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Pregnant and non-compliant: Rejecting fear-based healthcare and regaining informed consent

AIMS Journal, 2021, Vol 33, No 3

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By Maria Lyons

Picture this scenario: a young couple, expecting their first baby, are waiting in the ultrasound clinic for their 12-week scan. A nurse approaches them with a clipboard and states she must give them some information prior to the scan, so that the mother-to-be is able to give her informed consent. The nurse starts by assuring the couple that there is no evidence to suggest the scan may harm the unborn baby. However, she goes on,

> "We must make you aware that there have in fact not been any studies on human populations since the 1990s. Because the technology and equipment have changed significantly since then, we cannot entirely rule out the possibility of harm.[1] Moreover, some more recent studies on animals have indicated that ultrasound can damage biological tissue, and for many years researchers have been calling for a cautious approach and further investigations.[2] Also, the screening is not 100% reliable, so we cannot guarantee that when you have your 20-week scan it *will* identify any problems that *do* exist, or that it will *not* identify problems that *do not* exist.[3] [4] Finally, while the scan today does provide us with some useful information, there is no evidence that it will reduce harms or improve outcomes for you or your baby.[5] [6] It is therefore, clinically speaking, not strictly

> necessary. Please take all the time you need to think this through and let me know if you would like to proceed".

Of course, this does not happen in reality. Ultrasound examination has become so routine that consent is assumed. In the same way, the pregnant woman assumes the procedure is safe, believing that otherwise it would not be recommended and/or that she would be told of any potential risks. The example of ultrasound illustrates two features of the healthcare system which have important implications for the processes of decision-making and informed consent.

Firstly, the word "safe" does not necessarily mean what it means in other contexts. If, for instance, a car is deemed "road safe", we can be sure this is based on the result of rigorous crash testing. In medicine, neither the patient nor necessarily the clinician will know if a product or procedure which has been approved under the banner "no evidence of harm" has undergone extensive and long-term safety trials or no trials at all.[7] Patients are not routinely and explicitly made aware of the distinction between evidence of safety and "to-date" no cause for concern.

Secondly, standard care guidelines and practices are not always informed by the best available medical evidence. Institutional culture and policies, professional norms, peer influence and enthusiasm for the latest technologies all play a more significant role than they ought to in a scientifically grounded healthcare system.[8] History is not very reassuring in this respect. To give just one of many possible examples, before ultrasound technology was developed, pregnant women were routinely examined using X-ray imaging, again on the principle that there were 'no known harmful effects on the foetus'. Studies in the 1930s were already showing that this exposure was damaging, yet the practice did not rapidly decline until as late as 1975.[9]

Today, the 'precautionary principle'[10]continues to be applied extremely inconsistently. Pregnant women are urged in the strongest of terms not to drink a drop of alcohol, visit a sauna or have a massage in the first trimester while simultaneously being not only offered but encouraged – and frequently *expected* – to undergo multiple medical interventions for which there may be no clear evidence of either safety or overall benefit.[11] If public trust and confidence in medical advice is rooted in beliefs which turn out to be unfounded, then the practice of gaining consent cannot be said to be an integral part of the healthcare system in any meaningful sense. This is particularly true in antenatal care where consent is for the most part implied rather than formally expressed.

The central and fundamental principle of consent is the disclosure of relevant information. This information must be clear, accurate, up-to-date and present any existing alternative options including the option of no action. Crucially, according to the latest guidance from the[General Medical Council (GMC)[12]](), when communicating potential benefits and risks of harm, the medical professional "should try to find out what matters to patients" as individuals with their own particular histories and priorities. In other words, he or she cannot "rely on assumptions" about what information might be wanted, what factors might be considered significant and the importance that might be attached to different outcomes. The patient has a right to be listened to, a right to make choices and a right to determine independently

what risks are and are not worth taking. In ultrasound examination and screening, formal consent is not currently considered necessary, despite these guidelines. The RCOG does, however, acknowledge that the "uncertainties involved…may be great", giving as examples, the risk of false positives or negatives in screening for abnormalities. "It is therefore essential that the woman is made aware of the purpose, uncertainties and implications of screening…".[13]

Personally, over the course of three pregnancies (one ending in miscarriage) and in the care of two different NHS Trusts, I received no fewer than 10 imaging scans in addition to many Doppler examinations. The possibility of harm of any kind was never once communicated to me either in writing or verbally, nor were any uncertainties surrounding the evidence and benefits ever discussed. Moreover, in my third pregnancy when I declined a routine scan, initially my choice was ignored (the scan was scheduled regardless; this also happened with an induction) and thereafter considerable efforts were made, by several different medical professionals, to convince me to change my mind. This experience was repeated every time I chose to forego a routine intervention (such as induction at 41 weeks, continuous EFM or a caesarean after a previous caesarean) in favour of doing nothing. On each occasion a message of disapproval was clearly conveyed to me, the implication being that I was choosing the "wrong" or perhaps a "riskier" option, including in circumstances where there was no evidence to support this view.

