is clear. Antenatal testing is 'just routine' and 'everyone has it'. Paternalistic messages in the pamphlets such as 'make sure that your pregnancy is progressing normally' carry an implication that women attending these clinics have little choice but to comply.[167] Whilst I did not directly observe the antenatal care provided to women with private health insurance, participants with private health insurance were significantly less likely to perceive not having received enough information or not being told the reliability of the tests. This supports findings from Shapiro who found public patients had a greater desire for information about antenatal care and were less likely to receive it.[117] Further examination of issues of informed consent are found in section 6.1.

The discussion of education level and health insurance status in the previous paragraph can be put in a wider context of the meanings of the term 'class' as it is used by sociologists such as Willis.[213] Using a sociological examination of medical dominance by class and gender partly reveals another explanation for the observed differences seen in participants' expectations by both education level and health insurance status. Some sociologists argue that there is an inherent compatibility of the class of medical professionals, what Willis calls the new middle class, and dominant class interests.[213,222,229] Such compatibility has played an important role in the support of medical dominance by professionalism and expertise. The paradox in the findings of this study, however, is that the dominant class are more cautious of the claims of medicine than their working class sisters. Educated women ask for greater

accountability. That is, whilst medical dominance has been sustained partly by support from the dominant class, it is at the same time challenged by it. This is consistent with the rise of consumerism from predominantly a white, middle class movement. Medical dominance appears to be more effective over the subordinate class. Further examination is required of the exact role of the education of women as distinct from their class, as defined by health insurance status, in this paradox in relation to gender and class.

Non-compliance

What of the participants who were not compliant with and did not demonstrate trust in the provision of antenatal care? The one participant who had not had any form of antenatal screening tests during her current pregnancy had made a conscious choice not to have screening, based on negative experiences in her previous pregnancy. But very few participants expressed negative feelings about screening. The primary concerns of these women were production of anxiety by the tests and loss of faith in the service provider and the test itself. That is, a negative experience of testing had lead them to be more cautious of its value. A few women also expressed concerns about the limited capacity of antenatal tests to provide certainty. *'...I think to place too much emphasis on tests is giving people a false sense of certainty in an uncertain life.'* Some raised concerns about the applicability of all tests for all women and felt the need for more judicious use of some tests. A few voiced some suspicions of who was actually benefiting from testing, the mother or the doctor. Whilst the views expressed above are in the minority, it is important to providing an comprehensive evaluation of the process of routine antenatal screening that these perceptions be examined. In the evaluation of screening it is not only important to detect any harmful effects, whether physical or psychological, in the screening itself, but it is also important to examine the interactions between antenatal services and the consumers. Without this examination, services that receive such high compliance run the risk of proceeding unchecked, justifying their existence on their high mandate. It has only been relatively recent in the history of antenatal screening that such perspectives have been

publicly reported. Social scientists have been largely responsible for this disclosure. [2,9,66,68-70,138]

Conclusion

Antenatal screening proceeds under a high level of medical sovereignty. Because of high compliance with, trust in and reliance on medical technologies, routine antenatal screening tests have proliferated. Approximately half of all participants in this study supported the development of more of these tests. Women want medicine and its technologies to provide certainty and guarantees in pregnancy. *'A guarantee that your baby would be born perfectly.'* Other authors have noted its success. Daly argues, 'The central role which technology plays in the ideological maintenance of medical profession's expert status has played an unrecognised role in the rapid proliferation of medical technologies over the past twenty years.'[233] The World Health Organisation (WHO) in 1985 also describes uncontrolled technological expansion as one of the difficulties facing maternity services.[234] So, is medical sovereignty, with its inherent high patronage, a legitimate determinant of the use and future use of routine antenatal screening? Is it appropriate to justify its use based on medical dominance, carefully disguised as consumer demand? The implications of this phenomenon are explored further in chapter 7.

Chapter 6. DISCUSSION - ETHICAL ANALYSIS

6.1 ROUTINE ANTENATAL SCREENING: NOT A CASE OF INFORMED CHOICE

Introduction

There has been increased debate about informed consent for consumers in Australia over the past decade. For the providers of health care, this debate is unavoidable. There are implications from an ethical, a medico-legal and importantly, a public health perspective. This section examines factors that influence women's perception about the information supplied and, in particular, their capacity to make informed choices about antenatal screening. These form the fundamental pre-requisites for informed consent. The section also examines the role of informed consent on the utilisation of routine antenatal screening tests in an 'opt out' system of screening.

What is informed consent - bioethical or medico-legal?

Informed consent in obstetrics has traditionally been examined from a bioethical or medico-legal perspective. The general bioethical discourse about informed consent centres on the respect for persons with application of the principle of autonomy.[235] It includes not only the provision of information in this process but also the issues of coercion, comprehension and competence.[235] These issues are central to a patient's right to choose. Much of the bioethical discourse about informed consent particular to antenatal diagnosis has centred on the rights of the individual to self determination obtained through the process of being given information.[134] Until recently the medico-legal interpretation of informed consent has lacked the ethical framework as described above. However, the High Court's 1983 interpretation of informed consent in Australia brought the medico-legal construction of informed consent more nearly into line with contemporary ethical perspectives. The practice of professional peers is no longer the dominant determinant of what is sufficient informed consent.[236,237] Pincus argues that 'informed consent', in the Australian legal system, has come to mean a

recognition of the patient's right to self determination, and to be given sufficient information to make an intelligent decision.[238] Such changes have lead to formal statements on informed choice from medical defence bodies[237] and professional bodies such as the Royal Australian College of Obstetricians and Gynaecologists.[239] These statements have adapted a largely medico-legal framework. Relevant to the process of offering pregnant women testing, the college states, 'The pregnant woman has the right... to be informed about diagnostic tests, medications and procedures likely to be used, reasons, common risks and benefits of proposed treatment and possible alternative courses of action'. and the right 'to exercise informed choice including refusal of treatment and/or participation in teaching and research'.[240] Therefore, obstetrics is not sheltered from the increasing debate about informed consent for consumers of health care services. Adequate information is a necessary prerequisite for satisfactory informed consent.

Information and pregnant women: the psycho-social perspective

In addition to a bioethical and medico-legal perspective, social scientists have contributed another dimension to the informed consent discourse. Various authors have identified information given by health care providers during the antenatal period as an important issue for pregnant women.[118,138,241] Oakley, from her work in the late 1970s initiated much of the public debate about women's unfulfilled desire for information in antenatal care.[138] Shapiro's Australian study also found that women failed to obtain the information they wanted from the obstetric encounter.[118] Many authors have examined, in particular, information pregnant women receive about antenatal screening.[4,5,8,9,73,112,133,242,243] Green, in the Cambridge prenatal screening study of 1200 women,[111] performed a comprehensive examination of pregnant women's factual knowledge of prenatal tests and found that fundamental knowledge of whether tests had been done or not was lacking. Lumley, following investigation of ultrasound practices in Victoria in 1991-92, questioned the notion of informed choice for women having ultrasound for fetal abnormalities.[5]

The findings from this study support findings by others that some women perceive that they do not receive adequate information about routine antenatal screening tests.[4,9,242] *'There wasn't enough information given. If there had been more information given I wouldn't have been at all stressed and I wouldn't have been worried.'* Approximately 8% of women perceived they had not been told what tests would be done and why the tests would be done. This is not inconsistent with the small number of women who were not sure about whether they had had specific tests or not. Irregularities with information perception are further demonstrated by the discrepancy noted between public patients' perception of screening for spina bifida and Down syndrome with a hospital practice that does not offer and is unable to perform these screens. Public patients were also less likely to perceive that they had had screening for diabetes and vaginal infection and this perception was lower than the hospital utilisation rates would predict. Anomalies in information perception by these women form the basis of inadequately informed consent to participate in a screening program. Not only is this women's 'right to information' unmet, but their ability to exercise informed choice, as prescribed by the Royal Australian College of Obstetricians and Gynaecologist's policy,[239] is impaired.

Role of lack of information in the utilisation of routine antenatal screening.

Findings from this study demonstrate that lack of information about screening tests that are performed routinely in an 'opt out' system, in which women must request not to participate in the screening test, means women are more likely to utilise such testing out of ignorance and 'going along' with the standard practice. That is, they are not given an effective choice. Whilst these findings are supported by Thornton's intervention study,[244] they differ from those of Marteau[4] and Kyle[243] who suggest that lack of information, in an 'opt in' system, is associated with poor utilisation of prenatal screening. Thornton, in a large randomised controlled trial in the United Kingdom, examining the effectiveness of the intent to provide extra information on prenatal testing, found that when a screening blood test has a high background use, extra information is associated with reduced utilisation of the test by women.[244] High background use of a screening test suggests the practice of an 'opt out'

system, similar to the system in this study. Marteau [4,8] questioned the role of women's knowledge and attitudes in the determination of their utilisation of prenatal screening. Both Marteau[4] and Kyle[243] found that lack of information was associated with low utilisation of alpha feto-protein (afp) screening. Both these studies were performed with an 'opt in' system of screening in which women had to request to have, rather than decline, screening tests.

There have been no studies examining the role of information in the utilisation of antenatal screening tests, in an 'opt out' antenatal screening program common to Australian public hospital outpatient services. Neither has there been study of women's perception and knowledge of routine antenatal screening tests. Whilst my cross-sectional study was not directly able to examine the effect of providing extra information to women, the study findings suggest that, for some women, having more information would have made a difference. Many of them said they would have known what questions to ask and would have had a choice as to whether they had the tests or not. *'I could have made a personal, somewhat informed decision, about whether to have all tests knowing the possible implications. I would have felt more of a participant.'* That is, further information may alter utilisation rates. An intervention study similar to Thornton's is required in an Australian setting to test this hypothesis.[244]

The role of health insurance status

The findings of this study demonstrate disturbing differences of information perception between public and private patients. Health insurance status was the greatest factor determining perceived access to information for women about routine antenatal screening. Public patients were five times more likely to perceive not getting enough information about the screening tests or the results of the screening tests and were five times more likely not to then ask for the results. Whilst this study has examined women's perceptions of the information received, other authors have examined the amount of pregnancy information exchanged in the consultation between women and care givers and women's actual knowledge of pregnancy information. These authors have noted discrepancies in the amount

of information women get as it relates to their class, education and socio-economic background.[112,118,241,242,245] Shapiro and Najman[241] demonstrated that women of low socio-economic background were more likely to perceive themselves receiving less information about pregnancy despite wanting more. This findings of this study are also consistent with Shapiro's findings, in another Australian study, where health insurance status was a more important factor than class.[118,241] Unlike Green's study, educational level was not a factor in my Melbourne study in determining perceived access to information.[112] A larger study is required to examine more adequately the impact of both education level and health insurance status on access to information on routine antenatal screening tests.

Perceived lack of information was compounded by difficulties women expressed in accessing appropriate information.

> *I had to ask what they were for!! Drs often don't give enough information- you shouldn't have to ask your G.P. very much. They should render the information as they are doing the tests/prescribing medication etc.*

> *I found him* (the senior obstetrician) *a bit brusque but I can't understand why that would be and felt a little bit intimidated about asking questions...*

These issues were more commonly expressed by public patients. As the chairperson of Consumer Health Forum states, 'many consumers have years of experience in being rushed, of not being taken seriously and of only being half listened to'.[246] Clearly, barriers to adequate information are significant to a woman's ability to make an informed choice.

This study also found differences between information delivery in the private and public setting. How routine antenatal screening tests are presented in the public outpatient department further demonstrates the lack of choice for pregnant women. Lack of a policy about antenatal screening and a practice culture of performing tasks routinely maintain a milieu whereby the genuine option for women to 'opt out' is lost. In addition, the pamphlets supplied to women in the antenatal period also did not specify that women had a choice about antenatal screening tests. A pamphlet called 'Being Pregnant' merely says: 'You will also be asked for a urine sample, have some blood taken, as well as have a smear test done. These tests are to make sure that your pregnancy is progressing normally'.[167] Women are not

given the right to refuse. With the lack of choice, utilisation of all routine antenatal screening tests becomes universal. That is, tests that may be of limited benefit to a few become routine for all.[29] This is supported by the significant difference demonstrated in perceived utilisation rates of blood tests for infection and diabetes and vaginal swab for infection by public patients in the outpatient clinic and private patients managed solely by an obstetrician. Private patient's lower perceived utilisation rates of these tests can possibly be explained by these women being more likely to be given an effective choice not to have these tests. Variations in clinical practice of individual private obstetricians may also explain these differences. The practice culture of the public outpatient department in relation to 'routine' tests, that fails to present a genuine choice to women, clearly is a determinant of public patients' high perceived utilisation of screening. Evaluation of antenatal screening services based on the broad principles of best practice finds the public outpatient department lacking. That is, it fails to incorporate sound research based practice and consumer input into its practice. It is far from best practice. In a climate of increasing demands for greater efficiencies and throughput in outpatient clinics, time to enable adequate informed choice may be squeezed further and further disadvantage women in the public system.

The role of perceived reliability of screening tests

This study also clearly revealed a lack of accurate information about the reliability of routine antenatal screening tests. Whilst 48% of women perceived not being told or not being sure they were told of the reliability of the tests, 98.1% of respondents believed the tests to be mostly or very reliable or perfect. Strong beliefs in the reliability of the tests, combined with a perceived lack of information about reliability, are likely to sustain high compliance with routine testing. This is consistent with Marteau's study of the uptake of afp screening where perceived reliability of the test is described as being one of the three factors influencing whether or not a woman undergoes the test.[8] This is supported by women's responses to the question of having a screening test with reduced reliability. Many said they would be unsure or choose not to have such a test. *' No, I don't think I would, because it*

wasn't 100% accurate and it might cause more concerns giving you a wrong answer. And you would have that stress through the pregnancy, worrying about it...'

Increased information about the reliability and limitations of many of the screening tests may lead to more discriminatory use of some tests. That is, given information about a test's inability to provide certainty, more women may elect to 'opt out' of the screening test, believing it to be potentially harmful rather than beneficial for them. A practice of giving women accurate information about the reliability of each of the screening tests is necessary to allow for adequate informed consent by pregnant women undergoing screening. However, the construction of what is reliable may be different for each woman and different from the epidemiological criteria. Therefore, interpretation of this finding is limited. For many, however, the opportunity to detect a potential abnormality, what ever the reliability of the test, was paramount and reliability was not an issue in their choice. *'I would probably still take it because I'd still think that I was better off than not having had it done - there was still like, a 50% chance that it would let you know.'*

Is information always useful?

Responses from a few participants in this study suggest that not all information received during the antenatal period was perceived as useful. One respondent said '*...I think a lot of the stories are incorrect, a lot of the information is incorrect and they've created sensationalism for the sake of sales...'* Pregnant women receive a large volume of information from varied sources. The antenatal care provider should be conscious not only of these factors but also of the context in which pregnant women receive this information. Issues of privacy,[247] confidentiality, not making a woman feel rushed or a burden must all be considered during any consultation or episode of care. These, in addition to adequate, reliable information, are important contextual components of informed consent.

Strategies for change

Participants in this study identified simple, instructive pamphlets given prior to antenatal screening as being an effective way of providing information and choice about routine antenatal screening. In addition, many women also spoke of the value of support and time to ask questions. Wood, in discussing issues of informed consent from a consumer viewpoint, argues that consumers have 'rejected the concept of informed consent' in favour of the broader concept of informed decision making. Such a concept 'recognises the role of good quality communication and partnership between consumers and providers'.[248] Whilst some guidelines already exist [236,239] to address informed consent in clinical practice, this study identifies a large discrepancy between policy and practice. In addition, the lack of adequate local practice guidelines for the providers of antenatal care within a busy public outpatient antenatal clinic may also contribute to the lack of consideration of the general principles of informed consent. Before adequate time can be allocated to women in antenatal clinics the quality of service provision must be considered, as well as the quantity and throughput. This probably requires a major cultural shift in attitude amongst the service providers.

A memorandum issued May 5, 1995 by the clinical services manager at the Royal Women's Hospital demonstrates the degree of barrier to change. 'In recent years it has become common for antenatal clinics to over run their allotted time. This is not due to an increased number of patients..... the increase in "consumerism".... has lead to an increase in the amount of time spent on individual patients. There are also inefficiencies in the way the clinics are organised..... there is little that can be done about the increased expectations of patients regarding the amount of time that will be spent with them.'[249] Clearly, going overtime is seen as unacceptable to the clinical services manager. It may be acceptable if it means seeing more patients in that time. In addition, spending increased time with individual patients is viewed as inefficient. That is, the clinical services manager uses throughput and efficiency as the outcome measures for the service. Providers are then faced with evaluation of the service by these outcomes to the exclusion of other outcomes such as service quality and patient satisfaction. This memorandum implies that consumer

expectations of consulting time and information are problematic and are in direct conflict with the outcome measures of the service

Conclusion

One of the measures of effectiveness of universal screening programs is the attainment of high utilisation rates. Perceived lack of information in an 'opt out' system of routine antenatal screening contributes to high utilisation rates. But in a climate of heightened awareness and debate about informed consent and choice will the attainment of such measures be done at the profession's peril? Can the providers of antenatal care justify high utilisation rates at the expense of loss of choice for women? And how does such practice perform when compared with public health philosophy that promotes an active role of the consumer in the health service encounter? Criteria such as ensuring adequate informed choice, equity in access to information about antenatal screening and the provision of reliable information about the rationale and the limitations of the tests, are important evaluation tools for screening programs at the service delivery level. These measures of service quality must be addressed in addition to the current obsession with service quantity and throughput. Failure to consider these criteria ignores the ethical principles of informed consent and is poor practice.

6.2 EXERCISING INDIVIDUAL RIGHTS

Introduction

Support for the exercising of one's individual rights is integral to the rhetoric of the Australian health care system. Standards of health and medical care are high. Little is denied to consumers of health care services. Screening programs are no exception. It is not surprising that consumers of routine antenatal screening tests both exercise their individual rights to utilise available screening tests and, in the main, do not question such fundamental rights. But what are the consequences of such beliefs and practices for resource allocation in health? This section examines the role of women's perceptions about their rights in the utilisation of routine antenatal screening tests and explores the context in which such beliefs are expressed. To do so it draws on an ethical analysis of rights, autonomy and justice.

Rights

Jonsen, writing in the Encyclopedia of Bioethics,[251] describes a right as an 'active moral power of a person to receive something from another as a matter of moral necessity'.[252] He goes further to say that a right is asserted as 'a strong moral justification for possessing, doing, or receiving something of considerable importance in human life'.[252] Participants in this study expressed the 'right to choose', the 'right to refuse' and the 'right to termination of pregnancy'. Few discussed the fundamental right to have routine antenatal tests. That is, women in this study protected their interests by claiming these rights and by doing so they also demonstrated rights primarily as a manifestation of autonomy. This position is consistent with the early phases of the evolution of the theory of rights.[251] Jonsen describes autonomy by saying that 'each person is a unique center of reflection and affection and an original source of action. In this, all persons are equal.'[252] Examination of this position raises issues about its place in modern society. As Jonsen argues, the complexity of current society and its health care system means that such traditional expressions of rights become problematic.[251] Jonsen goes further to say, 'the autonomy of persons which they affirm is

often frustrated by conditions of social and economic life'.[252] That is, assertion of individual rights in society can lead to conflict.

Contemporary theorists have attempted to change the emphasis from autonomy, as a basis of rights, to need.[251] They go closer to explaining the place of rights in a modern social and economic context.[251] Participants in this study predominantly demonstrated their beliefs about rights in relation to the notion of autonomy rather than need. Only a few women discussed utilisation of screening based on need. *'I am a bit concerned about tests becoming 'routine' because society 'expects' them rather than genuine medical need. There sometimes appears a spectra of overservicing and an offering of false guarantees.'* Theorists who seek to justify rights based on need have identified three fundamental human needs: nutrition, housing and health.[251] These have been incorporated into the Universal Declaration of Human Rights of the United Nations in 1948 where 'everyone has a right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, medical care and necessary social services'.[250] In this study, womens' desire for antenatal screening appears to take precedence over their actual need for these services. Oakley argues that, in the minds of the women she describes, these two notions are conceptually separable.[253] Whilst traditional notions of rights in this context were founded on the right to health care, the right to medical care is not automatically the same.[251] I explore the potential reason for expansion of the traditional rights to health care into the realm of medical care later in this section.

Participants in this study also demonstrated a readiness to transfer to others what they saw as acceptable rights for themselves. More than 90% of women believed that routine antenatal screening tests should be available to all pregnant women and that all pregnant women should have screening. That is, women showed a generosity of spirit where what was seen as good for them was also good for others and therefore all should have the same right. This was further demonstrated by participants giving similar reasons as they gave for themselves when asked why all women should have tests. Such a view is consistent with a definition of autonomy used by moral theorists as diverse as Hare, Aiken and Sartre.[254] That

is, 'Moral agents are "free" to adapt their own principles limited only by requirements such as sincerity, consistency, thinking of oneself, and willingness to apply the same principles to others.'[255]

Participants who express these particular interpretations of rights largely fail to place their individual demands within the wider context of resource allocation. Branson, calls this the 'entitlement position'. That is, such a position is 'so concerned with the rights of individuals that it ignores crucial issues of distributive justice'.[256] For the purpose of this discussion, distributive justice is 'the form of justice concerned with distributing among persons the benefits and burdens that are due to them.'[257] Among women who say that routine antenatal screening tests should be available to all pregnant women and how much these tests cost should not influence their use, the majority of the participants in this study demonstrate a lack of consideration of the notion of distributive justice. They perceive justice as rights and therefore everyone has equal rights to a test. Nozick, who privileges individual rights above distributive justice, recognises that distributive justice can be a threat to those rights.[258]

Many ethicists have discussed the conflict between the rights of individuals and the needs of populations.[259-261] However, few women in this study even examined that possible conflict in relation to antenatal screening. For many women, rights based justice and justice as fairness go together. That is, they were unaware of, or unconcerned about, the potential conflict that was raised concerning the individual rights of other women when they expressed their own beliefs. One participant, in discussing her beliefs about the value and use of screening tests became aware of this potential conflict. *'Some tests should be compulsory, especially to make sure mothers health is good. But how can I have my rights if I expect to take away another mother's?'* Others addressed the issue of conflict between their rights and those of others by arguing for the maintenance of every individual's right to choose. That is, utilisation of a resource was solely the responsibility of the individual, based on their desire. *'Routine tests should be made available to all pregnant women. They should have the right to refuse.' 'I believe it should be the women's choice after they have had the reasons for the*

tests well explained to them.' The rights of the individual play a dominant role in these women's values and motivation.

