

Screening and the consequences of knowledge

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As midwives, we do lots of things, often simultaneously. We build relationships, gather information, determine and meet needs, offer tips, reassurance, information and advice, soothe concerns and much, much more. During an antenatal check, for example, we might do all of these things while also assessing the health of women and their babies by means of carrying out those screening tests which have become a routine part of such meetings; blood pressure, urinalysis, examining the woman's abdomen and listening to the fetal heart. Often, depending on the circumstances, we may also be talking to the woman about whether she would like to avail herself of other available screening tests such as blood and antibody checks, ultrasound, glucose tolerance testing, maternal serum screening and group B strep testing. While our activities are myriad, a fair proportion of our time is spent undertaking activities which relate to the search for knowledge that may help prevent or detect problems.

On the surface, focusing on preventative health and undertaking screening tests seems like a jolly good idea. If we can detect potential problems at an early stage, we can put measures in place in an effort to prevent those problems being harmful to women or their babies. This rather lofty aim, however, is merely the tip of the iceberg that is screening, and a whole raft of issues is raised by this concept in practice. This article focuses on the consequences of the knowledge that is gained by undertaking screening tests and raises questions about whether this knowledge carries risks as well as benefits.

Beginning with Bloods...

Once upon a time, I shared a house with a couple of scientist friends who worked in a laboratory. At that time, I was vegan, they were both dedicated carnivores and we had a

very friendly and very ongoing argument over our dinner most evenings. This argument was based around whether or not, as a non meat-eater, I could have a reasonable haemoglobin level. One day I invited them to draw a few millilitres of my blood and spin it in the lab so that they could check my haemoglobin for themselves and we could finally settle this argument one way or the other. This idea went down really well; one of them was also a phlebotomist and he gathered his kit and was literally just about to put the needle in when he suddenly stopped and swore quietly under his breath. I asked him whether there was a problem and he said, "I've just realised ... I can't do an Hb independently of a full blood count". "OK", I smiled. "Do a full blood count then, I don't mind." "Well..." he replied. "Trouble is ... what about if I find out that you have acute lymphoblastic leukaemia? Would you want to know?"

I can't say that was the first occasion on which I ever thought about the potentially enormous consequences of the kinds of information that we gather daily and routinely, but when I am asked to speak to groups of midwives about screening I often begin with that story as an illustration of how very momentous the implications of even the simplest tests can be. In just a few decades, Western culture has embraced the notion that preventative health care and screening are beneficial tools and there has been a metaphorical explosion in the growth of technologies related to this area. Knowledge, however, can have serious consequences and simply because we **can** do something doesn't necessarily mean that we always **should** do it. Because of this, I believe that it is important to consider the consequences that can arise from the gathering of information about the human body.

An Excess of Information?

One of the first pieces of birth-related research to explore this area was Barbara Katz Rothman's "Spoiling the Pregnancy", in which she talked with sixty Dutch midwives about their experiences with prenatal fetal anomaly screening and diagnosisⁱ. The findings of this study illustrated the way in which the knowledge that is gained through prenatal screening and diagnosis can have a profound effect on women's experiences of childbirth as well as on society's understanding of birth and motherhood. This study highlighted the way in which such technologies carry costs as well as benefits, not least of which are the false negative results that are an inevitable consequence of screening tests and the false positive results that the midwives described as giving a false sense of security and control. We know that the psychological and personal downsides of screening include intense feelings of anxiety and grief and the midwives in Katz Rothman's study understood that, "while some of these "false alarms" are inherent in the nature of screening itself, others come because a baseline for normal has not yet been established"ⁱⁱ.

The problem of establishing what is normal is an ongoing one, and is further highlighted by a recent systematic review and meta-analysis that looked at medical imaging in relation to low back painⁱⁱⁱ. When magnetic resonance imaging (MRI) technology started to become widely available, it was assumed that the detailed images of the interior of the human body that it creates would have a positive impact on improving the care and experiences of people with lower back pain. For the first time, doctors might actually be able to see problems such as trapped nerves and would thus be able to diagnose and treat back pain more effectively. In reality, however, the effects of introducing MRI scanning in this area were nowhere near as positive as had been hoped and in some cases the overall effect was actually negative. After excluding patients whose health histories suggested the possibility of a serious underlying condition (which included, for instance, a history of

cancer, unexplained fever or recent trauma), the meta-analysis showed that imaging did not improve the outcomes of patients who had low back-pain compared with usual clinical care.

There are a number of reasons why this might be the case, but one is particularly pertinent here. The images that are produced by MRI are so highly detailed that it can be difficult to differentiate relevant from coincidental information. An earlier study^{iv} asked two neuroradiologists to comment upon MRI scans of a number of people who had no back pain or other physical symptoms in this area. Of these basically normal people, 64 per cent were found to have an intervertebral disc anomaly and 38 per cent were found to have an abnormality at more than one level. The relationship between the experience of physical symptoms and the appearance of apparent pathophysiology on MRI is clearly not a direct one. The use of MRI for lower back pain leads to a significant potential for over-diagnosis and some specialists in this area argue that we do not yet know enough about how the normal body appears on MRI for this to be an effective diagnostic tool in relation to lower back pain. This does not mean, of course, that MRI is not useful in diagnosing other problems, but it is clearly not useful on a routine basis in this area and the detailed knowledge that it provides carries risks as well as benefits.

Appropriate Intervention?

Of course, many midwives already perceive that intervention may be a more positive addition to our toolkit when it is used appropriately and individually rather than on a population basis. Our view of childbearing as a normal life event during which intervention is needed only occasionally tends to make us wary of the use of routine or universal intervention and more focused on using specific interventions on an individual basis when it is truly warranted within the context of a particular woman's experience. We understand that it can be useful to ask

some questions of screening tests on a population level^v, but we focus our actions on what women want. We talk with women and their families about whether or not they would like to have a particular screening test and thus acknowledge that decisions are personal and contextual. We make women aware of the limitations of knowledge and we discuss with them the potential for false positive and false negative results.

This is not necessarily the approach taken by all health care providers. Within modern medical care, it is generally deemed beneficial to create guidelines which encompass population-level recommendations about screening. Some specialties, however, are arguably more likely to undertake and act upon analyses of the pros and cons of screening tests when constructing those guidelines than others. For example, the US Preventive Services Task Force recently reviewed the evidence in relation to screening men over the age of 75 for prostate cancer and concluded that this was probably not beneficial on a population basis^{vi}. Their analysis of the evidence showed that, when the cascade of intervention that results from a positive screening test (which in some cases is inevitably going to be a false positive result) is weighed against the potential benefits of treating a form of cancer that is often slow-growing, the overall benefit is small to none. Furthermore, they were concerned that the issue of labelling again ensures that any individual who is found to have a positive result has to deal with the consequences of this knowledge, which can lead to a high level of anxiety for them and their families.

Screening for Group B Strep

I cannot help but wonder whether, if the same kind of rigorous analysis and thoughtful consideration of the implications of knowledge upon people's feelings was applied to some of the screening tests that are available to pregnant women, fewer screening tests and more information might be offered? Group B strep (GBS) testing, for example,

carries significant consequences for women who are found to be GBS positive. They have to decide whether to have intravenous antibiotics during labour with the additional interventions and risks that go along with this, and their decision is complicated by the fact that they have to consider the health and wellbeing not just of themselves but of their babies as well. As is the case with a number of the prophylactic interventions that are offered in maternity care, a treatment is offered in order to attempt to prevent a rare but potentially serious or fatal condition, yet the treatment itself may involve invasive procedures or drugs which carry risks of their own^{vii}.

In this case, the intervention itself may not even be effective. The Cochrane Collaboration review of the evidence showed that, although antibiotic treatment reduces the rate of colonisation and infection in babies compared to no treatment, it does not reduce mortality^{viii}. When this detail is weighed up against the potential risks of antibiotics and the impact that being tethered by an intravenous drip has on a woman's ability to move around in labour, it seems reasonable that some women would choose to decline such treatment. Their choices, however, are not always respected, and some of the responses that some units and professionals are choosing in relation to this highlight some rather worrying issues.

In some areas, if a woman who is found to be GBS positive declines intravenous antibiotics in labour, she is advised that her baby should be admitted to a special care unit and given antibiotics immediately after birth. I know of cases where health care professionals have told women that they are prepared to take legal action in order to force this intervention upon babies if necessary and it is perhaps inevitable that some midwives are now advising women who would not want themselves or their babies to have antibiotics to think carefully before consenting to GBS testing. The response to such measures, though, is that some hospitals now insist on treating a woman who has not consented to

GBS screening as if she is GBS positive; a rather inflexible and arguably unacceptable stance which further restricts women's options and which, anecdotally, is leading some women to choose home birth even where this is not necessarily ideal for them in other respects.

Knowledge, Choice and Timing

The story with which I began this article further illustrates the relative inflexibility of some of the technologies and systems that are used in screening. When my scientist friends wanted to measure my haemoglobin level, it simply wasn't possible for the machine to provide this outside of the context of a full blood count ~ which, as my friend realised, carried the risk of providing information above and beyond that which we wanted. In the same way, it is impossible to carry out certain genetic tests for pregnant women without gaining knowledge about the gender of the baby, which some parents do not wish to know ahead of time. In such cases, it may be possible to enlist the help of those who are carrying out the tests in removing such information, yet there are also situations where the people who work in these areas feel compelled to follow the rules and protocols that have been set up in their area of practice. A colleague of mine recently sent a woman's blood sample to her local lab with a form requesting a specific test for rhesus antibodies. When the results came back, they were accompanied by the results of a full blood count. She queried this with the lab, as she had not requested this information and was told, "But we ALWAYS do a full blood count routinely, whatever the form says."