Rights in context

Why are expressions of individual rights such a significant component of the values of the participants of this study? Moreover, is it surprising? Such a response is predictable if one examines the context in which women express such rights. In particular, the very way in which medical care is delivered in Australia upholds the rights and choices of the individual.[259] The doctor-patient relationship thrives on the one-to-one contact between individuals. Whilst at the level of policy and funding, issues of resource allocation and population need are considered, the coalface practice of delivering medical care is strongly focused on the individual. Therefore, it is not surprising that the dominant culture and values of medicine were manifested in the participants' responses.

Secondly, the particular high standards of health demonstrated in the majority of non-indigenous Australians, in part, explains the capacity of the consumers of health care to transfer presumed rights for health care to rights for medical care. That is, for most non-indigenous Australians the need for care is limited and the right to health care is a given. As the right is largely satisfied, many presume that this right now extends to the right to receipt of all forms of medical care including new medical technologies, treatments and services that, till recently, have been subject to little restraint. The same is true for antenatal services and screening: the very nature of our excellent health care system supports the dominance of individual choice and rights.

Thirdly, the notion of screening tests as 'routine' is an important factor in the discussion of individual rights. If a test is presented to the consumer as 'routine', various assumptions are made. Routine denotes universality; everyone has it. For a test to be offered to everyone, the reason for the test must be important. That is, the test must be addressing a significant health problem. More importantly, if the experts (health care professionals) ask everyone to have

such a test, it must be inherently good for all individuals. Whilst the principle of universal screening is to detect the few abnormal cases and, by doing so, improve the health of the population screened, individuals receiving the test perceive that test to be necessary and significant for themselves. Whilst the test may be of limited value to all but a few, its importance to the particular individual being screened is exaggerated.

Thus, the predominance of the individual is sustained by a current health care system that to date has delivered highly individualistic, high quality medical care as the mainstay. Chapter 7 considers further a number of related questions, including whether it is reasonable to ask the consumer to be more discerning in relation to their expression of individual rights and whether the dilemmas raised by the conflict between individual rights and needs of the population should be addressed by the policy developers, the funders and the providers of health and medical services.

Education and rights

How can the differences in expression of rights and ability to locate them within a broader context between women of different education level and health insurance status be explained? Participants with higher education level and higher age were significantly less ready to transfer what they saw as acceptable rights for themselves to others. Those with higher education level and those with private health insurance were also more likely to consider the broader implications of all individuals claiming access to a test and its potential costs. This is not to say these women would not prioritise their own individual desires and rights over the needs of the population as seen by the other participants. However, examination of their reflections of these issues demonstrated a greater capacity to consider a broader perspective beyond their individual experience. Education of women may be one avenue in which to broaden the perspectives of consumers of health care services. In considering this avenue it is important to be mindful of a contemporary view that education and health promotion can both inform and enlighten, provided that it involves 'working with people's attitudes and beliefs' and accepting 'the autonomy of the individual'.[262,263] Weare

goes further to stress that 'if health promotion wishes to work within an educational framework as a whole, it must make more use of the insights of the philosophy and sociology of education'.[263]

Conclusion

Whilst the ultimate availability of an antenatal screening test is largely determined by the providers of the service, the ability of any one individual to choose to utilise routine antenatal screening tests is in part dependent on the individual's values and beliefs in relation to their rights. A predominance of the expression of an individual's right to use available services contributes to the high utilisation of routine antenatal screening tests as found in this study. It is not, however, surprising to discover the dominance of such values in the context of the how health care is delivered in Australia. The predominance of these values will assist in promoting increased availability of more tests to more people. That is, values based on individual rights or autonomy, rather than on need, will perpetuate the expansion of antenatal screening programs. This has implications, addressed in chapter 7, for the appropriate allocation of increasingly scarce resources in health. Whilst increased education of women may be one way to introduce a more judicious use of screening tests the responsibility for this process, given the context in which health care is delivered, more appropriately lies with the policy makers and service providers.

6.3 ALTRUISM AND PREGNANCY

Introduction

An increase in the debate about fetal and maternal rights is evident in contemporary ethical and medico-legal literature. This debate raises concerns not only for those providing pregnancy care but also for pregnant women who bear the responsibility for the care of their fetus. Examination of the perceptions about these rights by pregnant women is lacking. How do pregnant women perceive their fetus? Is it a person? Does it have rights? How are those rights expressed? In addition, are pregnant women altruistic and how is that expressed? What are the implications of these concerns and perceptions? This section examines women's own perceptions about self and their fetus through examination of their beliefs and utilisation of routine screening tests during pregnancy. I draw on ethical and feminist constructs of the notion of person to examine the findings. In addition, the notion of altruism in pregnancy, its context and its potential abuse is examined. Further, the role of altruism as a determinant of the use of antenatal screening tests is explored.

Fetus as a 'person'

Ethical interpretations and justifications for the concept of person are varied.[264] Contemporary writers attribute personhood based on 'an assumption of moral agency, at least on the part of those whose duty it is to respect others' lives or rights'. [265] As van Melsen states 'as a responsible being, a person is subject to rights and duties'.[266] That is, possession of rights is bestowed on a person as a result of being a person. However, the construct of fetus as person or not is dependent on the definition of person. Ethicists such as Dennett, Frankfurt, Tooley and Warren attribute conditions necessary for the exercise of responsibility as well as rights including the capacity for moral agency and as such do not attribute personhood to the fetus.[264] Others, however, attribute personhood to fetuses such that they have rights without responsibility whilst others suggest there is a developmental

character of personhood and as such a fetus may become a person over time.[264] Some feminists, relying on the concept that personhood is socially constructed, agree with the former ethicists in relation to the fetus. That is, 'There is no 'personhood' for the fetus apart from its relationship to the woman.'[267] Such diverse definitions of person underpin much of the debate about the rights of the mother and the fetus. In the recent inquiry into 'Fetal welfare and the law', commissioned by the obstetric and paediatric colleges, the Australian Medical Association and the Medical Protection Association of Australia, a diverse range of opinions about fetal rights were collected from health care providers, lawyers and consumers.[268] In this report the position of the fetus was stated as follows: 'Under Australian law, a fetus is not a person. It follows that it does not have the rights possessed by a human being.' However, the report went further to state that 'there are a number of situations in which the law has recognised the existence of the fetus' and that 'it is capable of possessing interests which will crystallise at birth'.[269]

Pregnant woman as a 'person'

Whilst the notion of person is discussed in relation to the status of the fetus in ethical discourse, examination of the notion of person in relation to pregnant women is problematic. That is, in some ethical discourse the construct of person is presumed to be masculine. In discussion of person, van Melsen writes, 'Each individual man is an original centre of being and action. His actions are his own.'[266] This is a dismissive notion of person. Discussion of the concept of person and rights for pregnant women, however, is expanded in feminist discourse.[270-276] Much of these examinations suggest an impoverished notion of person pertaining to pregnant women. Macklin argues that women, and more so, pregnant women, are subject to violation of respect for person and should be treated 'with dignity and respect instead of as "fetal containers" '.[270] Such examination suggests that the definition of person is gendered. That is, as the construct of person is masculine, pregnant women are denied the same rights, respect and autonomy as 'person'. Lebacquz's entry on feminist ethics in the Encyclopedia of Bioethics, points out that by being denied the freedom of reproductive choice by society, women are made to be 'less than fully human' and therefore

'denied their intrinsic value as persons'.[267] Maier goes further to suggest that, 'When fetal rights take precedence over women's rights, women are, in effect, declared nonpersons under the law.'[272] On the other hand, Mahowald, another feminist bioethicist argues that 'the status of the pregnant woman as a person is generally uncontested' and that 'like other women, the pregnant woman is a biologically mature human being capable of bearing a child; unlike some other women, she is actually exercising that capability'.[277] She, like others though, examines the maternal-fetal relationship through differences in moral agency.

Conflict of rights

Feminist authors have also added to the critique of the potential competition of rights between the fetus and the pregnant woman.[271-274,276] Maier objects that 'seeing fetal rights in opposition to women's rights is a distortion of the condition'.[272] but, because of rising threats to the autonomy of pregnant women in the workplace[271] and in society,[273] especially in the United States, much of the debate has focused on the rights of one pitched against another. Not only have these threats sought to violate pregnant and non pregnant women's rights as person, but they have sought to elevate the rights of the fetus and, in some cases, a potential fetus[271] above that of the woman.

Rothman's critique of fetal rights addresses the role that medical technology has to play in the debate.[274] She argues that medical technology in pregnancy has not only rendered the fetus visible and the mother invisible but also makes 'us aware of the "unborn" as people'. Further, she suggests that in the context of women saying they are well and healthy, providers of pregnancy care may see the fetus as 'tiny, helpless, dependent'. Millikin agrees, stating that 'improved technologies have given the fetus an enhanced human identity and status as a direct patient of the obstetrician'.[279] Lebacquz states further that 'prenatal diagnosis begins to "commodify" pregnancy, turning it into a search for the perfect product'.[280] That is, medical technology in pregnancy has contributed to the potential conflict of needs between the pregnant woman and her fetus as experienced by the providers of pregnancy care.

The inquiry into 'Fetal welfare and the law' [268] acknowledges that the use of rights to discuss these issues is both unhelpful and adversarial and as such should be abandoned for a 'more flexible analysis.'[281] It, too, argues that medicine and technological advancement has allowed the fetus to be seen as a separate entity and as such has produced the rights discourse and ultimate conflict. Further, it recommends that a pregnant woman's autonomy should be respected and that ' the interests of the fetus should not over-ride those of the woman'. [281]

Womens' experience

Both the recently conventional ethical and the feminist theoretical positions lack examination of the majority of women's lived experiences during pregnancy as it relates to person.* How do pregnant women construct person for themselves and for their fetus? And what is the role of routine antenatal screening tests in this construct? Findings from this study suggest two elements of an answer. Firstly, the study shows that women do perceive their unborn baby to be a person. The language of the women supports Thornton's view that they have a 'behavioural definition of personhood' which is socially constructed.[282] Secondly, women also believe their unborn baby has rights. *'All unborn babies should have the same fair chances to rectify any problems.' '...because I think it is the right of the baby to have a good chance at a healthy life.'* In many instances, these rights are elevated in consideration above their own.

> *Tests still should be carried out even when a healthy pregnancy - it's the baby that counts.*
>
> *It is the best care for the baby* (having routine antenatal screening tests) - *almost a form of child abuse not to test.*
>
> *I believe people should take a more proactive attitude to all health care issues - but especially during pregnancy where you have a responsibility also to another life to give it the best chance possible.*
>
> *I was always concerned about her. I was much more concerned about her than me. In fact, the weekend before last when I was really sick, I thought if*

* W.T. Reich, editor of the Revised edition of the Encyclopedia of Bioethics, explicitly notices the emergence of various schools of thought and the significance of both old and new 'voices' in any up to date understanding of bioethics. [276]

anything happened to me could they save her not me? ...When the first lot of tests came through they said she's not at risk, you are. You are at risk now and we have to deliver her for your safety. And I said, 'oh can't we wait just a little bit longer, can't we go for another one or two weeks?', and they said no - it's just not safe for you anymore.

Well I mean, any woman if you ask them truthfully, if there's a choice between their husband and their child, saving one or the other from a wreck - which would they save? I think you'd probably find 99% would save the child. It's that protecting. I don't think there's anything you could get closer to.

Altruism

Whilst only 3.4% (12 of 344) of women expressed negative feelings about being tested, some participants also endured negative experiences of routine antenatal screening tests for the sake of their unborn baby. *'I wanted to stop taking prescribed medication but kept saying to myself, "just think of the baby".'* That is, pregnant women's regard for their baby's rights is the principle for action. Responding to the rights of others shows women to be altruistic. Altruism, in this context, is consistent with the Oxford dictionary definition of 'regard for others as a principle of action; unselfishness'.[283] This is also consistent with ordinary usage of the term altruism which is restricted to ' a placing of the interests of others ahead of those of oneself' without the addition of ' for its own sake'.[284] Rothman would agree that this is not a new phenomenon.[274] That is, the notion that women are fetal advocates, is inherent in the notion of motherhood. Altruism is virtuous. It is a precious commodity. It, therefore, demands a higher order responsibility than it is often given by society.

This study further suggests that altruism is, in part, a determinant of the use of routine antenatal screening tests. This is supported by the findings that 95.2% of respondents believed even maternal routine antenatal screening tests were done for the benefit of the baby. Participants both highly valued and utilised routine antenatal screening tests because of perceived benefit to their fetus and their ability to address the right to health for their unborn child.

Abuse of altruism

Altruism is also vulnerable to exploitation and abuse. It is potentially abused by the providers of antenatal care who support the medicalisation of pregnancy and birth and the increasing role of medical technology. That is, deference to the rights of the fetus over the mother by health care providers, can be used to justify and increase the use of screening and other interventions in pregnancy. It also allows the opportunity to criticise women for not being entirely altruistic. For whose benefit is counselling about drug intake, diet and other behaviours done during pregnancy? Are pregnant women really considering the impact of maternal behaviour on their fetus? In a context also, where society attempts to devalue women, as supported by Rothman,[274] the inability of pregnant women to be altruistic may potentiate feelings of guilt, fear, and burden. She argues that pregnant women are often viewed as 'a potential adversary, a potential barrier to the optimum medical care of the fetus'.[285] Many participants in this study expressed concerns for women, about the potential negative impact of their inability to be completely altruistic during pregnancy.

> (I worried) *That I may have done something/not done something which would harm my baby.*
>
> *That they* (pregnant women) *will do damage to their baby if they do or don't do certain things.' 'Will the baby be healthy -eg. the time you took medication, had a fall, got drunk etc. before you knew.*
>
> *If they* (pregnant women) *are doing the right things, eating properly.*

These concerns were highlighted by women with drug dependencies.

> *...but my greatest fear was because I'm a smoker. So everyone sort of scared me. And all the things you hear and you read, you know, 'am I putting my baby that much at risk?*
>
> (I was anxious) *Because I was on methadone and there is a chance that the baby may hang out.' 'Through my own selfishness,* (being addicted to drugs) *never again.*

Whilst the inquiry into 'fetal welfare and the law' recognises that pregnant women go 'to great lengths of personal discipline' to put fetal wellbeing ahead of their own, the recommendations in relation to responsibility are potentially problematic.[286] By

recommending the placing of responsibility on the women themselves it negates the need for legal intervention but leaves room for exploitation of pregnant women.[268]

Whilst the conventional ethical notion of person would appear to be insufficient to explain the findings of this study, the feminist perspective of the gendering of person alerts us to the vulnerabilities of the altruism expressed by pregnant women. It tells us to be critical of the dangers of interpretation of women's altruism. It tells us to examine altruism in the context of society's values of the role of women.[274] Although they are not examined here, a number of questions about society's values and the role of women arise from the argument from the preceding paragraphs. Whilst women are being asked to be responsible and consider the rights and needs of the unborn child, what is also being asked of fathers, families and society in relation to these needs? Feminist perspectives allow some protection to pregnant women from exploitation and abuse.

Altruism and termination of pregnancy

The findings of this study also suggest that altruism appears, on the surface, to be incomplete. Participants valued routine antenatal screening tests because they believed that they gave them choice, including the choice to terminate a pregnancy, if a fetal abnormality was found. Is this at odds with women's altruism? Thornton would argue that parents still view their abnormal fetus as a person but can consider termination of the pregnancy based on what the author calls, 'The Golden Rule.'[287] That is, parents can choose to terminate a fetus with an abnormality, that they consider to be a person, by following the rule of 'do unto others as you would they do unto you'.[288] The implicit premise is that they consider 'I would not like to be like that myself.' But, for parents to consider the potential impact of a fetal abnormality on that child and other family members, they must also act altruistically. Therefore, both perspectives appear relevant.

Conclusion

Women are not altruistic in isolation. Increasing medicalisation of pregnancy, including the introduction and development of antenatal screening tests, has directed its attention to the survival and wellbeing of the fetus. Medical technology, that provides potential to more closely examine the fetus, has heightened the perception of risk to the fetus by pregnant women, and made the construct of altruism in pregnancy irresistible. Altruism, must therefore be recognised in such a context. Balancing this version of altruism with the conventional ethical definition of person and the feminist concept of the gender of person is paramount in reducing potential abuse of this worthy position. Compliance and altruism sometimes comes at a price. Altruism must also be considered as a powerful agent in the use of routine antenatal screening by pregnant women.

6.4 THE ACT OF OFFERING SCREENING

Introduction

Medicine has embraced the development of screening tests as a worthwhile advance in the prevention of illness and maintenance of health, even as a way to optimise health.[289] But is screening good for our health? Is the act of offering screening harmless? In obstetrics screening tests have also been found to be highly regarded by the providers of antenatal care, in some instances, regardless of the actual tests offered.[290] A study in 1985 of clinicians in 67 teaching hospitals in the European Community examining their antenatal screening policy found that 'screening activity was seen as beneficial regardless of which tests were used.'[291] What do the recipients of antenatal care feel about antenatal screening? This section examines the experience of pregnant women of being offered screening tests. It explores the implications of offering screening programs to a largely young, healthy population. In a climate of good health outcomes for mothers and babies are we creating the 'worried well'?[63] Are our tools for measuring the effectiveness and worth of screening tests inadequate? Further, I discuss the role of offering screening in relation to its uptake by pregnant women and the context in which this occurs.

Why are screening tests special?

Many argue that screening tests, as opposed to diagnostic tests, are performed on people who would otherwise consider themselves to be healthy.[39,63,289] The definition of screening used in this dissertation is 'the identification, among apparently healthy individuals, of those who are sufficiently at risk of a specific disorder to justify a subsequent diagnostic test or procedure'.[46] Screening tests are usually initiated by health care providers for individuals perceived to be healthy. As such, the term 'non-compliance' is not appropriate to use for non attenders or non-users of screening programs.[292] Evaluation of a screening test differs from that of a diagnostic test. Examination of the prevalence of the disorder, the natural history of the disorder and the epidemiological parameters of the test are particularly important. The

lack of a gold standard against which a screening test is judged, such as the criteria for diagnosis of gestational diabetes, adds to the complexity of evaluation of a screening test. Screening tests offer the potential for prevention of disease, illness and harm. So they are rarely considered for any potential harm they may cause.

What are the potential consequences of offering screening?

As previously discussed in chapter 2.3, offering screening to otherwise healthy individuals has the potential to arouse fears and suspicions of potential disease in a person.[63,64,292] Maclean and others, in their study of women who declined to attend screening for breast cancer, suggest that offering screening may invoke the same fears as when a woman suspects she has breast cancer.[292] As discussed in chapter 2.3, Shickle and Chadwick argue that the act of offering screening, in itself, implies to recipients, that they may not be healthy after all and that by promoting screening we create a community of 'worried well'.[63] Does this process also occur in screening in pregnancy and, in particular, routine screening activities in pregnancy? Because of the unique features of screening, Cuckle and Wald caution providers of antenatal care to be conscious of the consequences of this process. 'there is therefore a special obligation not to initiate any action unless the full consequences of doing so are known'.[46] Do we know the consequences of offering screening tests to pregnant women?

Screening and pregnancy

In examining the role and consequences of offering routine tests to pregnant women it is important to consider the special features of pregnancy.

i) The population

The population of women screened during pregnancy is congruent with populations undergoing screening for many other conditions. That is, they are usually young, fit and healthy. Findings from this study are consistent with such a population. The median age group was 27-34 years and the majority of mothers were in good health. In Australia,

maternal and fetal mortality and morbidity rates are also extremely low. Such outcome measures reflect, in part, a healthy population. Women and babies can expect not only to survive childbirth, but to be healthy. Whilst women with stillbirths, neonatal deaths and severely sick infants were not approached for this study, the congenital abnormality rate was low (4.5%) and the majority of abnormalities were mild.

ii) Medicalisation of pregnancy

Coincident with the improvement in health outcomes, pregnancy care over the past century has undergone a process of medicalisation. There is a certain irony in this. Pregnancy and childbirth are now regarded in medical terms as being potentially abnormal: as Enkin and Chalmers argue, 'obstetrics has moved toward the concept that no pregnancy is normal, except in retrospect'.[29] The development of screening programs in antenatal care has been consistent with the medical model of pregnancy at the very time when the need for screening has, in a sense, diminished. In a further irony, there is now the potential for an illness paradigm of pregnancy in which the whole process is seen as a pathological process with specific illness parameters.[80] MacIntyre, a sociologist, argues that the illness model of pregnancy is a dominant paradigm that divorces itself of the social and psychological context in which the alternate paradigm of pregnancy and childbirth as a natural process is embedded.[293]

Antenatal screening tests seek to detect the abnormal and therefore assist in defining pregnancy as a potential abnormal or pathological process. Such views are very persuasive to both the antenatal care provider and to the recipient. Thus, the act of offering screening, within a context of pregnancy as an illness, strengthens the likelihood of the recipient of the screening test perceiving herself as potentially abnormal. This is supported by the findings of this study that 57% of participants expressed negative expectations about the tests. Participants feared the tests might have detected abnormality with themselves, their pregnancy or their baby. *'To detect any abnormalities/deficiencies that could effect mother or baby during pregnancy and when baby is born.' '...they allow early detection of any*

abnormalities in the fetus and the mother.' In particular, many participants described how undergoing screening had changed their perspective about their health and well being.

> *...I do get concerned about overtesting. I've known of other women who I think have had a test every second or third week for what I don't know. And they're almost convinced something's wrong because they're having all these tests.*
>
> *It was only after I'd been to the doctor that I spent the rest of the time concerned that something might be going to go wrong.*

Therefore, the process of offering screening tests for these women accorded well with the belief that pregnancy and childbirth are potentially abnormal. If pregnancy and childbirth are potentially abnormal then utilisation of tests that will declare such abnormalities will be enhanced.

iii) The 'magic' of screening

Findings from this study suggest that the screening process itself had another magical dimension in pregnancy. It was ascribed the ability of conferring or ensuring health and normality on the pregnancy and the fetus. *'They ensure the baby's health is well and its progress is normal.' 'To determine baby's future...'* By ascribing such powers to testing, two things happened to women during pregnancy. Firstly, women in this study said that they 'put the pregnancy on hold' until the screening tests conferred normality or abnormality. These findings are consistent with those of Rothman, who studied 120 women and their perceptions about amniocentesis.[274] She argues that technology changes the meaning of pregnancy for the mother and demands that the pregnancy begin with a separation and distancing that she calls 'the tentative pregnancy'.[274] That is, pregnancy does not begin until the tests give the 'all clear'. This is a very powerful and emotive role ascribed to antenatal screening tests. No longer do women believe physical changes in their body or quickening to signal pregnancy. Secondly, participants demonstrated a reliance upon these screening tests and medical technology to determine the outcome of their pregnancy. The reliance on testing to both signal pregnancy and determine healthy outcomes is a strong determinant for the utilisation of routine antenatal screening tests by pregnant women. The notion of reliance on medical technology is discussed further in section 5.2.

iv) The role of 'routine'

Screening tests in pregnancy are distinctive in that the majority are offered as routine, most commonly in an 'opt out' system. Many argue that in the history of the life of a screening test becoming routine, the compliance with screening increases and the test is eventually viewed as innocuous and 'matter of fact'.[119,232] Green states that 'Their (pregnant women's) assumption that the procedure is benign is, of course, encouraged by the fact that scans are routine and given to everyone.'[294] In my Melbourne study, 93.8% of participants regarded routine antenatal screening tests as a necessary part of a normal pregnancy and complied with the majority of tests available. High compliance would suggest that the tests were perceived as benign but, despite high compliance and acceptance, participants did not expect the tests to be normal. Whilst they hoped for health and normality, a high percentage feared, and indeed, expected negative outcomes for their pregnancy and their baby. Thus, routine screening tests, despite high compliance, still represented potential abnormality.

v) Two patients

Screening programs in pregnancy are unique in that they are directed at two patients. Thus, there is potential for the pregnant woman and the fetus to be abnormal. Since the 1960s, screening has offered the ability to obtain knowledge about the fetus and thus to consider another potential abnormal patient.[12] X-ray, and then ultrasound, were able to give inside pictures of the pregnancy and the fetus that were not previously possible. This is a very potent consideration for pregnant women. As Green states, 'To have doubt cast upon the health of the fetus is very stressful especially for a woman with no prior reason to consider herself at risk.'[295] That is, not only can the act of offering screening raise the potential of abnormality in oneself, but more importantly, abnormality in the fetus. As is discussed in section 6.3, pregnant women in this study demonstrated strong values in relation to fetal rights above their own. The potential for abnormality in their unborn child would raise considerable concerns and support the utilisation of all available antenatal screening tests.

vi) Role of the expert

The act of offering screening can not be viewed context free. It is not a neutral process. Screening for conditions in pregnancy, as others, is generally offered to people by experts. Shickle and Chadwick[63] recognise these phenomena and argue that acceptance of a screening test will be enhanced by the fact that it is being offered by someone who is seen to know best, usually a doctor. Maclean, who studied the perceptions of attenders and non-attenders at breast screening clinics, suggested that the fact that the invitation to screening was given by a woman's doctor meant greater compliance by the attenders.[292] In the study by French et al of women attending breast screening in the United Kingdom, the role of the doctor in attendance at screening was also a dominant feature.[296] Thirty three per cent of attenders in French's study agreed they had been influenced by their general practitioner's interest in screening. Screening is 'official' was given by many women as one of the 'passive' reasons women gave for attending: this demonstrates further the lack of neutrality of decision making.[297] Thus, when an expert in disease, who believes that there could be something potentially wrong, offers a screening test, the notion of health and wellness changes to suspicion of illness and abnormality. In relation to childbirth and pregnancy, MacIntyre argues that women 'cede control over the process to medical experts' with the implicit corollary that 'Childbearing is regarded as highly hazardous, with medical assistance and intervention being uniformly necessary.'[293] In my Melbourne study of postnatal women, utilisation of antenatal testing was found to be supported by women's high level of trust in and regard for the provider of their antenatal care. Further discussion about trust in medicine is explored in section 5.2.

Are the tests to blame?

Reasons for the utilisation of antenatal screening, as demonstrated by this study thus far, are complex. In addition to the act of offering screening, many other factors may explain the high utilisation seen in this study. People who utilise screening may be those people in the population who already view themselves as potentially abnormal and therefore seek out screening. Studies examining the perceptions of attenders and non-attenders at breast

screening clinics suggest that the women who attend are more likely to participate in other health promotion behaviours such as cervical smears, regular visits to dentists, use of health foods and attendance at keep fit classes.[292,296] But such activities suggest a positive attitude to health and normality rather than abnormality. Are some women anxious about potential abnormality beforehand? The Cambridge Prenatal study, that examined anxiety levels in women before and after screening, suggests that screening was utilised by those who were more anxious initially.[119] In this study, as seen in section 5.1, a potent determinant of the utilisation of routine antenatal screening was found to be fear or a feeling of being at risk. So, are the expectations of negative outcomes for the pregnancy a reflection of a pre-existing notion of risk or a result of the medicalisation of pregnancy, which includes antenatal screening programs? Both are probably true and contribute to women's utilisation of screening.

Differences in screening

The act of screening, by raising awareness of the possibility of the abnormal, leads to high utilisation of screening by pregnant women. This finding is not congruent with findings from screening programs offered for cancer.[292,296,298] That is, if the act of screening raises potential fears and anxieties in women, should not the utilisation of such tests be low as seen by the non-attenders at breast screening clinics?[292,296] I suggest that the incongruity lies in the difference between screening in pregnancy and screening for cancer in an individual. Firstly, as discussed in section 6.3, pregnant women demonstrate altruistic beliefs about the rights of their unborn child and, as such, these beliefs may override their own anxieties and fears of adverse outcomes that would otherwise have inhibited their capacity to participate in screening. In addition, this study has also demonstrated that many women undergoing antenatal screening tests are not given a choice or right to refuse, unlike an invitation in the post to attend a breast screening clinic. Therefore, there may be a group of women who have participated in antenatal screening through lack of choice who would otherwise be non-attenders at other screening programs and not participate in other health promotion

activities. As Maclean suggests, the organisation of obstetric and midwifery care may be contributing to applying undue pressure on these women who can't decline testing.[292]

Conclusion

The practice of screening in a context of increasing medicalisation of pregnancy and childbirth, illustrates well the potential harm created by the act of offering screening tests to apparently healthy individuals: the very act of offering screening implies the potential to consider oneself or the pregnancy and fetus at risk or abnormal. Particular to the act of screening in pregnancy is its elevation in status to a major determinant of the outcome of the pregnancy. Elevation in status brings with it unrealistic expectations of, and a reliance upon, ensuring normality and health: it also runs counter to the standard criteria about evaluation of screening tests according to predictive values, false positive and negative rates and cost benefit analyses. A consideration of sociological perspectives about the role of screening, within the two paradigms of health and illness helps to illuminate the potential problems of routine screening. Recognition of the potential negative impacts of offering screening to healthy individuals is necessary to fulfil the moral obligation of 'do no harm'.

Availability of termination of pregnancy

Findings of this study, where 33% of participants would consider and 50% were not sure about having a termination of pregnancy in the event of a diagnosis of a fetal abnormality, demonstrate that many women would answer this question with an underlying assumption that termination of pregnancy was available for such a reason. As Halliday's Victorian study indicated, 'Women who have prenatal diagnostic tests are likely to have considered carefully the possibility of termination of pregnancy, if an abnormality were detected.'[299] This is further supported by participants who expressed the value of routine antenatal screening tests as being the ability to detect fetal abnormalities and allow for choice of termination of pregnancy or not. In practice, in Victoria, this is the case. Terminations of pregnancy for

fetal abnormalities following prenatal diagnosis rose from 82 in 1986 to 250 in 1994.[94] (These statistics are issued from the registry for fetal abnormalities and may under represent the true number arising from termination of pregnancy) However, legally in Victoria and New South Wales, '...fetal abnormality is not a ground for termination of pregnancy and that, at least in theory, doctors who undertake a termination on that ground may be prosecuted for abortion or child destruction'.[300] Abortion, under Section 65 of the Crimes Act 1958, is still a crime in Victoria. But because of the difficulty in proving (beyond reasonable doubt) a negative (that the doctor did not honestly believe that the termination of pregnancy was necessary to preserve the physical and mental health of the woman), there have been no prosecutions for abortion since the 1970s.[301] Skene, a senior lecturer in law, argues that the law should be changed to support the practice especially since prenatal screening is part of routine obstetric practice.[301] I support this view.

CONCLUSION

Utilisation of routine antenatal screening is determined, in part, by a complex array of social and ethical factors. Such factors are inherent in the values, beliefs and practices of women during pregnancy. To date, many of these factors have been absent from the debate about the worth of antenatal screening. Exploration of the experiences and perceptions of the users of routine antenatal screening has enabled consideration of these factors. In particular, awareness of the role of pregnant women's perception of risk and the way in which this perception is addressed by medical technologies, is important to the understanding of the use of routine antenatal screening programs.

Chapter 7 THE FUTURE

7.1 IMPLICATIONS

Introduction

High utilisation of and support for routine antenatal screening tests as demonstrated in this study raises a number of implications for the future practice of obstetrics and public health. In particular, the social and ethical influences on the use of antenatal screening demonstrated above raise a number of significant issues for both the consumers and providers of antenatal care. Those issues are medicalisation of pregnancy, resource allocation, expectations for pregnancy care in the future and medico-legal implications. This section explores some of these issues.

1. Medicalisation of pregnancy

The majority of women in this study do believe that routine antenatal screening tests are a necessary part of normal pregnancy for all pregnancies. That is, these technologies have been incorporated into what women now believe to be normal pregnancy care. In addition, participants demonstrated high levels of trust and acceptance of the pregnancy care offered to them by professional health care providers. Both of these components clearly contribute to the medicalisation of pregnancy care. But what is the basis for women's acceptance of this medicalisation?

The the pattern of provision of antenatal care services and its contribution to the medicalisation of pregnancy has come under increasing criticism by various interests over the last 30 to 40 years. Many concerns have been raised about the medical context in which antenatal care is delivered. In 1963, Atlee, a Canadian obstetrician, published his concerns about the profession managing pregnancy as abnormal or a pathological process. He was critical of the pathological philosophy of maternity hospitals and medical education.[302] Hern,

in 1975, took the concept of pregnancy as pathological to its extreme in his publication.[80] The 1970s and 1980s witnessed the surge of feminist and social science critique of the medicalisation of pregnancy and childbirth. Oakley, Mitchell, Kitzinger and MacIntyre documented their concerns about this medicalisation of pregnancy and childbirth following the growth of qualitative methods to explore women's experience.[81,136,138,225,303] Kitzinger, in her discussion of the 'technological take-over of childbirth stated that 'The modern technology of obstetrics, with its winking lights and humming machinery, is reassuring for some women but alarms many others.'[304] These authors raised not only concerns about the impact of professionalism in pregnancy care but discussed issues of control and gender.

Today, concerns about the medicalisation of pregnancy and childbirth are raised by clinicians,[29,42] anthropologists[305] and social scientists.[77,213,222,306] Keirse was concerned about specialist obstetricians who appeared to 'do everything possible to prevent even the rarest occurrence of disaster'.[307] In particular, Lumley suggests that pregnancy screening tests are at the top of the intervention cascade in pregnancy management.[77] That is, the chance of medical intervention in pregnancy management increases after performance of screening tests.

Notwithstanding this critique pregnant women demonstrate high acceptance of this medicalised service. One of the explanations for pregnant women's acceptance of these services is revealed by examination of the interaction of pregnant women with these services. Common to much of the above discourse is the portrayal of pregnant women as being passive or even as a victim in this interaction with antenatal service provision.[81,302,303,306] Kitzinger states that as a result of medicalisation of childbirth 'many mothers feel that it is not they, but the doctors, who are having the baby'.[304] In addition, Oakley discusses the perception of pregnant women as just the containers for unborn children.[303] However, Sargent, in a qualitative study of patient and staff perceptions about caesarean section, argues that pregnant women are not passive and that there was a high acceptance of the medicalisation of birth and an expectation that technological intervention at delivery was

not a failure.[305] Further, Steer argues that individual choice or 'consumer convenience' partly drives further developments in medical technology in maternity.[308]

I argue that it is pregnant women's beliefs and values in relation to their medical care which are critical to the understanding of this interaction. Modern obstetric care offers expertise, professionalism and science.[213,222] Modern obstetric care offers the promise of certainty in the context of uncertainty. Modern obstetric care offers insights into the unborn baby. It offers magic and mystique.[213,214,229] Therefore, this medicalised approach to antenatal care is trusted, relied upon and complied with. In addition, the particular act of offering screening to otherwise healthy women raises the potential for abnormality or pathology and therefore encourages a dependence on medicine to manage such events. That is, they create their own demand and their own market. No longer are the physiological changes of pregnancy trusted to signal pregnancy; that is the domain of antenatal tests. One of the outcomes of this interaction is that medical dominance of pregnancy care is disguised as 'consumer demand'.

In addition to the patronage of medicalised pregnancy demonstrated above, the findings of this study suggest that two other factors are important in sustaining this process. Firstly, the high perception of risk of adverse outcomes demonstrated by the participants of this study suggests that the use of routine antenatal screening tests is seen as a way of taking out insurance against bad outcomes. Technology in pregnancy care is viewed by these women as a way to provide reassurance, safety and ultimate insurance. Many participants of this study also expressed support for more technology, more insurance. Support for these interventions may also involve support for other medical interventions in pregnancy and birth that are perceived to provide insurance against adverse outcomes, in particular, antenatal and intrapartum electronic fetal monitoring and caesarean section.

Secondly, medical technologies that offer the promise of protection of the fetus and insights into its welfare have the potential to exploit the altruistic nature of pregnant women who not only perceive their fetus to be a person but also to have rights that predominate over their

own. For many women, the responsibility of care of their fetus is entrusted to technology and the doctors, the ones 'who know best'.

Thirdly, this study also demonstrates only a complicit acceptance of these tests by some participants who have not received adequate information or opportunity to make informed choices about whether to have the tests or not. Lack of informed choice is associated with increased utilisation of antenatal screening and thus supports the role of medicalisation of pregnancy care.

Is the medicalisation of pregnancy, based on consumer demand, justified? I have argued above that lack of informed consent, medical dominance disguised as consumer demand and a society that feels 'at risk' of adverse outcomes are not legitimate reasons to support the growth, development and application of medical technologies and expertise to all pregnant women. As other authors have noted, the application of sophisticated medical technology is totally inappropriate to most.[29,306] Support for the medicalisation of pregnancy will in turn support the need for more technologies and more experts, a need that is unnecessary for the majority of pregnant women. The consequence of this process is not only inappropriate use of expertise and technology but additional monetary, physical and psychological costs to those who will not benefit from these interventions. Some of the adverse effects of antenatal screening are discussed in chapter 2.3. Many authors have discussed the impact of medicalisation of pregnancy and childbirth on pregnant women.[81,225,234,303] It is beyond the scope of this dissertation to explore the potential negative outcomes of the medicalisation of pregnancy and childbirth.

2. Resource allocation in health

The values, attitudes and beliefs of the consumers of routine antenatal screening tests reported here demonstrate that consumers both promote and support the use of these tests. That is, they support the role of this facet of medical technology in the management of their pregnancies. But the use of these technologies generates costs in the form of money, time,

resources and expertise. Thus, support for the high utilisation of these tests is relevant to the resource allocation debate. Concerns about the allocation of resources in health have been raised by health economists, policy makers, health care providers, politicians, ethicists and social scientists. The last two are germane to the topic of this dissertation, although the language of the economists and the policy makers who follow them are the more prominent features of the public debate.

In 1993-94, as this study began, the Australian health expenditure was $36,663 million or an average of $2,066/person.[85] Health's share of the total economic resources or Gross Domestic Product (GDP) in that year was 8.6%. Whilst Australia, like most other Organisation of Economic Collaboration and Development (OECD) countries, showed a levelling off of health expenditure as a percentage of GDP since the mid 1980s, the United States of America has continued to increase with a health expenditure of 14.3% of GDP in 1994.[85] These figures do not factor in costs from other sectors such as housing, transport, or environment that also contribute to the maintenance of health of a population. Taking into account changes in population growth, there has been an increase of 2.1% or approximately $680 million extra spent per year on health from 1975-76 to 1993-94 in Australia. This is secondary to an ageing population and to a greater use of health services by people of all ages.[85,309]

What is less clear from the data is the exact burden of medical technologies on current health expenditure. The Australian Institute of Health & Welfare (AIHW) holds that the use of health technologies has 'significant cost implications for the allocation of health care resources, the expenditure on them in Australia is not definitely known, although it is certainly substantial'.[310] AIHW reports that a wide range of technologies including pathology, radiology and some diagnostic surgery generated 44% of the total claim for Medicare benefits paid in 1991-92.[309] This pattern of expenditure occurs in an environment where there is a dominant rhetoric to the effect that 'there is a finite amount of money and resource allocation decisions need to be made at many levels'.

There are many ethical issues raised here. Since I am not a professionally trained ethicist, I will make use of the ethicist's bible, the *Encyclopedia of Bioethics*,[276,311] to discuss these issues. Allocation of health-care resources, as discussed above, concerns the macroallocation of resources. That is, macroallocation 'entails decisions that determine the amount of resources available for particular kinds of health care services',[312] including antenatal screening services. Ethicists such as Branson[313] and Feinberg[260] argue that consideration of health care resource allocation requires application of the principles of distributive justice. Branson defines distributive justice as 'the form of justice concerned with distributing among persons the benefits and burdens that are due to them'.[257] He argues that the conceptual positions taken by ethicists and philosophers in utilitarianism, entitlement and egalitarianism to discuss distributive justice are complex and lack clarity.[313] Kilner, therefore, considers a broader view of macroallocation of health care resources.[314] Kilner argues there are three ethical concerns: individual claim to health care using the rights position, community responsibility to health care and efficiency in health care. He also argues that the principles of justice as well as the competing considerations of liberty, care and utility are operating in all three. Importantly, he acknowledges the allocation of resources in non-medical interventions such as environmental regulations that also contribute to a population's health.[314]

Kilner's examination of these issues assists in explaining some of the findings of this study. In discussing community responsibility to health care, Kilner argues that 'while people have rights, they have no "right to rights" '[315] The problem, as also demonstrated in the findings of this study, is people's preoccupation with their own right that potentially conflicts with and undermines the rights of all. As Kilner further argues, the rights position or individual claim to health care is 'hopelessly unsuited to a world of limited resources'.[316]

Therefore, should individuals using antenatal screening services consider issues of macroallocation of health care resources? Is it a responsibility for us all? A closer examination of the rights position demonstrates some of the difficulties for the individual. The rights position, as espoused by Veatch[317] and Jonsen,[251] although seen as conditional,

lacks clarity of distinction between the rights to health care and the rights to medical care. This lack of distinction is reflected in the findings of this study. Australians generally enjoy very high standards of health where not only basic health but basic medical care is rarely denied at the level of microallocation. Therefore, not only are people preoccupied with their own right but they don't distinguish between their right to medical care and their right to health care. This produces expectations, within the individual, of unrestricted right to all available medical care. I argue that the concept of distributive justice in the allocation of medical resources is, therefore, too theoretical for the majority of individuals to comprehend. Further, that increasing and unrestrained availability of technologies in antenatal care will be supported by strong expressions of individual rights by the consumers. Consumers will have little reason to believe they should be questioning the justice of its availability, especially if its use becomes routine.

Are these ethical principles adequate to debate issues of macroallocation of health care resources and the role of the consumer within it? Seedhouse, a controversial medical ethicist, argues that traditional ethical principles are inadequate for the debate on resource allocation. He argues that ethical principles, grounded in rational thought, are not useful in the resource allocation debate that he sees as both irrational (activities consistently directed towards goals which are known to be conflicting) and non-rational (activities that are random or have no detectable overall pattern).[318] He goes further to argue that the context in which health care is delivered is critical as 'what is available is governed by the very messy real-world cultural and historical context, and not by planning according to logic and principle'.[319] Seedhouse argues that, whilst the philosophical principles of what is fair and just are important, examination of the socio-cultural context in which resources are allocated in health is more relevant because they demonstrate the complexity of principles and context in this debate.

Should antenatal screening go under the spot light of the resource allocation debate at all, when the general belief is that prevention is more cost effective and under-resourced compared with treatment options? Evaluation of many of the screening tests reveals only

limited benefit to some and largely inappropriate use for most normal pregnancies. The trend toward the universal application of many antenatal screening tests is problematic. Such practices are very relevant to the debate over just allocation of resources. Enkin, too, states his concerns at 'the current bizarre approach to antenatal care in which a bulldozer is used to unearth the pathology, whatever the cost'.[320]

3. Considerations relevant to the future of pregnancy care

The findings of this study suggest that pregnant women already demonstrate a high reliance on their medical care to ensure healthy outcomes for themselves and their unborn babies. Such expectations are likely to increase if medical technology continues to offer perceived certainties and 'miracles' in pregnancy and childbirth. The search for the perfect test and 100% normal outcome will still be seen as potentially attainable. '*Medicine is advancing everyday, more babies and mothers are surviving childbirth and if testing continues, advances in controlling abnormalities will occur.*' As one participant noted, perhaps antenatal tests could tell her '*That the baby would be perfectly healthy. (Rich, good looking and successful!)*' And if the real risk of adverse outcomes such as perinatal mortality and morbidity continues to fall will the perceived risk of adversity, by the consumers of antenatal care, increase ? If this occurs, how can it be addressed? This study demonstrates already a perception of pregnancy, by the consumers, as a risky and uncertain time to which medical care offers insurance against possible adverse outcomes. Expectations by consumers of antenatal care cannot be addressed without first understanding the socio-cultural context in which women are fearful and the dominant role medical sovereignty plays in the interaction between the consumer and provider. The context in which these expectations arise is complex and therefore does not lend itself to simple solutions. It is the responsibility of all parties to address these issues without blaming, demeaning or dismissing.

4. Medico-legal implications

Findings from this study indicate the potential for two fundamental mismatches in perceptions between the consumers and providers of antenatal care, with implications both for poor resolution of conflict and potential unfavourable attitudes toward pregnant women. The first mismatch is demonstrated by the differences in perceptions of risk by the consumers (as demonstrated by the participants of this study) and the antenatal care providers. Women in this study demonstrated a high individual perception of risk of adverse outcomes during pregnancy. Because of the scientific and medical training of the majority of antenatal care providers, risk perceptions by the providers are more likely to be formed on epidemiological risks or the true hazard rate of adverse outcomes. These rates, as have been shown, are much lower than the risks as individual participants perceive them. Pregnant women chance being dismissed or not having their fears being taken seriously by the providers of antenatal care. They may even be seen as 'silly' or 'inappropriate'. These discrepancies in perceptions may interfere with relationships between the consumer and provider.