No matter whether it is the result of the limitations of technology, the attempt to create standardised systems within bureaucratic organisations or for some other reason, the grouping of tests into indivisible packages (such as the full blood count) has become increasingly common. In some countries, including New Zealand, it is virtually impossible for women to choose which of a

plethora of tests will be carried out on blood taken via a neonatal heel prick for the purposes of newborn screening; you can choose all of them or none at all. In some areas it is also not possible to have such a test carried out without also accepting that the baby's blood will be stored in a central repository and possibly used in the future to gain genetic or other knowledge about the baby. This is of particular concern to those people who have discovered that genetic or other testing has caused them to either be ineligible for certain types of insurance or to be asked to pay far more than they were expecting to for policies on the basis that they fall into an 'at risk' category.

In many of these examples, timing is a key factor. One of the most profound aspects of Barbara Katz Rothman's analysis was the way in which she unpacked the concept of screening in relation to time, noting that,

"Prenatal diagnosis never tells anything one wouldn't have found out later on anyway. It simply changes the timing. In having prenatal testing the woman seeks immediately the information she would have had eventually."^{ix}

There are some situations where being forearmed with knowledge can prevent potentially serious problems. In others, there may be very little that we can do except to create anxiety and potentially 'spoil the pregnancy'. As Katz Rothman discussed, the reason for early prenatal screening and diagnosis relates to the fact that abortion is possible at this stage in pregnancy. Yet, while some women welcome this option, others do not. Equally, some women would prefer to be forearmed with knowledge, even if nothing can be done to change the outcome, while others would rather wait and see. As is so often the case, it is no more useful to argue against any intervention than to argue for routine intervention. It seems so obvious that decisions can only be made by individual parents within the context of their family and situation, and yet the systems and guidelines that make recommendations about screening seem not to acknowledge the importance of

taking into account people's feelings around knowledge, choice and timing.

As midwives, we face a difficult task. In addition to the hundreds of things that we already do, the increased number of available tests and the attendant complexity of the issues mean that it is next to impossible to discuss every aspect of these in depth. Many midwives are rightly concerned about the potentially negative implications of piling mountains of information upon pregnant and labouring women when that information and the need to make decisions can itself create stress and anxiety. There are, unfortunately, no easy solutions. It is my hope, however, that by talking more about the specifics and complexities of such issues amongst ourselves we can deepen our own understanding of the threads that run through them. These threads include our society's continued focus on risk, the problems that can arise from centralisation and bureaucratic organisation and the impact of our modern perception of time upon women's birth experiences. Perhaps we can seek positive ways of opening such discussions with women and their families ~ both before and during pregnancy ~ and thus look together at the bigger picture in a way that will enable women to see the range of approaches that is on offer and choose the one that is most aligned with their hopes for their childbirth experience.

ⁱ Katz Rothman B (2001) *Spoiling the Pregnancy: Prenatal Diagnosis in the Netherlands*. In: De Vries RG, Benoit C, Van Teijlingen E and Wrede S (2001) *Birth by Design*. New York: Routledge. Chapter 9: pp 180-198

ⁱⁱ *Ibid*, p. 194.

ⁱⁱⁱ Chou R, Fu R, Carrino JA and Deyo RA (2009). Imaging strategies for low-back pain: systematic review and meta-analysis. *Lancet* 2009; 373: 463–72.

^{iv} Jensen MC, Brant-Zawadzki MN, Obuchowski N et al (1994). Magnetic Resonance Imaging of the Lumbar Spine in People without Back Pain. *New England Journal of Medicine* 331(2) 69-73.

^v See, for instance, Nielsen C and Lang RS (1999). Principles of Screening. *Medical Clinics of North America* 83(6): 1323-1337.

^{vi} U.S. Preventive Services Task Force (2008) Screening for Prostate Cancer: U.S. Preventive Services Task Force Recommendation Statement. *Annals of Internal Medicine* 149: 185-191

^{vii} For further information, see Wickham S (2003). The war on group B strep. *AIMS Journal* 15(4): 7-9.

^{viii} Smaill FM. Intrapartum antibiotics for Group B streptococcal colonisation. *Cochrane Database of Systematic Reviews* 1996, Issue 1. Art. No.: CD000115. DOI: 10.1002/14651858.CD000115.

^{ix} Katz Rothman B (2001). *Op cit*; page 189.