The second mismatch, which is more commonly discussed in the medico-legal discourse in obstetrics,[121,321-324] relates to a difference in expectations of what medicine, technologies and expertise can provide. Results from this study suggest that participants have a high reliance and trust on medical technology and expertise to ensure normal outcomes. Because of the high perception of risk they seek to take out what they believe to be very reliable insurance against adverse outcomes in the form of antenatal care and testing. For some, the ability to acquire more insurance would be even better. Thus whilst the perceived risk of adverse outcomes is high, routine antenatal tests appear to promise certainty and insurance against these events occurring. Providers, on the other hand, are more likely to believe the tests to be fallible and to know that 'things do go wrong'.[34] Often a view predominates that 'nothing's perfect' and, therefore, no one is to blame. Herein lies a fundamental mismatch of expectations.

As discussed in chapter 2.4, discourse relating to expectations within the obstetric literature usually refers to this mismatch as consumers' or patients' 'unrealistic expectations'.[105,120,121,122] Few attempt to address the role of medicine in this process.[121,324,325] Bastian, in one of the only critiques of this process from a consumer viewpoint, states that '...in an enthusiasm to promote the capabilities of medical practice, the profession has, deliberately or not, fostered a consumer perception that, essentially, childbirth can be more or less controlled and babies can be saved if only enough money is spent on the appropriate technology'.[326] It is important to see the elements in this mismatch and that pregnant women have not formed these perceptions in isolation. Whilst the consumer and the provider perspectives are viewed as poles apart, an adversarial relationship may develop.

A mismatch of expectations combined with feelings of being dismissed may lead, as Bastian says, to loss of trust and confidence by pregnant women in their carers.[324] This may form the basis of discontent, disillusionment and disappointment and, coupled with guilt and fear, raise two needs in parents faced with an unexpected outcome. The first is a desire to attribute a cause and the second is to seek compensation or, as Bastian says, responsibility for the outcome.[324] One way of addressing these two issues is through the medico-legal system. A noteworthy study performed in the United States in 1989 attempted to examine patients' reasons for filing a malpractice claim.[327] Despite the expected difficulties in attempting to provide insights into sensitive areas such as perinatal injuries and perceived medical negligence, the study found that 24% of respondents filed a claim because they perceived the doctors to be dishonest or misleading. A further 19% stated a need to punish the health care provider, and 44% stated needing money for long term care or compensation for 'lack of the child's future' as reasons for filing a claim.[327] Further, 70% of respondents in that study claimed that no one involved in their care told them that their infant might have permanent medical problems or die.[327]

Seeking compensation through litigation is problematic. In the past decade, there has been an increase in the debate about medico legal issues in the obstetric literature.[321-324,327-329] Most of these concerns have been raised by the profession and examine the impact of the

perceived litigatious climate on the practice of obstetrics. Much of the debate has been fuelled by the 'crisis' in the United States.[327-330] An American Medical Association gallup poll in the early 1990s found that 79% of obstetricians had been sued at least once.[331] A further study suggests that an obstetrician in the United States can expect to be sued eight times in his or her career.[329] Studies from the United Kingdom also suggest a rise in medical negligence claims with obstetrics and gynaecology currently making up 30% of claims.[328] In Australia, the debate is also prominent in the obstetric literature.[321-324] The major issues raised for the profession are the practice of defensive medicine [328,331-333] and the potential impact on the obstetric work force. Whilst Clements defines defensive medicine in the perjorative as 'clinical interference that is for the benefit of the doctor and not of the patient', he also argues that 'one man's defensive medicine is another man's risk management'.[334] That is, he argues that extra caution and monitoring of adverse outcome is good clinical practice.

What is lacking in the debate generally is discussion of the impact of the real or perceived threat of litigation to the providers on the consumers of obstetric services. In addition, the 'risk' and insurance debate has public health implications. For the consumers of obstetric services a climate of threat of litigation can lead to an adversarial approach to both the woman and the fetus.[324,333] As Bastian states, 'If obstetricians increasingly view each woman - and even each fetus - as a potential litigant, the impact on the quality of the childbirth experience is likely to be profound.'[335] The practice of defensive medicine is likely to lead to an increase in interventions during pregnancy and birth including antenatal testing[328,331-333] but few authors elaborate on the potential iatrogenic complications which this involves.[332] As this study shows, increased promotion of technologies and interventions by the providers of antenatal care is likely to encourage further reliance and dependence on medical technology to ensure a normal outcome. This may in turn broaden the gap in expectations between the consumer and the provider. In any case, seeking compensation for unmet needs through the medico-legal system does not guarantee that consumer needs will be met. The often long demanding court process can be equally traumatic and unsatisfactory for the litigant.

From the broader public health perspective, all consumers of health care services will be affected by the cost implications of defensive medicine.[332,333] A study in the United States in 1992 showed that the increase in prenatal care and delivery services that have resulted from defensive medicine practices and liability insurance, account for 20 billion dollars annually.[332] Defensive medicine will further drive the medicalisation of pregnancy care with the resultant need for better technology and more experts to manage the majority of pregnancies which are normal.

Is there another way? In addition to the debates about the legal system and the merits or not of the tort system versus a no fault compensation scheme, little discussion is found in the literature as to other ways of addressing the more fundamental issues of the mismatch in perceptions and expectations. One arm of the debate is demonstrated by Sweet who argues that 'To some extent, obstetricians are victims of the technological advances and the media publicity of such advances'.[336] Whilst acknowledging the need for doctor education, accountability and maintenance of high standards, he argues for the 'communication' of realistic expectations to consumers and the cessation of engendering false hopes by the media as ways to address the medico-legal issues.[337] Whilst the issues are complex and involve a number of players including the legal system and the media, closer examination of the relationship between the consumer and the antenatal care provider and medicine is an important step in the way forward. Since 'no one practitioner could ever meet every expectation', as Bastian recognises, it behoves the profession to be more open about the real limitations of medicine and technologies.[326]

As I have argued, pregnant women do not form expectations in isolation. In addition to behavioural factors, there are structural factors arising from the way medicine is practised. Pregnant womens' concerns need to be addressed with respect and in earnest. Where possible, open discussion about the range of adverse outcomes that may occur and the tragedy that may present to a family should be encouraged. This may be a new role for the traditional antenatal classes. It could include discussion about how parents would feel if their pregnancy and childbirth expectations were not met and how they would deal with

those feelings. Should conflict arise as a result of unmet needs or disappointment, it is important to explore other ways of conflict resolution and compensation.[324] Early, honest contact with parents following an unexpected outcome is vital. Early use of mediators and counsellors for all parties is also indicated.

Conclusion

Utilisation of routine antenatal screening tests provides safety, reassurance and, in some cases, bonding for pregnant women. But the determinants of the use of antenatal screening such as high perception of risk, a belief in the authority of medical technology, and perceived individual rights to access all available medicine, have implications for all who access health services. There is a potential for crisis if pregnancy care continues to be medicalised, drains more health care resources, and ultimately fails to deliver the promise of certainty to pregnant women. Some say we are already there.[321,329,333]

7.2 THE WAY FORWARD

Limitations of this study

Generalisation from this study to antenatal practices in Australia and beyond is limited, to a degree, by both the chosen methodology and the representativeness of the study sample. Whilst validity has been partly addressed by the use of varied methods, a cross sectional and qualitative study is limited in its reliability and ability to generalise. As discussed in chapter 3, this study represents views from one point in time. A longitudinal or comparison study would detect better any significant changes over time and could address, in particular, the question of whether women's attitudes and beliefs are different during pregnancy than they are up to one week post partum. Use of a control group in this comparison would further validate any differences found and an analysis of those participants who declined entry or were lost to follow up would provide evidence of any potential participation bias.

As discussed in chapter 4.2, the study sample is not fully representative of women giving birth in Victoria and Australia. Because of the inclusion/exclusion criteria, women from rural background, women of non-English speaking background not literate in English and women with early fetal loss or severely sick neonates are under represented. Because of difficulty accessing and getting permission from obstetricians to approach their private patients, the private patients represented in the sample have been cared for by only a small number of obstetricians and have delivered in a tertiary referral hospital. Therefore, there may be an under-representation of low risk private patients, who may receive a more varied pattern of care. The sample available to me under-represents younger women, women with lower education levels, women not in the paid work force and women in occupations such as sales and clerical. Would women with different cultural experiences of pregnancy and birth, especially women without a background in English, perceive risk similarly to their anglophone sisters? Would their access to informed choice of obstetric services be different? Would women from rural Australia have other priorities during pregnancy? The

voices of these women may offer new insights to the discussion that I have not addressed. These questions are worth pursuing in future research.

As the study sample size was calculated on two key responses from the pilot study of a cross-sectional survey, the study does not have the power, in some cases, to demonstrate differences between subgroups within the sample. Therefore, many of the statistically non-significant findings may be altered with a larger sample size designed to detect differences. The study also lacked power to demonstrate significant prevalences to the responses to three survey questions; whether the participant knew someone with an abnormal baby, whether the participants were anxious about an abnormal pregnancy and how common participant's believed having an abnormal tests result was. As the responses to these closed questions related to feelings and beliefs, the sample size is not critical to the analysis.

Whilst the study findings explore through various methods the beliefs and attitudes of the consumers of antenatal care, they are unable to demonstrate the corresponding views of the antenatal care providers who are also critical players in the research question. And while, through the exploration of other researchers' findings and analyses, I have discussed the potential role of medicine and the antenatal care provider in the research question, examination of the providers perspectives requires further study.

I have discussed a number of social and ethical factors that are determinants for the use of routine antenatal screening tests by the participants. As I was interested in pregnant womens' beliefs and values, the potential role of factors such as the age of parenting, size of families, paid work force participation, availability of termination and the views of society in relation to normality and abnormality, that may play a part in determining the use of antenatal testing, have not been discussed. In particular, the role of availability of tests in the utilisation of testing has not been discussed. Such factors warrant further study.

Future research directions

Further studies using comparative and controlled intervention methodologies could elaborate the findings of this study. Intervention studies, such as the use of antenatal classes to reduce risk perception or seminars/newsletters disseminating the findings of the Cochrane pregnancy and childbirth data base[28] about the evaluation of antenatal screening to providers, offer possible further research directions. Opportunities exist for clinicians, epidemiologists and social scientists to be involved in collaborative research to address consumer and public health concerns. Different methodologies also offer various strengths and perspectives to research questions in pregnancy and childbirth. The multi-centre randomised controlled trial including a qualitative component, as is used by Mary Hannah et al in the Term PROM study,[338] offers a new and innovative perspective to research in obstetric care. Further study of the perceptions of the antenatal care providers is clearly needed to resolve my research question completely. Such an inquiry lends itself initially to a cross sectional and qualitative study that explores the beliefs and values of antenatal care providers including specialists, general practitioners and midwives.

Policy implications

Whilst policy direction at a national and state level is important, the translation from policy at this level, without intervening policy at the local level, may be problematic (as demonstrated in chapter 2.6). It is critical that policy guidelines be available to assist the antenatal care provider and the consumer at the local level. These guidelines, ideally, should be based on the prior evaluation of antenatal screening tests within the local population, taking into consideration the prevalence of conditions being screened for. This is important to prevent indiscreet use and inappropriate universal screening for all pregnant women. Policy guidelines should also address the relationship between the consumer and the provider.

Findings from this study point to specific areas of emphasis within policy statements on routine antenatal screening. Policies that address the involvement and expectations of the consumer in the provision of antenatal care services, including antenatal screening, are crucial. In particular, policies should include explicit statements on how pregnant women are to be kept informed during their antenatal care. Statements concerning the length of time for consultations and question asking and the role of appropriate accompanying literature could be included. The importance of spending adequate time with women having their first baby should be emphasised. Policies directed at pregnant women's risk perception might include statements that encourage the following to occur at each consultation: open discussion about women's fears in relation to pregnancy and birthing outcomes, discussions about potential adverse outcomes, with less emphasis being placed on the provision of actual risk figures and more discussion of women's individual perceptions of risk. In addition, policies could address the potential role of antenatal classes in the reduction of fears by the commitment of time to the open discussion of fears and potential adverse outcomes. However, these issues should be addressed at a research level prior to any change to policy.

Policies should also state the importance of the role of the antenatal care provider in the provision of realistic information about pregnancy and birthing outcomes, including the limitations of their care and screening tests. Policies should encourage full explanation of antenatal screening tests to all women, including provision of test results, whether positive or negative. Policies might also include ethical statements that recognise pregnant women's individual rights and consider them alongside the broader health needs of the population. They might include acknowledgment of pregnant women's altruism and the importance of respecting this position without exploitation.

Policies that address the education of health care professionals including midwives, general practitioners and specialist obstetricians about the consequences of antenatal screening and the context in which pregnant women use screening are clearly needed. Professional bodies governing these service providers must read the findings of this study and examine their

policy and practice in relation to antenatal screening. In particular, such policies must raise awareness of their professional behaviour during the provision of antenatal care and examine their beliefs about consumer risk perception, informed choice and compliance with medical care. In addition, professional bodies must examine the role of consumer feedback in the evaluation of their service delivery. Above all, policy statements must incorporate the promotion of sound research based practice and consumer feedback.

Lack of uniform policy about the funding and provision of medical technologies at a hospital and state level makes the task of evaluating the financial costs of these technologies, including antenatal screening, difficult.[16,339] As a review of medical technology strategies in the US in 1982 found, 'Anyone attempting to study the diffusion of new procedures faces the immediate obstacle that they cannot be identified reliably from existing data sources. This is of obvious concern to policy makers.'[340] The same is true in Australia in 1996. Therefore, the Australian Institute of Health and Welfare attempt to reveal the, so far, invisible costs of antenatal screening by desegregating the health budgets of both Medicare and the public hospitals involved in the provision of antenatal screening tests. Politicians involved in the health sector must then consider these findings in the development of policies that address the macroallocation of health care resources.

Chapter 8 CONCLUSION

A complex of factors determines the use of routine antenatal screening tests by pregnant women. Utilisation of tests is not a simple product of availability and a contract between the consumer and health care provider based on shared information. Exploration of consumers' beliefs and values related to pregnancy, birthing outcomes and testing reveals an intricate array of social and ethical factors that are operating in the process of antenatal screening. Findings from this study identify a perception by pregnant women of risk as a dominant factor in the use of antenatal screening. Where the incidence of perinatal hazards is low, pregnant women should feel safe and assured. The perception of risk among the pregnant women I studied is universal, pervasive and disproportionate to the actual epidemiological risk. The socio-cultural foundations of pregnant women's risk perception are also complex. Routine antenatal screening tests are perceived to provide reassurance, and more importantly, insurance against these perceived risks.

The second major determinant of the use of routine antenatal screening is medical sovereignty. Because of the high trust in, compliance with and reliance on medical input into pregnancy care demonstrated by pregnant women, medical dominance in antenatal care is often disguised as consumer demand. Medical technology and expertise, in the form of antenatal screening tests, appear to offer certainty and guarantees and therefore attract high patronage. Thirdly, in an 'opt out' system of screening, lack of information encourages increased utilisation of screening. This high utilisation accompanies loss of choice for pregnant women. Fourthly, the act of offering screening to otherwise healthy pregnant women supports the paradigm of pregnancy as an illness and thus raises the potential threat to women of abnormality in themselves or their fetus. This act of offering screening, including antenatal screening, generates its own demand for and, thus, reliance on medical technology to address these potential abnormalities. Fifthly, in the context of high standards of health and medical care, an individual pregnant woman is largely unable to consider a notion of distributive justice based on need rather than desire. This means the concept of

what is perceived as 'good for self is good for all' will predominate and increase the demand for more extensive use of screening. Availability of a test is seen as justification enough for its use. Lastly, whilst pregnant womens' altruism is contextual, such values are likely to be exploited by medical technology that attempts to offer information and beneficence to the fetus. Routine antenatal screening tests, including maternal screens are perceived to benefit the fetus and therefore enjoy strong support.

Some determinants, including lack of informed choice, patronage of the role of medicine in antenatal care and women's desire not to subject their unborn baby to undue harm are of particular relevance to the use of routine as opposed to non-routine or more invasive antenatal screening tests. Routine testing, particularly as practiced in public outpatient clinics, represents an 'opt out' system of screening and lack of informed choice in such a system generates high compliance with what is standard or accepted practice and therefore high utilisation. The notion of 'just routine' and 'everyone has it' also promotes a trust in the tests: because everyone has the test, 'everyone must need it' and 'it will benefit me'. That is, the fact that the test is routine must mean it is of benefit to all who have it. Routine tests, as opposed to non-routine antenatal screening tests, may also be perceived as less invasive and therefore harmless to the fetus. Whilst pregnant women will endure many inconveniences and discomfort for the sake of their fetus, the ability to avoid potential harm to their fetus is also important. Tests described as routine are therefore likely to be supported.

Whilst this study depicts the utilisation of and beliefs about routine antenatal screening tests through the experiences and perceptions of the consumers of screening, such views reflect the broader social and ethical context in which these views arise. Consumers of antenatal care are the vectors for perspectives about their interaction with health care providers and with society in general.

To believe that the introduction, maintenance and growth of antenatal screening is determined only by sound clinical judgement and epidemiological evaluation is naive. Clearly other factors are important. Many are not immediately obvious and are only revealed

following subtle examination of the context in which screening is practised. Such factors, as described above, however, assist in explaining why the number and frequency of testing is increasing and why tests, once introduced, are difficult to remove from the repertoire of routine use. Continuation of these factors is likely to support further growth in antenatal screening and medical technology. Examination of the rise of technologies in antenatal care through history already cautions the crediting of improvements in perinatal and maternal outcomes to medical advancement alone. The role of broader public health initiatives such as improved sanitation, education, diet and housing has been largely overshadowed by advances in medical technology.

Fears of adverse outcomes, lack of informed choice, patronage for the medicalisation of pregnancy, expression of individual rights and support for measures that are perceived to uphold the rights of the fetus are questionable legitimate determinants for the use of routine antenatal screening tests. I argue that the utilisation of antenatal screening, as determined by these factors, raises serious concerns for the future of pregnancy care. I predict that the medicalisation of pregnancy and childbirth will increase. Not only are these factors determinants of the use of routine antenatal screening tests but they are potentially relevant to other obstetric and perinatal interventions. An increase in the expectations by consumers that medical technology will ultimately deliver the certainty of no adverse outcomes, is also a likely result. Medical advancement has already been seen to take much of the credit for improvements in obstetric and perinatal outcomes. Failure to deliver such certainty is likely to widen the gap in expectations between the consumer and health care provider and lead to increasing dissatisfaction and conflict. Whilst an individual's desire, rather than need, for medical care continues to be met by unrestricted availability of technologies applied to pregnancy and childbirth, the drain on health resources will continue. A crisis point will soon be reached.

The task of applying the findings of this study to the evaluation process of antenatal screening programs is a difficult one. The issues discussed are complex and well entrenched in cultural norms, both professional and societal. To date, the epidemiological evaluation of

antenatal screening, based on worth, has been fraught with difficulties and therefore sometimes disregarded. Consideration of these additional social and ethical issues adds further complexity to the evaluation. However, complexity of a process should not be a legitimate reason to ignore the perspectives of the consumer when addressing antenatal services, such as screening programs. Much can be addressed at the policy and service delivery level. Public outpatient clinics, in particular, must address issues of service quality and adequate time allocation in addition to the current obsession with quantity, efficiency and throughput. If the gap between consumer and health care providers' expectations is to be narrowed, the service must also address issues of information provision that is honest, realistic and enables opportunity for informed choice. Policies that stress the importance of offering, rather than 'doing', routine antenatal screens to pregnant women with provision of adequate information about the limitations of the tests should be encouraged. The specific details of such policy would need to be considered in practice.

Routine antenatal screening programs can not continue to hide under the guise of being good for all pregnant women. Indiscriminate use of antenatal screening tests provides the means for potential harm to the recipients of screening and society in general. Understanding the determinants of the use of such screening programs, particularly through the perspectives of the consumers, is paramount to curtailing this trend. Pregnancy care in the future will not provide 100% guarantees but it can provide honesty, authenticity and hope.

EXCURSUS

Whilst my initial research proposal included a component of discourse analysis of the popular press within the methodology, it has been omitted in the final study due to substantial coverage of the research question by the methods of survey research and interviews. Item 44 of the substantive questionnaire (see Appendix 4) asked participants what magazines they had read in the previous month. Following completion of the survey, I selected the four most popular magazines and collected these over a 12 month period. Of the 42 magazines named, the four most popular were *Woman's Day*, *New Idea*, *Mother and Baby* and *Women's Weekly*. Discourse analysis examining themes related to pregnancy, birth and birthing outcomes, including a textual and contextual examination, was intended.

Had such a component been included, there would have been the potential to place the perspectives of the participants in a broader societal context, as reflected in the popular press. In particular, using the assumption of ethnography that 'every human group that is together for a certain period will evolve a culture',[1] examination of the popular press may have given some insights into the health professional and social cultures within Australian society. The popular press plays a significant role in our identity as a society whilst recognising themes from various cultures within it. Discourse analysis has evolved over the last 30 years as a legitimate method for the analysis of media discourse[2,3] and in particular, health issues disseminated in the popular media.[4] Such analysis provides an understanding of health and illness in its socio-cultural context and is therefore valuable in addressing public health concerns.[4] Lupton believes this is particularly relevant to the exploration of risk perception within society.[4]

The findings from this study recognised that participants' responses and beliefs were not formed in isolation. Whilst only 4.9% of participants believed that the media had influenced them in their beliefs about the value of routine antenatal screening tests, 77.5% of participants had read one or more magazines in the previous month. This demonstrates the common use of this form of media. Whilst participants' beliefs and values about pregnancy

and birth may have been formulated much earlier, the depiction of pregnancy and birth by the current magazines would enable insights into society's values now. Magazines, as in other areas of the media are likely to portray the unusual, the tragic[4] and the newsworthy[3]. Stories and photos are likely to portray negative experiences and may therefore play a role in pregnant women's risk perception.

I was particularly interested to examine the portrayal of normality and abnormality as it relates to pregnancy, birth and birth outcomes. Firstly, whilst not attempting to define 'normal', it is likely that a discourse analysis of these magazines would have revealed unrealistic and generally unattainable portrayals of the perfect pregnancy, the perfect baby and the perfect supportive relationship. Much of this would be done through the use of celebrities or 'elite personalities'[5] who are usually photographed smiling, fully rested, in clean size 10 clothes, with make up, holding a cute, happy baby and being cuddled by the ever-helpful-always-at-home husband. Such portrayals are likely to reinforce an unrealistic and narrow notion of what is normal. They may add undue pressure to new mothers who are unable to conform to these images, and therefore perceive themselves or their babies to be other, or abnormal. Such portrayals are consistent with Newell's discussion about society's perceptions of disability: he argues that normality is a social construction and that 'there is little tolerance of anything that deviates from a narrowly constructed norm.'[6]

Secondly, at the other end of the spectrum, a discourse analysis would likely demonstrate an over representation of the weird, the unusual, the sensational or the tragic in relation to pregnancy and birth outcomes. Stories about Siamese twins or 'the 24 week miracle' are likely to potentiate unrealistic perceptions of the frequency of such events and thus the risk of such events occurring.

Lastly, an analysis of these magazines in relation to disability would likely demonstrate conflicting messages. If, as Newell argues, disability is a social construct,[7] stories of tragic congenital or birth traumas and injury may reinforce negative views of disability. Such a portrayal of disability would be important as 'how we see disability and how much we fear

it' will influence decisions to have prenatal screening.[8] However, the media is also likely to portray positive success stories of accomplishment over the adversity of a disability. As Elkins and Brown argue, disability groups within our society have made rapid progress and 'they remind us that definitions of normalcy are artificial and fragile.'[9] Marteau also recognises the positive changes in society's values toward disability through mainstream schooling, equal opportunity policies and changes in the use of language.[10] Such breakthroughs for people with disability are likely to be portrayed in the media. But would the stories behind the stories be shown; the everyday struggles and the prejudices? Pregnant women would likely receive confusing messages about normality and abnormality from the popular press.

I believe a follow up discourse analysis of these magazines in relation to pregnancy, birth and birthing outcomes is warranted. As Turner notes, 'much of the social production of meaning through media is invisible to us.'[11]

References:

1. Patton M, Quinn M, Westby C. Ethnography and Research: A qualitative view.Top Lang Disord 1992;12:2.
2. van Dijk TA. Media contents: the interdisciplinary study of news as discourse. In: Jensen KB, Jankowski NW, eds. A handbook of qualitative methodologies for mass communication research. London: Routledge, 1991:108-119.
3. Turner G. Media texts and messages. In: Cunningham S, Turner G, eds. The media in Australia: industries, texts, audiences. St. Leonards: Allen & Unwin, 1993:205-266.
4. Lupton D. Discourse analysis: a new methodology for understanding the ideologies of health and illness. Aust J Public Health 1992;16:145-150.
5. Turner, 1993:225.
6. Newell C. A critique of the construction of prenatal diagnosis and disability. In: McKie J. Ethical issues in prenatal diagnosis and the termination of pregnancy. Melbourne: Centre for Human Genetics, 1994:93.

7. Newell C. A critique of the construction of prenatal diagnosis and disability. In: McKie J. Ethical issues in prenatal diagnosis and the termination of pregnancy. Melbourne: Centre for Human Genetics, 1994:89-95.
8. Borthwick C. The prevention of disablement. In: McKie J. Ethical issues in prenatal diagnosis and the termination of pregnancy. Melbourne: Centre for Human Genetics, 1994:113.
9. Elkins TE, Brown D. Ethical concerns and future directions in maternal screening for Down syndrome. Women's Health Inst. 1995;5:17.
10. Marteau TM. Psychological implications of prenatal diagnosis. In: Drife JO, Donnai D, eds. Antenatal diagnosis of fetal abnormalities. London: Springer-Verlag, 1991: 243-254.
11. Turner, 1993:232.

References:

1. Enkin M, Chalmers I. Effectiveness and satisfaction in antenatal care. In: Enkin M, Chalmers I, eds. Effectiveness and satisfaction in antenatal care. London: William Heinemann Medical Books Ltd., 1982: 266.
2. Marteau TM, Johnston M, Shaw RW, Michie S, Kidd J, New M. The impact of prenatal screening and diagnostic testing upon the cognitions, emotions and behaviour of pregnant women. J Psychosom Res 1989;33:7-16.
3. Farrant W. Stress from amniocentesis for high serum alpha-fetoprotein concentrations. Br Med J 1980;Aug 9:452.
4. Marteau TM, Johnston M, Kidd J, Michie S, Cook R. Psychological models in predicting uptake of prenatal screening. Psychol Health 1992;6:13-22.
5. Lumley J. Uncertainty and ultrasound diagnosis. In: McKie J. Ethical issues in prenatal diagnosis and the termination of pregnancy. Melbourne: Centre for Human Genetics, 1994:25-28.
6. Beeson D, Golbus MS. Anxiety engendered by amniocentesis. In: Epstein CJ, Curry CJR, Packman S, Sherman S, Hal BD, eds. Risk, communication and decision making in genetic counselling. New York: Alan Liss, 1979:191-197.
7. Fava GA, Kellner R, Michelacci L, et al. Psychological reaction to amniocentesis: a controlled study. Am J Obstet Gynecol 1982;143:501-503.
8. Marteau TM. Psychological implications of prenatal diagnosis. In: Drife JO, Donnai D, eds. Antenatal diagnosis of fetal abnormalities. London: Springer-Verlag, 1991:243-254.
9. Reid M. Consumer-orientated studies in relation to prenatal screening tests. In: Huisjes HJ, Buekens P, Reid M, eds. Antenatal screening: Current policies in the EC and evaluation. Eur J Obstet Gynecol Reprod Biol 1988; 5 Suppl: 79-92.
10. Huisjes HJ, Buekens P, Reid M, eds. Antenatal screening: Current policies in the EC and evaluation. Eur J Obstet Gynecol Reprod Biol 1988; 5 Suppl: 1-105.

11. Mohide P, Grant A. Evaluating diagnosis and screening during pregnancy and childbirth. In: Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press, 1989:66.
12. Oakley A. The origins and development of antenatal care. In: Enkin M, Chalmers I, eds. Effectiveness and satisfaction in antenatal care. London: William Heinemann Medical Books Ltd., 1982:1-21.
13. Shearer MH. Maternity patients' movements in the United States 1820-1985. In: Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press, 1989:110-130.
14. Reiser SJ. Technology: History of medical technology. In: Reich WT, ed. Encyclopedia of bioethics: Revised edition. New York: MacMillan, 1995:2472.
15. Reiser SJ. Technology: History of medical technology. In: Reich WT, ed. Encyclopedia of bioethics: Revised edition. New York: MacMillan, 1995:2472-2477.
16. Showstack JA, Schroeder SA, Matsumato MF. Changes in the use of medical technologies, 1972-1977. N Eng J Med 1982;306:706-712.
17. Reiser, 1995:2477.
18. Fuchs VR, Garber AM. The new technology assessment. N Eng J Med 1990;323:673.
19. Enkin M, Chalmers I, eds. Effectiveness and satisfaction in antenatal care. London: William Heinemann Medical Books Ltd., 1982:xi.
20. Enkin et al, 1982:2.
21. Munro Kerr JM, Johnstone RW, Phillips MH, eds. Historical review of British obstetrics and gynaecology: 1800-1950. Edinburgh: E&S Livingstone Ltd, 1954: 148-149.
22. Forster FMC. One hundred years of obstetrical and gynaecological teaching in Victoria. Aust NZ J Obstet Gynaecol 1966;6:100-111,161-170.
23. Townsend L. Letter from Australia. Obstet Gynaecol Surv 1967;22:203-223.
24. Forster, 1966:105.
25. Cope I. Obstetrics and gynaecology in Australia, 1914-1994. Med J Aust 1994;161: 22-23.

26. Moss JR, McMichael AJ. Inequalities in health: The epidemiological evidence - and the gaps. In: McNeil JJ, King RWF, Jennings GL, Powles JW,eds. A textbook of preventive medicine. Caulfield East, Victoria: Edward Arnold, 1990:253-268.
27. Garcia J, Blondel B, Saurel-Cubizolles MJ. The needs of childbearing families: social policies and the organisation of health care. In: Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press, 1989:205-220.
28. The Cochrane Collaboration. The Cochrane pregnancy and childbirth database. Oxford: Update Software, biannual updates.
29. Enkin M, Chalmers I. Effectiveness and satisfaction in antenatal care. In: Enkin M, Chalmers I, eds. Effectiveness and satisfaction in antenatal care. London: William Heinemann Medical Books Ltd., 1982: 266-290.
30. Hicks N. This sin and scandal: Australia's population debate, 1891-1911. Canberra: Australian University Press, 1978.
31. Oakley, 1982:6.
32. Shearer, 1989:114.
33. Oakley, 1982:9.
34. Cope I. Obstetrics and gynaecology in Australia, 1914-1994. Med J Aust 1994;161: 22-28.
35. Oakley, 1982:17.
36. Enkin et al, 1982:267.
37. Shearer, 1989:111.
38. Heringa M, Huisjes HJ. Prenatal screening: Current policy in EC countries. In: Huisjes HJ, Buekens P, Reid M, eds. Antenatal screening: Current policies in the EC and evaluation. Eur J Obstet Gynecol Reprod Biol 1988; 5 Suppl:7-52.
39. Cuckle HS, Wald NJ. Principles of screening. In: Wald NJ, ed. Antenatal and neonatal screening. Oxford: Oxford University Press, 1984:1-22.
40. Grant A, Mohide P. Screening and diagnostic tests in antenatal care. In: Enkin M, Chalmers I, eds. Effectiveness and satisfaction in antenatal care. London: William Heinemann Medical Books Ltd., 1982:22-59.

41. Wald NJ, ed. Antenatal and neonatal screening. Oxford: Oxford University Press, 1984.
42. Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press, 1989.
43. Mohide P, Grant A. Evaluating diagnosis and screening during pregnancy and childbirth. In: Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press, 1989:66-80.
44. Last JM. A dictionary of epidemiology. New York: Oxford University Press,1983: 95-96.
45. Last, 1983:95.
46. Cuckle et al, 1984:1.
47. Mohide et al, 1989:68.
48. Buekens P, Kaminski M. Epidemiological evaluation of prenatal screening procedures. In: Huisjes HJ, Buekens P, Reid M, eds. Antenatal screening: Current policies in the EC and evaluation. Eur J Obstet Gynecol Reprod Biol 1988; 5 Suppl:53-67.
49. Thomson WAR. A dictionary of medical ethics and practice. Bristol: John Wright & Sons Ltd, 1977.
50. Wald NJ, Cuckle HS, Densem JW, Kennard A, Smith D. Maternal serum screening for Down's syndrome: the effect of routine ultrasound scan determination of gestational age and adjustment for maternal weight. Br J Obstet Gynaecol 1992; 99:144-149.
51. Wald NJ, Kennard A, Densem JW, Cuckle HS, Chard T, Butler L. Antenatal maternal serum screening for Down's syndrome: results of a demonstration project. Br Med J 1992;305:391-394.
52. Department of Medical Genetics. Annual report of prenatal diagnosis in South Australia. South Australia: Adelaide Medical Centre for Women and Children, 1990.
53. Clift TJ. Antenatal screening for Down's syndrome.[Letter] Br Med J 1992;305:768.
54. Wald NJ. Conclusions. In: Wald NJ, ed. Antenatal and neonatal screening. Oxford: Oxford University Press, 1984:547.

55. Wald NJ. Conclusions. In: Wald NJ, ed. Antenatal and neonatal screening. Oxford: Oxford University Press, 1984:539-551.

56. Sheldon TA, Simpson J. Appraisal of a new scheme for prenatal screening for Down's syndrome. Br Med J 1991;302:1133-1136.

57. Cooper M. Ethics of screening for Down's syndrome.[Letter] Br Med J 1991;303:56.

58. Ewigman B, Green J, Lumley J. Ultrasound during pregnancy: A discussion. Birth 1993;20:212-215.

59. Berwick DM, Weinstein MC. What do patient's value? Willingness to pay for ultrasound in normal pregnancy. Med Care 1985;23:881-893.

60. Enkin et al, 1982:284.

61. Garland SM, Kliman LJ. Routine antenatal screening for HIV- not justified at present.[Letter] Med J Aust 1991;154:566.

62. Gilbert GL. Routine antenatal screening and prenatal diagnosis of vertically transmissible infection. Baillieres Clin Obstet Gynaecol 1993;7:1-23.

63. Shickle D, Chadwick R. The ethics of screening: Is 'screeningitis' an incurable disease? J Med Ethics 1994;20:12-18.

64. Stoate HG. Can health screening damage your health? J R Coll Gen Pract 1989; 39:193-195.

65. Shickle et al, 1994:12.

66. Garcia J. Women's views of antenatal care. In: Enkin M, Chalmers I, eds. Effectiveness and satisfaction in antenatal care. London: William Heinemann Medical Books Ltd., 1982:81-91.

67. Reid, 1988:79.

68. Green J, Statham H, Snowden C. Pregnancy: a testing time. Report of the Cambridge prenatal screening study. Cambridge: Centre for Family Research, University of Cambridge, 1993.

69. Reid ME, McIlwaine GM. Consumer opinion of a hospital antenatal clinic. Soc Sci Med 1980;14A:363-368.

70. Reid M, Garcia J. Women's views of care during pregnancy and childbirth. In: Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press 1989;131-142.
71. van Zuuren FJ. Coping style and anxiety during prenatal diagnosis. J Reprod Inf Psychol 1993;11:57-59.
72. Robinson JO, Hibbard BM, Laurence KM. Anxiety during a crisis: Emotional effects of screening for neural tube defects. J Psychosom Res 1984;28:163-169.
73. Statham H, Green JM. Serum screening for Down's syndrome: some women's experiences. Br Med J 1993; 307: 174-176.
74. Marteau TM, Cook R, Kidd J, et al. The psychological effects of false positive results in prenatal screening for fetal abnormality: A prospective study. Prenatal Diag 1992;12:205-214.
75. Burton BK, Dillard RG, Clark EN. The pyschological impact of false positive elevations of maternal serum a-fetoprotein. Am J Obstet Gynecol;151:77-82.
76. Ferguson J. Serum screening for Down syndrome at 16 weeks gestation: maternal anxiety and pregnancy outcome. Paper presented at the Australian Perinatal Society Meeting. Hobart, July 1993.
77. Lumley J. Having a baby in Victoria. Melbourne: Health Department Victoria, 1990.
78. National Health & Medical Research Council. Draft report on options for effective care in childbirth: Consultation document 2nd stage. Canberra: NH&MRC, 1994.
79. Lumley, 1990:90-91.
80. Hern WM. The illness parameters of pregnancy. Soc Sci Med 1975;9:365-372.
81. Kitzinger S. Pregnancy and childbirth. London: Dorling Kindersky Ltd, 1980.
82. Hern, 1975:366.
83. McIlwaine G. In: Enkin M, Chalmers I. Effectiveness and satisfaction in antenatal care. In: Enkin M, Chalmers I, eds. Effectiveness and satisfaction in antenatal care. London: William Heinemann Medical Books Ltd., 1982: 266.
84. National Health & Medical Research Council. Report on maternal deaths in Australia 1985-87. Canberra: Australian Government Publishing Service, 1991.

85. Australian Institute of Health and Welfare. Australia's Health 1996: The fifth biennial health report of the Australian Institute of Health and Welfare. Canberra: Australian Government Publishing Service, 1996.

86. South Australian Health Commission. Maternal, perinatal and infant mortality in South Australia 1993. South Australia: SAHC, 1994.

87. Pregnancy Outcome Unit, Epidemiology Branch. Medical termination of pregnancy in South Australia - The first 20 years 1970-1989. South Australia: South Australian Health Commission, 1991.

88. Perinatal Data Collection Unit. Births in Victoria. Victoria: PDCU, 1994.

89. Women's and Children's Hospital. The South Australian birth defects register Annual report 1992. South Australia: WCH, 1993.

90. Pregnancy Outcome Unit, Epidemiology Branch. Pregnancy outcome in South Australia 1993. South Australia: South Australian Health Commission, 1994.

91. Andersen G, Meffin E. Obstetric audit 1982-1991. Flinders Medical Centre. South Australia: Flinders University of South Australia, 1993.

92. The Consultative Council on Obstetrics and Paediatric Mortality and Morbidity. Annual report for the year 1993. Melbourne: CCOPMM, 1994.

93. Chan A, Robertson E, Haan E, Keane R, Ranleri E, Carney A. Prevalence of neural tube defects in South Australia, 1966-1991: Effectiveness and impact of prenatal diagnosis. Br Med J 1993;307:703-706.

94. The Consultative Council on Obstetric and Paediatric Mortality and Morbidity. Annual report for the year 1994. Melbourne: CCOPMM, 1996.

95. Beicsher NA. Major fetal malformations and perinatal mortality rates: The place of late terminations. Aust NZ J Obstet Gynaecol 1995;35:1-2.

96. McLennan W. Causes of death. Australia, 1994. Cat. no. 3303.0. Canberra: Australian Bureau of Statistics, 1995.

97. Lancaster P, Pedisich E. Congenital malformations: Australia 1981-1992. Sydney: Australian Institute of Health and Welfare National Perinatal Statistics Unit, 1995.

98 . National Health & Medical Research Council. Antenatal care: Report of the 106th session. Canberra: Commonwealth of Australia, 1989.

99. Beischer NA. Maternal mortality in Australia. Aust NZ J Obstet Gynaecol 1992; 32:183-185.

100. Shearman RP. Trends in the maternal mortality in Australia: Relevance in current practice. Aust NZ J Obstet Gynaecol 1990;30:15-17.

101. Gibb D. Confidential enquiry into maternal death. Br J Obstet Gynaecol 1990;97: 97-101.

102. King JF. Consequences of caesarean section. In: Australian Perinatal Society. 14th annual congress proceedings. Adelaide: APS, 1996.

103. NH&MRC, 1994:9.

104. Sandman PM. Hazard vs. outrage: How experts and the public see risk. In: Covello VT, McCallum DB, Pavlova MT, eds. Effective risk communication. New York: Plenum, 1989:45-49.

105. Enkin M, Chalmers I, eds. Effectiveness and satisfaction in antenatal care. London: William Heinemann Medical Books Ltd., 1982.

106. Daker M, Bobrow M. Screening for genetic disease and fetal anomaly during pregnancy. In: Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press, 1989:366-381.

107. Neilson J, Grant A. Ultrasound in pregnancy. In: Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press, 1989:419-439.

108. Palomaki GE, Knight GJ, McCarthy J, Haddow JE, Eckfeldt JH. Maternal serum screening for fetal Down syndrome in the United States: A 1992 survey. Am J Obstet Gynecol 1993;169:1558-1562.

109. Huisjes et al, 1988:5.

110. Rushworth RL, Bell SM, Rob MI, Taylor PT. Diagnostic testing during pregnancy: a descriptive analysis of utilisation data. Aust J Public Health 1994;18:401-406.

111. Beischer NA, Mackay EV. Obstetrics and the newborn: An illustrated textbook. Second Edition. Sydney: WB Saunders Company, 1991.

112.Green JM, Statham H, Snowdon C. Women's knowledge of prenatal screening tests. 1: Relationships with hospital screening policy and demographic factors. J Reprod Inf Psychol 1993;11:11-20.

113.NH&MRC, 1989:1.

114.Royal Australian College of Obstetricians and Gynaecologists. Screening in pregnancy. Policy no. 4. Melbourne: RACOG, 1992.

115.RACOG: Policy no.4, 1992:1.

116.Flower C. Antenatal clinic-The Royal Women's Hospital. Melbourne: The Royal Women's Hospital, 1979.

117.The Royal Women's Hospital. The Royal Women's Hospital ambulatory services-Midwive's cubicle. Melbourne: RWH, 1991.

118.Shapiro MC, Najman JM, Chang A, Keeping JD, Morrison J, Western JS. Information control and the exercise of power in the obstetric encounter. Soc Sci Med 1983;17:139-146.

119.Green JM. Women's experiences of prenatal screening and diagnosis. In: Abramsky L, Chapple J, eds. Prenatal diagnosis: The human side. London: Chapman & Hall, 1994:37-53.

120.Drife JO. Pitfalls of pregnancy. Med Protection Society Casebook 1995;5:4-6.

121.MacLennan A et al. Consensus statement on the origins of cerebral palsy. Aust NZ J Obstet Gynaecol 1995;35:126-131.

122.Robinson HP. Antenatal diagnosis: Techniques, accuracy and risks. In: Tonti-Filippini N, ed. Bioethics update and the role of Catholic hospitals. Melbourne: St.Vincents Bioethics Centre, 1987.

123.Shearman, 1990:17.

124.Enkin et al, 1982:268.

125.Drife, 1995:5.

126.Royal Australian College of Obstetricians and Gynaecologists. Will my baby be normal?: Realistic expectations of pregnancy and childbirth. Melbourne: RACOG, 1995.

127.Royal Australian College of Obstetricians and Gynaecologists. Health and wellbeing during pregnancy. Melbourne: RACOG, 1995.

128.Royal Australian College of Obstetricians and Gynaecologists. I want a natural birth. Melbourne: RACOG, 1995.

129.Royal Australian College of Obstetricians and Gynaecologists. After the birth. Melbourne: RACOG, 1995.

130.West R. Ethical aspects of genetic disease and genetic counselling. J Med Ethics 1988;14:194-197.

131.Drife JO, Donnai D, eds. Antenatal diagnosis of fetal abnormalities. London: Springer-Verlag, 1991.

132.McKie J. Ethical issues in prenatal diagnosis and the termination of pregnancy. Melbourne: Centre for Human Bioethics, 1994.

133.Marteau TM. Towards informed decisions about prenatal testing. Prenatal Diag 1995;15:1215-1226.

134.Harris J. Ethical aspects of prenatal diagnosis. In: Drife JO, Donnai D, eds. Antenatal diagnosis of fetal abnormalities. London: Springer-Verlag, 1991:279-293.

135.Robinson J. The role of the social sciences in evaluating perinatal care. In: Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press, 1989:81-85.

136.MacIntyre S. The management of childbirth: A review of sociological research issues. Soc Sci Med 1977;11:477-484.

137.Statham H, Green JM, Snowdon C. Psychology and social aspects of screening for fetal abnormality during routine antenatal care. In: Green JM. Women's experiences of prenatal screening and diagnosis. In: Abramsky L, Chapple J, eds. Prenatal diagnosis: The human side. London: Chapman and Hall, 1994:37.

138.Oakley A. Becoming a mother. Oxford: Martin Robertson, 1979.

139.Marteau TM, Johnston M, Plenicar M, Shaw RW, Slack J. Development of a self-administered questionnaire to measure women's knowledge of prenatal screening and diagnostic tests. J Psychosom Res 1988;32:403-408.

140.Gillot-de Vries F. Social and psychological research methods in the evaluation of prenatal screening procedures. In: Huisjes HJ, Buekens P, Reid M, eds. Antenatal screening: Current policies in the EC and evaluation. Eur J Obstet Gynecol Reprod Biol 1988; 5 Suppl:93-103.

141.Gillot-de Vries, 1988:103.

142.Stewart A. Qualitative Research Methods. Guide to learning. South Australia: Flinders University of South Australia, 1994:16-17.

143.Stewart A. A Constructivist Methodology for Qualitative Health Research.A contribution to conversation with students undertaking the elective 'Qualitative Research Methods'. South Australia: Department of primary health care, Flinders University of South Australia, 1992:4-6.

144.Steckler A, McLeroy KR, Goodman RM, Bird ST, McCormick L. Toward Integrating Qualitative and Quantitative Methods: An Introduction. Health Educ Quart 1992;19:1-8.

145.Bryman A. The debate about quantitative and qualitative research: a question of method or epistemology? Br J Sociol 1984;35:75-92.

146.Steckler et al, 1992:4.

147.Bryman, 1984:80.

148.Minichiello V, Aroni R, Timewell E, Alexander. In-Depth Interviewing: researching people. In: Stewart A. A Constructivist Methodology for Qualitative Health Research A contribution to conversation with students undertaking the elective 'Qualitative Research Methods'. South Australia: Department of primary health care, Flinders University of South Australia, 1992:3.

149.Stewart A. A Constructivist Methodology for Qualitative Health Research.A contribution to conversation with students undertaking the elective 'Qualitative Research Methods'. South Australia: Department of primary health care, Flinders University of South Australia, 1992:1-15.

150.Patton MQ. Qualitative evaluation and research. In: Stewart A. A Constructivist Methodology for Qualitative Health Research.A contribution to conversation with students undertaking the elective 'Qualitative Research Methods'. South Australia: Department of primary health care, Flinders University of South Australia,1992:4.

151.Stewart, 1992:4.

152.Patton, 1992:23.

153.Stewart, 1994:26-31.

154.Charmaz K. Discovering chronic illness: using grounded theory. Soc Sci Med 1989;30:1161-1172.

155.The Royal Women's Hospital. Annual report 1993. Melbourne: RWH,1994.

156.Marteau TM, Plenicar M, Kidd J. Obstetricians presenting amniocentesis to pregnant women: practice observed. J Reprod Inf Psychol 1993;11:3-10.

157.Dean AG, Dean JA, Burton AH, Dicker RC. Epi Info, Version 5: a word processing, database, and statistics program for epidemiology on micro-computers. Atlanta: Centers for Disease Control, 1990.

158.Halliday J, Lumley J, Watson L. Comparisons of women who do and do not have amniocentesis or chorionic villus sampling. Lancet 1995;345:704-709.

159.Fisher J. Obstetric interventions: Non-clinical determinants and clinical consequences. In: Childbirth and Parenting Education Resources & Services. Birth issues: International conference proceedings. Melbourne: CPERS, 1994.

160.Australian Bureau of Statistics. Women in Australia Cat. no.4113.0. Canberra: National Capital Printing, 1993.

161.Australian Bureau of Statistics and Office of Status of Women. Australian women's year book 1994, Cat. no.4124.0.Canberra: Australian Government Publishing Service, 1995.

162.Brown S, Lumley J, Small R. Reasons to stay Reasons to go. Victorian women talk about early discharge. Melbourne: Centre for Study of Mothers' and Children's Health, La Trobe University, 1995.

163.Medical records (database), The Royal Women's Hospital.

164.Australian Bureau of Statistics. The labour force Australia August 1995 Cat. no.6203.0. Canberra: Australian Government Publishing Service, 1995.

165.Flower, 1979:1.

166.The Royal Women's Hospital. Having a baby at The Royal Women's Hospital. Melbourne: RWH, 1994.

167.The Royal Women's Hospital. Being Pregnant. Melbourne: RWH, 1990:8-9.

168.The Royal Women's Hospital. Ultrasound patient information. Melbourne: RWH, 1990.

169.The Royal Women's Hospital. Some complications of pregnancy. Melbourne: RWH, 1992.

170.Yates JM, Lumley J, Bell RJ. The prevelance and timing of obstetric ultrasound in Victoria 1991-1992: a population-based study. Aust NZ J Obstet Gynaecol 1995; 35:375-379.

171.Pathology laboratory records (database), The Royal Women's Hospital.

172.Mulvaney N, Oct 1995.(Personal communication)

173.Department of Health, Housing, Local Government and Community Services. Medicare benefits schedule book. Canberra: Australian Government Publishing Service, 1993.

174.Women's Co-operative Guild. Maternity: Letters from working-women. In: Shorter E. A history of women's bodies. Suffolk: Basic Books, 1982:70

175.Shorter E. A history of women's bodies. Suffolk: Basic Books, 1982:69.

176.Shorter, 1982:71.

177.Farrant W. Who's for amniocentesis? The politics of prenatal screening. In: Homans H, ed. The sexual politics of reproduction. Gower: Hants, 1985 .

178.Kidd J, Cook R, Marteau TM. Is routine afp screening in pregnancy reassuring? J Psychosom Res 1993;37:717-722.

179.Marteau TM, Kidd J, Cook R , et al. Perceived risk not actual risk predicts uptake of amniocentesis. Br J Obstet Gynaecol 1991;98:282-286.

180.James DK, Stirrat GM. Pregnancy and risk: The basis for rational management. Chichester: John Wiley and Sons Ltd, 1988.

181.Enkin M. Risk in pregnancy: The reality, the perception and the concept. Birth 1994; 21:131-134.

182.Slovic P. Perception of risk. Science 1987;236:280-285.

183.Beers M. Disease control activities under threat. In Touch 1995;5:3-4.

184.Lupton D. Risk as moral danger: The social and political functions of risk discourse in public health. Int J Health Serv 1993;23:425-435.

185.Handwerker L. Medical risk: Implicating poor pregnant women. Soc Sci Med 1994; 38:665-675.

186.Patterson KA. Experience of risk for pregnant black women. J Perinatol 1993;13: 279-284.

187.Schuman AN, Marteau TM. Obstetricians' and midwives' contrasting perceptions of pregnancy. J Reprod Inf Psychol 1993;11:115-118.

188.Roelofsen EEC, Kamerbeek LI, Tymstra TJ. Chances and choices. Psycho-social consequences of maternal serum screening. A report from The Netherlands. J Reprod Inf Psychol 1993;11:41-47.

189.Lupton D. Risk as a sociocultural construct. In Touch Dec.1995;12:1, 4.

190.James et al, 1988:2.

191.Nelkin D. Communicating technological risk: The social construction of risk perception. Ann Rev Public Health 1989;10:95-113.

192.Fischoff B, Bostrom A, Jacobs Quandrel M. Risk perception and communication. Ann Rev Public Health 1993;4:83-203.

193.Beck U. Risk society. Towards a new modernity. London: Sage Publication Ltd, 1992.

194.Lupton, 1995:1.

195.Nelkin, 1989:100.

196.Gifford SM. The meaning of lumps: A case of the ambiguities of risk. In: Janes CR, Stall R, Gifford SM, eds. Anthropology and Epidemiology. Boston: D. Reidel Publishing Company, 1986: 213-246.

197.Childress JF. Risk. In: Reich WT, ed. Encyclopedia of bioethics. New York: The Free Press, 1978:1516-1522.

198.Gifford, 1986:230-231.

199.Patterson, 1993:281.

200.Elkins TE, Brown D. Ethical concerns and future directions in maternal screening for Down syndrome. Women's Health Inst. 1995;5:15-20.

201.Newell C. A critique of the construction of prenatal diagnosis and disability. In: McKie J. Ethical issues in prenatal diagnosis and the termination of pregnancy. Melbourne: Centre for Human Genetics, 1994:89-95.

202.Borthwick C. The prevention of disablement. In: McKie J. Ethical issues in prenatal diagnosis and the termination of pregnancy. Melbourne: Centre for Human Genetics, 1994:103-114.

203.Sjogren B, Uddenberg N. Attitudes towards disabled persons and the possible effects of prenatal diagnosis. An interview study among 53 women participating in prenatal diagnosis and 20 of their husbands. J Psychosom Obstet Gynecol 1987; 6:187-196.

204.Sjogren et al, 1987:195.

205.Gillam L. Does prenatal diagnosis discriminate against the disabled? In: McKie J. Ethical issues in prenatal diagnosis and the termination of pregnancy. Melbourne: Centre for Human Genetics, 1994:115-120.

206.Sykes JB, ed. The concise Oxford dictionary of current English. 6th Edition. Oxford: Oxford University Press, 1976:1229.

207.Mahoward MB. Women and children in health care: An unequal majority. New York: Oxford University Press, 1993:170.

208.Hicks, 1978:28.

209.Hicks, 1978:128.

210.Hyde B. An interview study of pregnant women's attitudes to ultrasound scanning. Soc Sci Med 1986;22:587-592.

211.Shearer EL. Many factors affect the outcome of prenatal classes. Birth 1995;22;27.

212.Simkin P, Enkin MW. Antenatal classes. In: Shearer EL. Many factors affect the outcome of prenatal classes. Birth 1995;22;27.

213.Willis E. Medical dominance. Sydney: Allen & Unwin, 1983.

214.Lumley J, Astbury J. Birth rites, birth rights: Childbirth alternatives for Australian parents. Australia: Thomas Nelson, 1980.

215.Milliken N. Medical aspects. In: Milliken N, Steinbock B, Johnsen DE. Maternal-fetal relationship. In: Reich WT, ed. Encyclopedia of bioethics: Revised edition. New York: MacMillan, 1995: 1403.

216.Porter M, MacIntyre S. What is, must be best: A research note on conservative or deferential responses to antenatal care provision. Soc Sci Med 1984;19:1198.

217.Milliken, 1995:1414.

218.Green, 1994:44.

219.Shapiro et al, 1983:139.

220.Shapiro et al, 1983:140.

221.Shapiro et al, 1983:145.

222.Willis E. Who does what to whom?: the social structure of health care delivery. In: Deakin University. Sociology of health care: A sss336: Work and occupations: Study guide. Geelong, 1989:17-33.

223.Willis, 1989:21.

224.Willis, 1983:24.

225.Mitchell J, Oakley A, eds. The rights and wrongs of women. Reading: Cox & Wyman Ltd, 1986.

226.Mitchell et al, 1986:29.

227.Marteau, 1991:243.

228.Lumley J, Astbury J. Advice for pregnancy. In: Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press, 1989:237.

229.Daly J, Willis E. Technological innovation and the labour process in health care. Soc Sci Med 1989;28:1149-1157.

230.Daly et al, 1989:98.

231.Lumley et al, 1980:77.

232.Richards MPM, Green JM. Attitudes toward prenatal screening for fetal abnormality and detection of carriers of genetic disease: a discussion paper. J Reprod Inf Psychol 1993;11:49-56.

233.Daly et al, 1989:97.

234.World Health Organisation. Having a baby in Europe: Public health in Europe. No. 16 Copenhagen: WHO, 1985.

235.Lebacqz K, Levine RJ. Informed consent in human research: ethical and legal aspects. In: Reich WT, ed. Encyclopedia of bioethics. New York: The Free Press, 1978:754-761.

236.Pincus RC. Has informed consent finally arrived in Australia? A comment on the law following the decision of the High Court of Australia in Rogers v. Whitaker. Med J Aust 1993;159:25-27.

237.Nisselle P. High Court of Australia judgement on informed consent. Med Protection Society Casebook 1993;2:3-5.

238.Pincus, 1993:26.

239.Royal Australian College of Obstetricians and Gynaecologists. Parents, obstetricians and childbirth. Rights and responsibilities. Policy no.16. Melbourne: RACOG, 1992.

240.RACOG:Policy no.16, 1992:2.

241.Shapiro MC, Najman JM. Socio-economic status differences in patient's desire for and capacity to obtain information in the clinical encounter. Aust J Soc Iss 1987;22:465- 471.

242.Turner J. Women's views of tests in pregnancy. Maternity Alliance News 1993;10: 7-8.

243.Kyle D, Cummins C, Evans S. Factors affecting the uptake of screening for neural tube defect. Br J Obstet Gynaecol 1988:95:560-564.

244.Thornton JG, Hewison J, Lilford RJ, Vail A. A randomised trial of three methods of giving information about prenatal testing. Br Med J 1995;311:1127-1130.

245.Jorgensen FS. Attitudes to prenatal screening, diagnosis and research among pregnant women who accept or decline an alpha-fetoprotein test. Prenatal Diag 1995;15:419-429.

246.Wood R. Informed decision making: Why does it have consumer's consent? Health Forum 1996;37:10.

247.Hall D. The research imperative and beauracratic control: The case of clinical research. Soc Sci Med 1991;32:333-342.

248.Wood, 1996:9.

249.Ratten GJ, Chatham E. Memorandum: Reorganisation of the antenatal clinics. Melbourne: The Royal Women's Hospital, 1995:1.

250.Jonsen AR. Right to health-care services. In: Reich WT, ed. Encyclopedia of bioethics. New York: The Free Press, 1978:623.

251.Jonsen AR. Right to health-care services. In: Reich WT, ed. Encyclopedia of bioethics. New York: The Free Press, 1978:623-630.

252.Jonsen, 1978:625.

253.Oakley J. Sketch of a virtue ethics approach to health care resource allocation. Monash Bioethics Rev 1994;13:27-33.

254.Hill TE. Autonomy of moral agents. In: Becker LC, ed. Encyclopedia of ethics. New York: Garland Publishing Co, 1992:71-75.

255.Hill, 1992:72.

256.Branson R. Theories of justice and health care. In: Reich WT, ed. Encyclopedia of bioethics. New York: The Free Press, 1978:631.

257.Branson, 1978:630.

258.Nozick R. In: Branson R. Theories of justice and health care. In: Reich WT, ed. Encyclopedia of bioethics. New York: The Free Press, 1978:632.

259.Calman KC. The ethics of allocation of scarce health care resources: a view from the centre. J Med Ethics 1994;20:71-74.

260.Feinberg J. Justice. In: Reich WT, ed. Encyclopedia of bioethics. New York: The Free Press, 1978:802-811.

261.Lyons D. Utilitarianism. In: Becker LC, ed. Encyclopedia of ethics. New York: Garland Publishing Co, 1992:1261-1268.

262.Weare K. The contribution of education to health promotion. In: Bunton R, Macdonald G, eds. Health promotion: Disciplines and diversity. London: Routledge, 1992:66-85.

263.Weare, 1992:81.

264.Mahowald MB. Person. In: Reich WT, ed. Encyclopedia of bioethics: Revised edition. New York: MacMillan, 1995:1934-1941.

265.Mahowald, 1995:1936.

266.van Melsen AGM. Person. In: Reich WT, ed. Encyclopedia of bioethics. New York: The Free Press 1978; 1207.

267.Lebacqz K. Feminism. In: Reich WT, ed. Encyclopedia of bioethics: Revised edition. New York: MacMillan, 1995:813.

268.Seymour J. Fetal welfare and the law. Canberra: Australian Medical Association, 1995.

269.Seymour, 1995:43,46.

270.Macklin R. Women's health: An ethical perspective. J Law Med Ethics 1993;21: 23-29

271.Daniels CR. Competing gender paradigms: Gender difference, fetal rights and the case of Johnson Controls. Policy Stud Rev 1991;10:51-68.

272.Maier KE. Pregnant women: Fetal containers or people with rights. Affilia 1989;4: 8-20.

273.Solomon RI. Future fear: Prenatal duties imposed by private parties. Am J Law Med 1991;17:411-434.

274.Rothman BK. The tentative pregnancy Prenatal diagnosis and the future of motherhood. London: Pandora, 1988.

275.Mahoward MB. Women and children in health care: An unequal majority. New York: Oxford University Press, 1993.

276.Reich WT, ed. Encyclopedia of bioethics: Revised edition. New York: MacMillan, 1995.

277.Mahoward, 1993:63-64.

278.Lebacqz K. Feminism. In: Reich WT, ed. Encyclopedia of bioethics: Revised edition. New York: MacMillan, 1995:808-818.

279.Milliken, 1995:1407.

280.Lebacqz, 1995: 814.

281.Seymour, 1995:211.

282.Thornton JG. The ethics of prenatal screening and abortion for fetal abnormality: a personal view. J Reprod Inf Psychol 1994;12:156.

283.Sykes JB, ed. The concise Oxford dictionary of current English. 6th Edition. Oxford: Oxford University Press, 1976:29.

284.Blum L. Altruism. In: Becker LC, ed. Encyclopedia of ethics. New York: Garland Publishing Co, 1992:35.

285.Rothman, 1988:28.

286.Seymour, 1995:213.

287.Thornton JG. The ethics of prenatal screening and abortion for fetal abnormality: a personal view. J Reprod Inf Psychol 1994;12:155-161.

288.Thornton, 1994:157.

289.Edwards PJ, Hall DMB. Screening, ethics and the law. BMJ 1992;305:267-268.

290.Heringa MP, Huisjes HJ. Antenatal care: current practice in debate. Br J Obstet Gynaecol 1988;95:836-840.

291.Heringa et al, 1988:839.

292.Maclean U, Sinfield D, Klein S, Harnden B. Women who decline breast screening. J Epidemiol Community Health 1984;38:278-283.

293.MacIntyre, 1977:482.

294.Green, 1994:48.

295.Green JM. Prenatal screening and diagnosis: Some psychological and social issues. Br J Obstet Gynaecol 1990;97:1075.

296.French K, Porter AMD, Robinson SE, McCallum FM, Howie JGR, Roberts MM. Attendance at a breast screening clinic: a problem of administration or attitudes. Br Med J 1982;285:617-620.

297.French et al, 1982:618.

298.Miller AB. Screening for cancer: Issues and future directions. J Chron Dis 1986;39: 1067-1077.

299.Halliday et al, 1995:708.

300.Skene L. Prenatal diagnosis and late termination: A legal perspective. Aust NZ J Obstet Gynaecol 1995;35:3.

301.Skene L. Prenatal diagnosis and late termination: A legal perspective. Aust NZ J Obstet Gynaecol 1995;35:3-6.

302.Atlee HB. After office hours: The fall of the queen of heaven. Obstet Gynecol 1963; 21:514-519.

303.Oakley A. The captured womb: a history of the medical care of pregnant women. Oxford: Blackwell, 1984.

304.Kitzinger, 1980:6.

305.Sargent C, Stark N. Surgical birth: Interpretations of cesarean delivery among private hospital patients and nursing staff. Soc Sci Med 1987;25:1269-1276.

306.Styles WM. Balancing technology with non-intervention: Discussion. In: Chamberlain G, Patel N, eds. The future of the maternity services. London: Royal College of Obstetricians and Gynaecologists Press, 1994:166-170.

307.Keirse MJN. Interaction between primary and secondary care during pregnancy and childbirth. In: Chalmers I, Enkin M, Keirse MJNC, eds. Effective care in pregnancy and childbirth. Oxford: Oxford University Press, 1989:198.

308.Steer PJ. Appropriate use of technology. In: Chamberlain G, Patel N, eds. The future of the maternity services. London: Royal College of Obstetricians and Gynaecologists Press, 1994:115-118.

309.Australian Institute of Health and Welfare. Australia's Health 1994: The fourth biennial health report of the Australian Institute of Health and Welfare. Canberra: Australian Government Publishing Service, 1994.

310.AIH&W, 1994:145.

311.Reich WT, ed. Encyclopedia of bioethics. New York: The Free Press, 1978.

312.Kilner JF. Health-care resources, allocation of: macroallocation. In: Reich WT, ed. Encyclopedia of bioethics: Revised edition. New York: MacMillan, 1995:1067.

313.Branson R. Theories of justice and health care. In: Reich WT, ed. Encyclopedia of bioethics. New York: The Free Press, 1978:630-637.

314.Kilner JF. Health-care resources, allocation of: macroallocation. In: Reich WT, ed. Encyclopedia of bioethics: Revised edition. New York: MacMillan, 1995:1067-1075.

315.Kilner, 1995:1071.

316.Kilner, 1995:1069.

317.Veatch RM. The foundations of justice: Why the retarded and the rest of us have claims to eqality. In: Kilner JF. Health-care resources, allocation of: macroallocation. In: Reich WT, ed. Encyclopedia of bioethics: Revised edition. New York: MacMillan, 1995:1069.

318.Seedhouse D. Why bioethicists have nothing useful to say about health care rationing. J Med Ethics 1995;21:288-291.

319.Seedhouse, 1995:289.

320.Enkin et al, 1982:283.

321.Blackledge D, Prendergast M. Litigation: obstetrics in crisis? Med J Aust 1991;154:709.

322.Sweet R. The obstetrician's dilemma. Med J Aust 1989;150:545-546.

323.Stanley F. Cerebral palsy: The courts catch up with sad realities. Med J Aust 1994;161:236.

324.Bastian H. Obstetrics and litigation: a consumer perspective. Med J Aust 1990;153:340-345.

325.Ragg M. Cases of baby blues. Bulletin 1993;Dec 21:39.

326.Bastian, 1990:345.

327.Hickson GB, Clayton EW, Githens PB, Sloon FA. Factors that prompted families to file medical malpractice claims following perinatal injuries. JAMA 1992;267: 1359-1363.

328.Ennis M, Clark A, Grudzinskas JG. Change in obstetric practice in response to fear of litigation in the British Isles. Lancet 1991;338:616-618.

329.Barber HRK. The malpractice crisis in obstetrics and gynaecology: is there a solution? Bull N Y Acad Med 1991;67:162-172.

330.Keifer WS. Preparing for obstetrics in the twenty-first century: Quo vadis? Am J Obstet Gynecol 1993;168:1787-1790.

331.Boehm FH. Medicolegal climate for obstetrician-gynecologists. Obstet Gynecol Surv 1993;48:715-716.

332.Harris JL, Davidsin EC. Sociologic aspects of pregnancy. Cur Opinion Obstet Gynecol 1992;4:797-801.

333.Rostow VP, Osterweis M, Bulger RJ. Medical professional liability and the delivery of obstetrical care. N Eng J Med 1989;321:1057-1060.

334.Clements RV. Litigation in obstetrics and gynaecology. Br J Obstet Gynaecol 1991; 98:424.

335.Bastian, 1990:340.

336.Sweet, 1989:545.

337.Sweet, 1989:546.

338.Hannah ME, Ohlsson A, Farine D, et al. Induction of labour compared with expectant management for prelabour rupture of the membranes at term. N Eng J Med 1996;334:1005-1054.

339.Bunker JP, Fowles J, Schaffarzick R. Evalution of medical-technology strategies. N Eng J Med 1982;306:620-624,687-692.

340.Bunker et al, 1982:624.

Appendix 1

Patient Information Sheet

All mothers hope for a healthy pregnancy and a healthy baby.

Today, a large range of routine tests are done during pregnancy to try to achieve this.

You probably had some of these tests during your pregnancy.

I am an Obstetrician interested in finding out what women think about these tests and what this means for women having babies in the future.

You are invited to take part in this survey to help find out how women feel about these tests.
If you agree to take part, it will mean answering some questions about your experience with routine tests you had during your pregnancy. Examples of some routine tests are ultrasounds and blood tests.
Information collected from this survey will be used to assist in the development and use of such tests in the future.
The questionnaire takes about 10 minutes to complete.
I stress that your answers are **CONFIDENTIAL.** No names will be used. The questionnaire can only be identified by an I.D. number.

Your involvement in this study is entirely voluntary, and your non-participation will not affect your treatment at the Flinders Medical Centre in any way. Should you decide to withdraw from the study you may do so freely and without prejudice to any future treatment at Flinders Medical Centre.

If you have any questions I will return tomorrow to collect the questionnaire and answer any queries or you can contact me by ringing the Dept. of Obstetrics and Gynaecology, Ext.4471

Please leave the completed questionnaire on your overway table if you are going to be out of your room the day it will be collected.

THANKYOU

Signed

Dr. Judy Searle

This study has been reviewed by the Clinical Investigations (Ethics) Committee at Flinders Medical Centre. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make a confidential complaint, you may contact the Executive Secretary of this Committee, Ms. Carol Hakof (204 4507)

I.D. No.

QUESTIONNAIRE
ON
ANTENATAL SCREENING

Please return completed questionnaire to Dr. Judith Searle by leaving it on your overway table where it will be collected the next day.

THANKYOU

Section 1.
This section will ask you how you feel about the routine tests you had during your pregnancy.
Please circle the ONE number which best fits your experience

1. Did you have an ultrasound(s) of your baby whilst you were pregnant?
   1 Yes
   2 No

   If you answered YES, proceed to question 2.
   If you answered NO , proceed to question 4.

2.a) How valuable was it to YOU to have the ultrasound(s)?
   1 very valuable
   2 valuable
   3 of minimum value
   4 not valuable

2.b) How valuable was it to your MAIN SUPPORT PERSON for you to have the ultrasound(s)?
   1 very valuable
   2 valuable
   3 of minimum value
   4 not valuable

3. Please explain why you think the ultrasound was valuable or not.

   _____

   _____

   _____

4. How valuable do you think ALL the other routine tests you had in pregnancy are?
   1 very valuable
   2 valuable
   3 of minimum value
   4 not valuable

5. For WHOSE BENEFIT do you believe are the routine tests you had during pregnancy done?
   1 doctor/midwife
   2 you
   3 your baby
   4 all of the above
   5 none of the above

6. Do you think routine tests during pregnancy benefit...
   1 all pregnant women?
   2 most pregnant women?
   3 few pregnant women?
   4 no pregnant women?

7. Do you think ALL pregnant women should have routine tests in pregnancy?

   1 yes
   2 no

8. Please explain WHY you think all pregnant women should or should'nt have routine tests in pregnancy.

_____

_____

_____

9. What did you expect the tests you had during pregnancy would tell you?

_____

_____

_____

10.a) Do you think a normal test result is reassuring?
1 yes
2 no
3 don't know

10.b) If you answered 'no', how DID it make you feel?

_____

_____

_____

Section 2.
This section will ask you some more general questions about routine antenatal tests.
Please circle the ONE number which best fits your experience

11. How reliable do you think the routine test results you had during pregnancy were?
1 perfect
2 very reliable
3 mostly reliable
4 minimally reliable
5 not at all reliable

12. Do you think the development of MORE routine tests in pregnancy should be encouraged?
1 Yes
2 Not sure
3 No

13. How much do you think existing routine tests you had during pregnancy cost?
(approximate cost per pregnant woman)
1 $10
2 $100
3 $500
4 $1000

14. Do you think how much they cost should influence whether they are done or not?
1 Yes
2 Don't know
3 No

Section 3.
This section will ask you some questions about your knowledge of the routine tests and their results.
Please circle the ONE number which best fits your experience

15. Were you told WHAT routine tests would be done during pregnancy?
1 Yes

16. Were you told WHY the routine tests would be done during pregnancy?
    1 Yes
    2 No

17. Of the routine tests you had at or around your first clinic visit, were you told the RESULTS of these tests?
    1 Yes completely
    2 Yes mostly
    3 No mostly
    4 No completely

    If you answered NO at all, proceed to question 18.
    If you answered YES at all, proceed to question 20.

18. Did you ask for the results?
    1 Yes
    2 No

    If you answered NO ,proceed to question 19.
    If you answered YES ,proceed to question 20.

19. Why do you think you didn't ask?

    _____

    _____

    _____

20. What effect did being offered routine antenatal tests have on your TRUST of your doctor or midwife?
    1 increased
    2 didn't effect
    3 decreased

21. Did you feel it would cause an inconvenience to the antenatal clinic staff if you declined any of the tests?
    1 Yes
    2 No

Section 4.
This section will ask some questions about your experience and feelings about the routine test RESULTS.
Please circle the ONE number which best fits your experience

22. How concerned were you that one of the routine tests would show an ABNORMAL result?
    1 very concerned
    2 concerned
    3 a little concerned
    4 not at all concerned

23. Did you think an ABNORMAL test result would tell you...
    1 there was something wrong with you or your baby?
    2 there was a high risk that something was wrong?
    3 you needed more tests?
    4 don't know

24. Did you have any abnormal results to any of the routine tests you had during this pregnancy?
1 Yes
2 No

If you answered YES, proceed to question 25.
If you answered NO , proceed to question 33.

25. What was/were the abnormal result(s)?

_____

_____

_____

26. Did the abnormal result(s) make you feel...
1 very anxious?
2 anxious?
3 anxious but willing to wait for more information?
4 not at all anxious?

27. Did you have FURTHER tests because of that abnormal result(s)?
1 Yes
2 No

If answered YES, proceed to question 28.
If answered NO , proceed to question 32.

28. What were the FURTHER tests?

_____

_____

_____

29. Did the further test results reassure you?
1 Yes completely
2 Yes mostly
3 No mostly
4 No completely

30. Do you feel you were given enough information about the ORIGINAL routine test(s) prior to having it/them?
1 Yes completely
2 Yes mostly
3 No mostly
4 No completely

31. Would you have the ORIGINAL routine test(s) again in a future pregnancy?
1 Yes
2 No

Section 5.

This section will ask some general questions about yourself.
Please circle the ONE number which best fits yourself.

32. Did you attend antenatal classes during this or any previous pregnancy?
1 Yes

33. Was your baby born premature?
    1 Yes Specify how many weeks early the baby came. ☐
    2 No

34. How old are you?
    1 18 years or less
    2 19 - 26 years
    3 27 - 34 years
    4 35 years or more

35. How many children including this baby have you given birth to?
    1 one
    2 two
    3 three
    4 four or more

36. Are you currently or have you recently been in PAID employment?
    1 Yes Specify _____
    2 No _____

37. What is the HIGHEST educational level you have reached?
    1 completed primary school
    2 left during high school
    3 completed high school
    4 completed a TAFE course
    5 completed a University/College course

38. Who was your main support person throughout your pregnancy?
    1 partner
    2 mother
    3 friend
    4 other relative
    5 other Specify _____

39. Are there any other languages other than English spoken at home?
    1 Yes Specify _____
    2 No

OPTIONAL QUESTION:

Have you any suggestions for improving this questionnaire for future women?

_____

_____

_____

_____

THANKYOU VERY MUCH FOR YOUR PARTICIPATION

Social and Ethical Determinants of the use of routine antenatal screening - through women's experience : A Pilot Study

Author: Dr. Judith Searle
B.M;B.S: F.R.A.C.O.G.

Appointment: Locum Visiting Medical Specialist

Address: 22 Dudley Road
Marryatville SA 5068

Abstract:

Routine antenatal screening programs are integral to modern antenatal care.[1] As the number and frequency of routine antenatal screening tests increase[1 2 3] what factors determine their continued use? This pilot survey examines, through women's experience, some of the social and ethical determinants of the use of antenatal screening.(n=19) In particular, this survey demonstrates that women have high expectations of and highly value antenatal screening tests and birth outcomes, have high faith in the health care system and fail to consider the impact of the conflict between autonomy and utility on resource allocation. These, combined with a high perceived notion of risk of adverse birth outcomes, appear to be determinants of the use of routine antenatal screening procedures in current obstetric practice. Identification and understanding of these determinants of one aspect of the current health care system will enable a more comprehensive evaluation of not only antenatal screening programs but other related health care services.

Introduction:

Routine antenatal screening programs are now integral to the current practice of antenatal care.[1] Over the past decade the number and frequency of routine antenatal screening tests has increased.[1 2 3] However, many of these tests have escaped thorough scrutiny and evaluation by established epidemiological prerequisites for a screening test.[3] Recent examination of women's experience of antenatal screening indicates that such testing can be socially costly to women.[4 5] Little analysis is found in the literature of the social and ethical determinants of the continued use of routine antenatal screening tests by pregnant women. Literature related to antenatal screening and ethical issues is largely confined to areas such as genetic counselling,[6] abortion or informed consent.[7] That literature is devoid of analysis that uses bioethical principles.

The aim of this pilot study was to examine, through women's experiences and feelings, some of the social and ethical factors reflected in their perspectives about antenatal screening tests. This survey asked:

.What are women's expectations of routine antenatal screening tests?
.How do women value these tests?
.What are women's values in relation to individual rights and utility?

By obtaining a better understanding of some of the social and ethical determinants of the use of one aspect of the current health care system this report provides a broader framework with which to consider health service provision.

Methods:

The pilot survey randomly selected 22 public patients who had delivered a live baby within one week prior to the survey at a major public teaching hospital in the southern suburbs of Adelaide. The hospital provides tertiary care to adults and neonates and has an average of 1870

public confinements per year. The survey population is 96% Caucasian and 43% primiparous. The median age group is 25-29 years.[8]

The study design consisted of a form of self-administered survey questionnaire. The pilot survey was approved by the hospital's Clinical Investigations Committee and respondents to the questionnaire were required to give written consent to participate.
Inclusion criteria included:
.delivery of a live baby(ies) at the hospital within one week of the survey
.literate in English
.public patient status
Selection of patients was done randomly from the eligible sampling frame who were current in-patients of the postnatal wards. The patients were approached individually by the survey researcher and the completed questionnaires were collected 24 hours later.
The questionnaire included 36 items containing both closed and open-ended questions. The quantitative survey data was analysed with the aid of a computer statistical package, Survey Research.[9] Standard univariate analysis was performed and gamma and tau coefficients and chi-squared calculated for bivariate correlations. A p value of <0.05 was considered significant.

The pilot survey is to be the basis for a substantive questionnaire of approximately 96 postnatal women to be conducted 1994/1995.

Results:

The response rate to the questionnaire was 86.4%(19)
a) Sample characteristics
The obstetric and demograghic characteristics of the sample are listed in table 1. The median age group was 27-34 years (47.4%) and the median parity was 2 (52.6%). The majority of women (84.2%) delivered at term.

Table 1. **Obstetric and demographic characteristics**

Maternal age	18yrs or less	19-26yrs	27-34yrs	35yrs or more
	1 (5.3%)	5 (26.3%)	9 (47.4%)	4 (21.2%)
Parity	primip	multip		
	6 (31.6%)	13 (68.4%)		
Preterm delivery (<37 completed weeks)	3 (15.8%)			
Paid employment	11 (57.9%)			
Highest education level	Didn't complete high school	Other	Completed Tertiary course	
	3 (15.8%)	13	3 (15.8%)	
Speak language other than English at home	4 (21.1%)			
Attended antenatal classes	8/11 (72.7%)		8 missing	
			n = 19	

b) Women's expectations of routine antenatal screening tests
Although 100% of women believed a normal test result was reassuring 47.4% expressed concern about having an abnormal test result during the pregnancy. None expressed no concern. Responses to the open-ended question regarding what women expected the results would tell them included:
."I think everyone expects the results to be normal. (I was hoping.)"
."Positive results."
."... I expected confirmation of my perception of good health and well-being"
and
."Whether the baby and I are alright."
."If everything is O.K."
57.9% of women believed the tests were either very reliable or perfect. Only 15.8% believed them to be minimally reliable.
Correlations between age, parity and educational level with women's expectations of antenatal screening tests are shown in table 2.

Table 2. **Correlations with concern re having an abnormal test result**

Variable	Gamma coefficient	chi-squared
Maternal age	-0.24	11.52 n.s.
Parity	-0.52	3.74 n.s.
High educational level	-0.46	3.97 n.s.

n.s. = not significant

Although a trend is seen between increasing maternal age and reduced concern regarding having an abnormal test result the correlation is poor (Gamma = 0.24) and not statistically significant. Similar results are seen for increasing parity and higher educational level.

c) Perceived value of routine antenatal screening tests
100% of respondents had at least one fetal ultrasound during pregnancy and 94.7% perceived the ultrasound as being valuable or very valuable. 79% of the sample also perceived the ultrasound to be valuable to their main support person. When asked why they thought the ultrasound was valuable the following responses were recorded:
."Reassurance - good to see an image of the baby and its movements, gives confidence..."
."It made me more aware that there was a baby growing inside me"
."It is important to me and my husband to be able to actually see the little baby in there and it is part of your family there and then..."
84.2% of women perceived all other routine antenatal screening tests to be valuable or very valuable. None perceived the tests to be of no value. Responses to the question, "why should or shouldn't pregnant women have routine antenatal screening tests?" included:
."It's the only way to ensure that everything is growing as it should"
."For their own peace of mind"
."If any problems do occur then they can treat it"

."Tests help to relieve tension etc. Answers questions of "is my baby O.K?"

75% of respondents believed that the development of more routine antenatal screening tests should be encouraged.

Correlations between age, parity and educational level with women's perceived value of antenatal screening tests are shown in table 3. Increasing maternal age is minimally associated with reduced perception of the value of antenatal screening tests (gamma = -0.38) but these findings are not significant.

Table 3. **Correlations with perceived value of antenatal screening tests**

Variable	Gamma coefficient	chi-squared
Maternal age	-0.38	9.89 n.s.
Parity	-0.07	6.23 n.s.
High educational level	-0.05	8.72 n.s.

n.s.= not significant

d) Ethical Considerations

1. Utility

100% of respondents believed routine antenatal screening tests benefited all or most pregnant women and 89.5% believed all pregnant women should have routine antenatal screening tests. 78.9% believed the routine antenatal screening tests benefited not only themselves but also the fetus and the health care provider involved in their care.

2. Individual Rights

73.7% of respondents believed the cost per pregnant woman for all routine antenatal screening tests was between $500 and $1000. 92.9% of respondents also believed how much the tests cost should not influence whether they are done or not.

3. Trust

47.4% of respondents felt that being offered antenatal screening tests increased their trust in their midwife or doctor. 52.6% felt it made no difference. In response to an open-ended question regarding why some women did not ask for the results of their tests, when they weren't otherwise told, these responses were recorded:

."If there was a problem I know my G.P. would have advised me"

."I assumed they were O.K."

Discussion:

Routine antenatal screening tests consume much time and resources in modern antenatal care in western societies. Only recently, though, has women's experiences and views related to these procedures been discussed in the literature.[4] Through these experiences it is possible to discern some of the social and ethical factors that underpin women's perspectives. Such factors may exist to support or refute current antenatal screening practices.

Increasingly there is discussion in the obstetric literature regarding society's high expectations of the perfect birth outcome.[2] Enkin goes further to discuss the need of pregnant women to take out a form of pschological insurance against adverse outcomes.[2] In the author's survey, although many of the responses to the open-ended question about their expectations of the tests included desire or hope to confirm normality or health, many of the women (47.4%) were still concerned or very concerned that a test result may be abnormal [ie. they did not expect a normal outcome.] Many respondents expressed an expectation that the test results would provide reassurance that both the "baby" and themselves were healthy. All believed a normal test result was reassuring. This concept of taking out insurance against the abnormal is further strengthened by the
belief of the majority of respondents (58%) who felt that the antenatal screening tests were either very reliable or perfect.

Although these findings were not statistically significant, due to the small sample size in this pilot survey, as parity and maternal age increased the concern about the possibility of an abnormal result decreased. Similarly, women of higher education tended also to be less concerned. This would support the view that previous experience and education may assist in providing more positive expectations of pregnancy and outcomes.
In this survey women's expectations of antenatal screening tests as being reliable in providing reassurance about normality were very high. The demand for insurance against the adverse outcome was also high. Such expectations by women lend strong support to the current practice of routine antenatal screening.

The expressed need by pregnant women for reassurance was further seen when examining women's perceptions of the value of routine antenatal screening tests. This survey supports previous observations that women perceive ultrasound to be very valuable and reassuring.[10 11] This survey also demonstrated the high value women placed on all antenatal screening tests. When asked why they thought the tests were valuable or not the major response was related to obtaining reassurance through testing. In addition there was a strong emphasis on the need to exclude or detect the abnormal. 75% of women also believed that the development of more routine antenatal screening tests should be encouraged. This not only supports Enkin's perception that women want insurance against adverse outcomes[2] but further suggests that more insurance is better. There exists the potential for a conflict of expectations of this insurance for those respondents who perceived that if an abnormality had been detected it could have been treated. Whilst this is true for the majority of conditions screened for antenatally it is clearly not so for maternal conditions such as hepatitis B or HIV and many fetal abnormalities for which there are no effective treatments.
Such a high perceived value of antenatal screening, as demonstrated by the respondents of this survey, may contribute to society's perceived value of antenatal screening tests and not only support its ongoing practice but also its expansion.

This survey also attempted to understand some of the basic ethical principles that operate when women participate in routine antenatal screening programs. This survey showed a general acceptance of the perceived utility of screening tests for all pregnant women. 89.5% of respondents believed all pregnant women should have routine antenatal screening. In the past many of these procedures were reserved only for a few. In current obstetric practice there is an increasing application of screening measures to all pregnant women.[2] It is not surprising to find this trend echoed by the recipients of antenatal care. If all routine antenatal screening tests were cheap, reliable, risk free and all women were better off as a result of being tested this view may be justifiable.

Women respondents in this survey asserted their individual right to have routine antenatal screening tests. When asked whether the cost of the tests should influence whether they are done or not 92.9% of women responded that the cost should not influence the decision. The body of literature on theoretical ethics identifies the conflict between autonomy and utility which is relevant to current pressures on health care resources. The women respondents to this survey, however, failed to identify the inescapable competition for resources between the individual and the greater population. Hence the majority of women respondents to this survey support widespread application of routine antenatal screening.

A common response of an individual about the beneficence and non maleficence of others is trust. Medical practice operates successfully within these principles. This survey demonstrated this notion of trust in relation to the role of antenatal screening tests and to faith in the health care system. 47.4% of respondents believed that being offered antenatal screening tests increased their trust in their doctor or midwife. Reasons given as to why women chose not to ask questions about the results of their tests also related to their trust in the health care provider or the system. In this survey trust appears to be an important principle underpinning the general acceptance by women of current practices in routine antenatal screening.

The results of the survey go further to demonstrate the notion of risk as perceived by pregnant women. Why, in a society where the perinatal and maternal mortality rates in non indigenous women are low, do women ask not only for insurance but for more insurance? This suggests that although the actual hazards of adverse outcomes are low the perception of risk is very high. As there is continued improvement in perinatal and maternal mortality and morbidity rates will the notion of risk still continue to escalate?

Conclusion:

This pilot survey of postnatal women has demonstrated some of the social and ethical factors underpinning women's perception of antenatal screening. In particular, women's beliefs in relation to:

.high expectations of antenatal screening tests and birth outcomes
.high perceived value of antenatal screening
.failure to consider the impact of the conflict between autonomy and utility on resource allocation
.trust in the health care system and providers
.high perceived risk of adverse outcomes

are shown to be related to the routine use of antenatal screening procedures in current obstetric practice.
This survey does not answer a range of other questions such as whether these factors are legitimate determinants for the provision of antenatal screening programs. Or where do these beliefs come from? Or how should they be considered when evaluating the practice of routine antenatal screening?

A larger study of recipients of antenatal screening would be required to support these findings. This will be done in conjunction with a survey of health care providers to assess the professional, social and ethical factors that may determine how this group practice in relation to routine antenatal screening.
It is important to identify and understand some of the more covert determinants specific to the use of routine antenatal screening if we are to comprehensively evaluate these programs. Such determinants may be applicable to the evaluation of the provision of health care services generally.

References:

1. Huisjes H.J,Buekens P,Reid M. (eds) Antenatal screening: Current policies in the EC and evaluation. Eur.J.Obstet.Gynecol.Reprod. Biol. 28,Supplement 1988;5
2. Enkin M,Chalmers I. (eds) Effectiveness and Satisfaction in Antenatal Care. William Heinemann Medical Books Ltd.,London 1982; 270
3. Grant A,Mohide P. Screening and Diagnostic Tests in Antenatal Care in Enkin M,Chalmers I. (eds) Effectiveness and Satisfaction in Antenatal Care. William Heinemann Medical Books Ltd.,London 1982; 22
4. Garcia J. Womens' Views of Antenatal Care in Enkin M,Chalmers I. (eds) Effectiveness and Satisfaction in Antenatal Care. William Heinemann Medical Books Ltd.,London 1982;81-103
5. Reid M. Consumer-orientated studies in relation to prenatal screening tests in Huisjes H.J,Buekens P,Reid M.(eds) Antenatal screening: Current policies in the EC and evaluation Eur.J.Obstet. Gynecol.Reprod.Biol.,28 Supplement 1988;79-92
6. West R. Ethical aspects of genetic disease and genetic counselling J.Med.Ethics 1988;14:194-197
7. Edwards P.J,Hall D.M.B. Screening, ethics, and the law. BMJ 1992; 305:267-268
8. Andersen G,Meffin E. Obstetric Audit 1982-1991 Flinders University of S.A. 1993
9. Bainbridge W.S. Survey Research-A computer-assisted introduction. Wadsworth Publishing Company 1989
10. Berwick D.M,Weinstein M.C. What do patients value? Willingness to pay for ultrasound in normal pregnancy. Med.Care 1985;23:881-893
11. Campbell S,Reading A.E,Cox O.N, et al. Ultrasound scanning in pregnancy: the short-term psychological effects of early real-time scans. J.Psych.Obst. Gynecol. 1982;1:57-61

Research Committee Document E/1

THE ROYAL WOMEN'S HOSPITAL

RESEARCH COMMITTEE

EXPLANATION AND CONSENT FORM

1.0 **Title of Project:** 'Survey of Patient's Understanding of Routine Antenatal Screening'

2.0 **Chief Investigator:** Dr. Judith Searle

3.0 **Description of Project in Plain Language:**

All mothers hope for a healthy pregnancy and a healthy baby. Today, a large range of routine tests are done during pregnancy to try to acheive this.
You probably had some of these tests during your pregnancy.
I am an Obstetrician interested in finding out what women think about these tests and what this means for women having babies in the future.
You are invited to take part in this survey to help find out how women feel about these tests.
If you agree to take part, it will mean answering some questions about your experience with routine tests you had during your pregnancy. Examples of routine tests are ultrasounds and blood tests.
Information collected from this survey will be used to assist in the development and use of such tests in the future.
The questionnaire takes about 15mins. to complete. I stress that your answers are CONFIDENTIAL. No names will be used.
The questionnaire can only be identified by an I.D. no.
You will also be asked at the end of the questionnaire whether you will take part further in an interview about this topic. It will give you a chance to talk,in more depth, about your feelings. The interview will take about 30mins. This would be done prior to your discharge from hospital.
If you have any further questions I will return tomorrow to collect the questionnaires.

4.0 **Possible Risks, inconveniences and discomforts:**

The answers to the questionnaire and interview will not be of direct benefit to you. The time you spend answering these questions will hopefully be of value to pregnant women in the future. Some of these questions you may not have thought about before. There are no right or wrong answers. Please answer exactly how you feel.

Please leave the completed questionnaire on your overway table if you are going to be out of your room the day it will be collected.

5.0 I, the undersigned .....

hereby consent to my involvement in the research project no. .....

Titled: 'Survey of Patient's Understanding of Routine Antenatal Screening'

5.1 I understand that this research project has been approved by the Board of Management of the Royal Women's Hospital after review by the Hospital's Research and Ethics Committees.

5.2 I understand that this project complies with the guidelines contained in the National Health and Medical Research Council Statement on Human Experimentation (1992).

5.3 I acknowledge that the nature, purpose and contemplated effects of the project so far as it affects me have been fully explained to my satisfaction by the research worker and my consent is given voluntarily.

5.4 The detail of the procedure proposed has also been explained to me, including the anticipated length of time it will take, the frequency with which the procedure will be performed and an indication of any discomfort which may be expected.

5.5 Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.

5.6 I have been given the opportunity to have a a member of my family or a friend present while the project was explained to me.

5.7 I am informed that no information regarding my medical history will be divulged and the results of any tests involving me will not be published so as to reveal my identity.

5.8 I understand that my involvement in the project will not affect my relationship with my medical advisers in their management of my health. I also understand that I am free to withdraw from the project at any stage.

5.9 I have received a copy of this document.

I consent to be included in this research study

Signature: ..... Date: / /

Witness: ..... Date: / /

I, ... Dr. Judith Searle ..... being the investigator named above, certify that I have explained the nature and object of the investigations and have made clear that declining to participate would bear no adverse consequences.

Investigators Signature:..... Date: / /

Name and phone number for emergency contact:

This is also the person to contact first if you require more information or have any concerns related to the study.

If you have an enquiry regarding patient rights or still have concerns related to the study, please contact:

The Patient Representative
The Royal Women's Hospital
PH: 344 2000 EXT. 2005

(Updated October, 1994)

Appendix 4

I.D. No.

QUESTIONNAIRE
ON
ANTENATAL SCREENING

Please return completed questionnaire to Dr. Judith Searle by leaving it on your overway table where it will be collected the next day.

THANKYOU

Section I
This section will ask you about the routine tests you had during your pregnancy and your expectations of the tests.

Please tick the appropriate box or boxes

1a). Did you have any of these tests during your pregnancy?

☐ yes ☐ no

b)i) If you answered no, why didn't you have any of these tests?

.....
.....

ii) If you answered yes, *please put a tick next to each test you had in* ***both*** *Group A and Group B*

Group A
- ☐ urine test for infection
- ☐ blood test for anaemia
- ☐ blood group and antibodies
- ☐ blood test for Rubella
- ☐ blood test for Syphilis
- ☐ blood test for Hepatitis
- ☐ blood test for HIV
- ☐ blood glucose test
- ☐ pap smear
- ☐ vaginal swab for infection
- ☐ blood tests for other infections

Group B
- ☐ ultrasound of the fetus
- ☐ alpha-feto protein blood test for spina bifida
- ☐ blood test for Downs Syndrome

2.a) How valuable do you think the tests in **Group A** are?
- ☐ very valuable
- ☐ valuable
- ☐ of minimum value
- ☐ not valuable

b) In what way do you think these tests are of value or not?

.....
.....
.....

3.a) How valuable do you think the tests in **Group B** are?
- ☐ very valuable
- ☐ valuable
- ☐ of minimum value
- ☐ not valuable

b) In what way do you think these tests are of value or not?

.....
.....
.....

4. Who do you think **most** influenced your beliefs about the value of these tests?
- ☐ self
- ☐ family/friends
- ☐ media ie.television,radio,magazines etc
- ☐ doctors/midwives
- ☐ other Please specify.....

5. What did you hope to find out from these tests?

.....
.....
.....

6. How did the actual **results** of these tests make you feel?

.....
.....
.....

Please tick the box that best matches your view

7. Routine tests during pregnancy should assure a normal pregnancy and a normal baby.

☐	☐	☐	☐	☐
strongly agree	agree	not sure	disagree	strongly disagree

8. The tests listed in **Group A** above are performed for the benefit of your baby(ies)

☐	☐	☐	☐	☐
strongly agree	agree	not sure	disagree	strongly disagree

9. How do you think the tests in **Group A** and **Group B** above benefit you and your baby(ies)?

.....
.....
.....

10. If there was one safe test in pregnancy that could tell you anything you wanted to know about your pregnancy what would you want it to tell you?

.....
.....
.....

Section II
This section will ask you some questions about your knowledge of the tests you had in pregnancy.

11. Were you told **what** tests would be done during your pregnancy?

☐	☐	☐
yes	no	not sure

12. Were you told **why** the tests would be done during your pregnancy?

☐	☐	☐
yes	no	not sure

13a). Did you think you were given enough information about the tests before you had them?

☐	☐	☐
yes	no	not sure

b) If you answered no, how would having more information have made a difference?

.....
.....

14. How reliable do you think the tests you had in pregnancy are?

☐ perfect ☐ very reliable ☐ mostly reliable ☐ minimally reliable ☐ not at all reliable

15. Were you told by your doctor or midwife how reliable the tests are before you had them?

☐ yes ☐ no ☐ not sure

16a). Were you told the results of the tests you had during your pregnancy?

☐ yes completely ☐ yes mostly ☐ no mostly ☐ no completely

b) If you answered no, did you ask for the results?

☐ yes ☐ no

c) If you answered no, why didn't you ask?

.....
.....
.....

Section III
This section will ask you some questions about how you think tests in pregnancy should be used and by what women.

Please tick the box that best fits with how you feel

17. Routine tests done during pregnancy are of benefit to all pregnant women.

☐ strongly agree ☐ agree ☐ not sure ☐ disagree ☐ strongly disagree

18a). All pregnant women should have routine tests during pregnancy.

☐ strongly agree ☐ agree ☐ not sure ☐ disagree ☐ strongly disagree

b) If you agree or disagree, please explain why.

.....
.....

19. If a new test in pregnancy is developed it should be available to all pregnant women.

☐ strongly agree ☐ agree ☐ not sure ☐ disagree ☐ strongly disagree

20. How much do you think existing routine tests during pregnancy cost?
(approximate cost per pregnant woman)

☐ less than $100 ☐ $100-300 ☐ $300-500 ☐ more than $500

21. The cost of routine tests done in pregnancy should not influence whether they are done or not.

☐ strongly agree ☐ agree ☐ not sure ☐ disagree ☐ strongly disagree

22. More routine tests in pregnancy should be developed.

☐ strongly agree ☐ agree ☐ not sure ☐ disagree ☐ strongly disagree

23. Routine tests done in pregnancy are a necessary part of normal pregnancy.

☐ strongly agree ☐ agree ☐ not sure ☐ disagree ☐ strongly disagree

Section IV
This section asks you some questions about anxiety during pregnancy.

24. What do you think women **most commonly** feel fearful of or anxious about during pregnancy?

.....
.....
.....

25. What were **your** fears or anxieties (if any) about:
a) your pregnancy?

.....
.....
.....

b) your baby(ies)?

.....
.....
.....

26. How do you think these fears have come about?

.....
.....
.....

27. Can you list some things that helped you to fell **less** anxious or fearful during your pregnancy?

.....
.....
.....

28a). Did having routine tests during your pregnancy help you to feel less anxious or fearful?

☐ yes completely ☐ yes mostly ☐ no mostly ☐ no completely

b) If you answered yes, **how** did the tests help you feel less anxious or fearful?

.....
.....
.....

29a). What do you think the chance is of having an abnormal baby(ies) in Australia today?

☐ 1 in 1000 ☐ 1 in 500 ☐ 1 in 100 ☐ 1 in 20 ☐ 1 in 10

b). What do the words *abnormal baby* mean to you?

.....
.....
.....

30. Do you know anyone who has had an abnormal baby?

☐ yes ☐ no

31. Were you anxious during your pregnancy that **your baby**(ies) would be abnormal?

☐ yes a lot ☐ yes sometimes ☐ no mostly ☐ no never

32a). Were you anxious that **your pregnancy** would be abnormal?

☐ yes a lot ☐ yes sometimes ☐ no mostly ☐ no never

b). What do the words *abnormal pregnancy* mean to you?

.....
.....
.....

33. How common do you think it is for pregnant women to get an abnormal test result?

☐ very common ☐ common ☐ not common ☐ rare

34. Were you anxious during your pregnancy that you would get an abnormal test result?

☐ yes a lot ☐ yes sometimes ☐ no mostly ☐ no never

35. If the test results had shown your baby(ies) had an abnormality would you have considered termination of the pregnancy?

☐ yes ☐ no ☐ not sure

36. Would you have the routine tests again in a future pregnancy?

☐ yes ☐ no ☐ not sure

Section V
This section will ask you some general questions about yourself.

Please tick the box that best fits you.

37. How old are you?

- ☐ 18 years or less
- ☐ 19 - 26 years
- ☐ 27 - 34 years
- ☐ 35 years or more

38. How many children including this baby(ies) have you given birth to?

- ☐ one
- ☐ two
- ☐ three
- ☐ four or more

39. Are you currently or have you recently been in paid employment?

- ☐ yes Please specify.....
- ☐ no

40. What is the HIGHEST education level you have reached?

- ☐ completed primary school
- ☐ left during high school
- ☐ completed high school
- ☐ completed TAFE course
- ☐ completed a University/College course

41. Was your baby(ies) born premature?

- ☐ yes Please specify how many weeks early the baby(ies) came.
  .....
- ☐ no

42. Was your baby(ies) born alive?

yes
no

43. Does your baby(ies) have any health problems or abnormalities?

- ☐ yes Please specify.....
  .....
- ☐ no

As part of this study I wish also to look at what some of the popular magazines say about pregnancy and birth. To assist in this part of the research could you please answer the following question?

44. What magazines have you read in the past month?
eg. Women's Day

.....
.....

45. Would you be prepared to be interviewed by myself further on this subject? (It would take approximately 30mins. and would be done before you leave hospital)

- ☐ yes
- ☐ no

THANKYOU VERY MUCH FOR YOUR PARTICIPATION

Semi - structured interview

Thank you for agreeing to further participate in this study.

Following on from the questions I asked you in the questionnaire I will ask you in more depth about your expectations and fears related to pregnancy, birth and birthing outcomes.
I will also about these things in relation to the tests you had during your pregnancy.

This interview should take approximately 30 mins.
With your permission I would like to record the interview on this dictaphone. If you wish that the interview not be taped I would like to take notes as you speak. You are free to stop the interview at any stage.

If you do not understand any of the questions you are free to ask me any questions which may help clarify the matter.
If you do not wish to answer any questions you are also free to decline to answer.
There are no right or wrong answers.
I am interested in your views and your own experience.

As with the questionnaire your answers to the questions are strictly ***confidential****. Your interview will be identified by an I.D. number only.*

Your participation or non participation in this interview will have no relation to or influence on your current hospital care or treatment.

Do you have any questions at this stage?

Let us begin.

1.The first lot of questions relate to your expectations of the tests you had during your pregnancy.

Did you have some tests during your pregnancy?
What were they?
Why did you have the tests?
What did you want the tests to tell you?

Tell me more about your fears about your pregnancy, birth and birthing outcomes.
Where do you think these fears came from?
Why do you think you worry about these things?

What do you think the chance is of having an abnormal baby is in Australia?
What did you feel your chances were? Are they different?

Do you think having the tests during your pregnancy helped to lessen these fears? How? If the tests had come back abnormal how would that have helped?

How reliable do you think the tests you had in pregnancy are?
Where do you think these beliefs came from?

What if I told you the tests are not always reliable and can give false results and the chance of having a major abnormality with your baby is extremely low? Would that make a difference?
Do you think the tests should be foolproof?
Now with a healthy baby in your arms do you think the tests were worthwhile? Did the tests help your baby be normal? Would you have the tests again in a future pregnancy?

If your baby had not been normal how do you think you would have felt? Do you think anyone should be to blame? Should women be compensated if something goes wrong? How?

2.The next section will ask your views about the use of tests in pregnancy generally.

Do you think all pregnant women should have tests during their pregnancy? Why? Should society pay for these tests? Should there be a limit on the number and tests and the amount of money spent? Should be develop more tests?

Do you think our society expects 100% perfect outcomes? Do you agree with this?

3.*Now I will ask you some questions about the role of antenatal tests in normal pregnancy and their use in the future.*

Do you think having tests in pregnancy is a necessary part of normal pregnancy? Have you any concerns about the tests? What do think pregnancy care will be like in the future? How would you like to see pregnancy care in the future?

4.Lastly I would like to ask you a few questions about how you felt about yourself when you were pregnant.

Did you think of yourself as different when you were pregnant? How did you view yourself when you were pregnant? What was your relationship with your baby at that stage? Did you make any changes to your lifestyle when you were pregnant? In what ways and why?

For whose benefit do you think the tests you had in pregnancy were done? Did they benefit one more than another?

We have now finished the questions I have here.

Are there any questions you would like to ask me or points you would like to raise?

THANK YOU VERY MUCH FOR YOUR PARTICIPATION

Appendix 6a)

Flinders Medical Centre

Bedford Park South Australia 5042

Telephone (08) 204 5511

International 618 204 5511

Committee on Clinical Investigation
Extension 4507
AV:CMH

Facsimile (08) 204 4006 International
618 204 5450

21 June 1994

MEMORANDUM

TO: Dr. J. Searle, | Road, MARRYATVILLE SA 5068

FROM: Dr. A. Vedig, Chairman, Committee on Clinical Investigation

TOPIC: **Research Application 88/94**

I am pleased to advise that the Committee on Clinical Investigation has approved your research application in accordance with the following extract from the Minutes of its meeting held on 6 June 1994.

3232 RESEARCH APPLICATION 88/94 - DR. J. SEARLE
Critical perspectives on antenatal screening.
Reviewer: Dr. K. Simmer

This pilot study was approved. Amended information sheet was received and approved. Questionnaires require some minor amendments. Mrs. R. Rutt will speak with the Investigator.

If conditional *('subject to' or 'in principle')* **approval** is granted, research involving human subjects **may proceed only after written acceptance of the conditions of approval** (including a copy of the modified research protocol) **has been received by the Committee**

This approval is for a period of one year. Application for re-approval must be made annually. Please note that if this trial involves normal volunteers it will be necessary for you to keep a record of their names and you will be required to supply this list with your annual report.

You are reminded that the Committee on Clinical Investigation must approve the content and placement of advertisements for the recruitment of volunteers.

The Committee must be notified and approve any changes (e.g. additional procedures, modification of drug dosage, changes to inclusion or withdrawal criteria, changes in mode and content of advertising) in the investigational plan particularly if these changes involve human subjects.

The safe and ethical conduct of a trial is entirely the responsibility of the investigators. While the Committee on Clinical Investigation takes care to review and give advice on the conduct of trials, approval by the Committee on Clinical Investigation is not an absolute confirmation of safety, nor does approval alter in any way the obligations and responsibilities of investigators.

It is the duty of the chief investigator to give prompt notification to the Committee on Clinical Investigation of matters which might affect continued ethical acceptability of the project, including:

1. Adverse effects of the project on subjects and of steps taken to deal with these.
2. Other unforeseen events.
3. A change in the base for a decision made by the Committee, e.g. new scientific information that may invalidate the ethical integrity of the study.

If patients are involved the chief investigator is also responsible for the process of notification, seeking approval or permission of Departments, Divisions or individual consultants.

G. Gourlay
Acting Chairman
for A. Vedig

Attachment I

Office Use Only.	Reg Key	

INSTITUTIONAL APPROVAL FORM FOR EXPERIMENTS ON HUMANS

One (1) copy of the completed approval form should be either attached to the original application or sent separately to the Secretary of Council no later than the acceptance and return of the Offer of Award

APPLICANT USE Please complete in BLACK type or ink only

Chief Investigator

Surname	Title	Initials
SEARLE	DR.	J

Scientific Project Title:

Critical Perspectives on Antenatal Screening

Administering Institution

Flinders Medical Centre

ETHICS COMMITTEE USE

Does this Project comply with the provisions contained in the Council's document 'Statement on Human Experimentation and Supplementary Notes' ? Y/N [Y]

Does this Project comply with the regulations governing experimentation on humans within your Institution and within your State or Territory? Y/N [Y]

Comments, provisos or reservations:

Approved

Name of responsible Ethics Committee

CLINICAL INVESTIGATIONS COMMITTEE

Name of Ethics Committee representative (Block letters):

Surname	Title	Initials
GOURLAY	DR	GK

Signature: [signature] Date: 22-6-94

Note: (1) This form has been produced in an effort to standardise and effectively record ethics approval for all projects submitted to the NHMRC. Should it prove inappropriate, an individual statement may be forwarded in lieu. As the Council cannot recommend support if ethics clearance is not provided, it is of utmost importance that this information is received.

(2) If there is no appropriate Ethics Committee at the institution concerned, the Head of Department, or, in the case of individual researchers, the applicants themselves, should ensure that the proposal is submitted to an established Ethics Committee at a hospital or university for comment, prior to completing and signing the rest of the form as an undertaking that the provisions of the NHMRC 'Statement on Human Experimentation and Supplementary Notes' will be observed.

THE ROYAL WOMEN'S HOSPITAL

EB/CT 205,239

16 March 1995

Dr J. Searle
Assistant Gynaecologist
Royal Women's Hospital

Dear Dr Searle,

RE: Project 95/04, Survey of Patient's Understanding of Routine Antenatal Screening

This project was considered at the most recent meetings of the Research and Ethics Committees of the hospital and approved for conduct within the hospital provided the following issues are satisfactorily resolved;-

1. It will be important that the final form of the questionnaire which you propose to use, is provided to be seen.

2. The Ethics Committee were concerned that your questions should incorporate the issue concerning the possibility of abnormal test results, that if there had been any abnormality, would the subject have considered termination.

Please let me know if there is any difficulty with these issues. I have included with this letter for your information a list of the duties and responsibilities of researchers undertaking projects within the hospital.

Yours sincerely,

Dr E. Bowman
Secretary
Research Committee

Enclosure

132 Grattan Street, Carlton, Victoria 3053 Australia. Tel: (03) 344 2000 ISD: 61 3 344 2000 Fax: (03) 348 1840

FLINDERS MEDICAL CENTRE **CONSENT TO PARTICIPATION IN RESEARCH**	Ward Unit No. Surname Other Names D.O.B./Sex Address

I, ... request and give consent to
(first or given names) (surname)

my involvement in the research project "Critical Perspectives on
(short title of research project)

Antenatal Screening"

I acknowledge that the nature, purpose and contemplated effects of the research project, especially as far as they affect me and (my baby) have been fully explained to
(my [foetus] baby, if applicable)

my satisfaction by Judy Searle and my consent is
(first or given names) (surname)

given voluntarily.

I acknowledge that the detail(s) of the following procedure(s)

answering questionnaire

has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time and the frequency with which the procedure(s) will be performed.

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project and/or the procedure(s) may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I understand that any payment made to me is simply an expression of gratitude for assistance in this research project.

.....2

Signature of research subject : ..... Date: .....

Signature of Witness: .....

Printed Name of Witness: Dr. Judy Searle .....

I, Judy Searle ..... have described to .....
the research project and the nature and effects of the procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature ..... Date .....

Status in project: Primary Researcher .....

RELATED PUBLICATIONS

Searle J. Passing the 'ethics board test' - an ethical dilemma. In: Where to now? Human research ethics committee's institutional providers conference. Adelaide: University of South Australia, 1996.

Searle J. Fearing the worst- Why do pregnant women feel 'at risk'? Aust N Z J Obstet Gynaecol 1996; 36: 279-286.

Searle J. Routine antenatal screening: Not a case of informed choice. (accepted for publication by the Aust N Z J Public Health, July 23 1996)

Searle J. The act of screening: does it harm pregnancy? (undergoing second revision by Birth, October 1996)