My own experiences, and I have no reason to believe they are atypical, raise another vital point about informed decision-making and consent. Again, it is clearly stated in the GMC guidance that both information itself and the manner in which it is presented to patients must be *objective*. Medical professionals must be conscious, in other words, that their own preferences (or more likely, the preferences of their professional organisations) do not unduly influence the language they use or information they provide. Ultimately, they "must not put pressure on a patient to accept [their] advice".[14] The times I received information which failed this test are so numerous I can offer only a small selection by way of illustration. Lack of objectivity took many forms:

- Information is one-sided, e.g. the risks of *not* having an induction are presented while the risks of induction itself are not; the risks of homebirth are emphasised whereas the risks of hospital birth are not mentioned
- Statistics are presented negatively, e.g. a small increase in the chances of stillbirth are emphasised whereas the overwhelming likelihood of a normal birth is not; figures are presented in relative rather than absolute terms, distorting a patient's perception of risks vs benefits
- Information is simply false, e.g. I was informed that one glass of wine during pregnancy could cause foetal alcohol syndrome when in fact the study referred to was on the effects of binge drinking
- Use of anecdotes or "scare stories" either alongside or instead of factual information, e.g. I was offered a distressing account of uterine rupture when I indicated a preference for homebirth

In each of the situations above I would argue that the information I was given was not designed to inform me but to influence me. This also applies where information was withheld. I had the distinct impression, particularly when I chose a path that deviated from the norm, that I was being managed. The pressure to

conform to expectations was immense.[15] In my attempts to shape my own birthing experience, I was continually coming up against barriers posed by someone else's (or some institution's) interpretation of what constitutes acceptable risk and of what constituted my "best interest". Women are told they have choices when it comes to where, when and how to give birth, yet in reality these choices are limited in a myriad of subtle and often arbitrary ways.[16] Moreover, these limitations are being imposed without women necessarily even being conscious that alternative options exist, let alone that they have a right to choose them.

Also notable in the above examples is the way that fear is used to encourage compliance. I observed a recurring pattern in how midwives and doctors presented information to me about my options, doing this in such a way as to heighten the perception of risk associated with*not* following the approved course of action while downplaying any risk associated with it. This is consistent with broader trends in healthcare and public policy generally. One only needs to look at the growth of government-linked organisations such as the Behavioural Insights Team (informally known as the "Nudge Unit") to see that the use of applied psychology and "emotional messaging" is increasingly seen as a legitimate tool in efforts by policy-makers and managers to incentivise desired behaviours.[17]The crucial difference between these techniques of persuasion and other forms of incentivisation (such as regulation or taxation) is that for it to be effective, the subjects must be unaware that it is happening. This is the antithesis of informed decision-making and it indicates that the erosion of consent in our health service is systemic. That is to say, the problem lies not with individual practitioners, who are for the most part acting in good conscience and in accordance with their training, but with professional and public health bodies and the governments which oversee them.

One could argue that in primary healthcare, as in public health, a certain amount of "nudging" is acceptable when it is "for our own good". To that I would respond, first of all, that the line between guidance and manipulation is very blurry. Secondly, as we have seen, the scientific and evidentiary foundation for these recommendations may be open to debate. Thirdly, the implication behind these techniques is that people cannot be trusted to make rational decisions when provided with objective information. Finally, if we surrender responsibility for determining what is in our best interest to an external authority, we are on a very slippery slope. Unquestioning faith in and obedience to the "experts" today is in principle no different to unquestioning faith in and obedience to any paternalistic authority figure who in the past claimed to know what was best for women, what they could or could not do with their bodies, and how their reproductive capabilities ought to be managed.

Responsibility cannot be given; it must be taken. Likewise, no one can empower anyone else. They can facilitate, listen to, respect and advocate for, but they cannot empower. Power is something only we as individuals can develop for ourselves and it entails the belief that we have a right to control our own lives and the confidence in our own capacity to do so. Information is also inextricably linked to power. We cannot all become experts in every field; but when it concerns our own health and that of our children if we do not do our own research, if we do not continually question, explore and challenge assumptions, then we risk forfeiting personal autonomy in exchange for what may turn out to be only an illusion of safety and improved overall wellbeing. As individuals, we can ensure that when we give our consent, it is

always consent in the truest sense of the word.

Author Bio: Maria is a full-time mum of two. When she can fit it around her family she works as an English language teacher, researcher and charity volunteer.

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[1] Haar, Gail ter, (2012), British Institute of Radiology, *The Safe Use of Ultrasound in Medical Diagnosis*, p.127 - www.birpublications.org/pb/assets/raw/Books/SUoU_3rdEd/Safe_Use_of_Ultrasound.pdf

[2] '*Fetal Thermal Effects of Diagnostic Ultrasound*' Journal of Ultrasound Medicine, 2008, https://www.ncbi.nlm.nih.gov/pubmed/18359908

[3] A. Debost-Legrand et al, *False Positive Morphologic Diagnosis at the anomaly scan*. BMC Pregnancy Childbirth, 2014 (14) - www.ncbi.nlm.nih.gov/pmc/articles/PMC3994389

[4] Jolly Joy, *Review: Is Ultrasound Safe?* Royal College of Obstetricians and Gynaecologists, 2006 - obgyn.onlinelibrary.wiley.com/doi/pdf/10.1576/toag.8.4.222.27271

[5] Whitworth M, Bricker L, Mullan C. (2015) Ultrasound for fetal assessment in early pregnancy. Cochrane Database of Systematic Reviews, Issue 7. Art. No.: CD007058. www.cochrane.org/CD007058/PREG_routine-compared- selective-ultrasound-early-pregnancy

[6] Bricker L, Medley N, Pratt JJ. (2015) Routine ultrasound in late pregnancy (after 24 weeks' gestation). Cochrane Database of Systematic Reviews 2015, Issue 6. Art. No.: CD001451. www.cochrane.org/CD001451/PREG_routine-ultrasound-in-late-pregnancy-after-24-weeks-gestation-to-assess-the-effects-on-the-infant-and-maternal-outcomes

[7] Groups that are considered "vulnerable", such as the elderly, children, pregnant women and those with existing health conditions, are routinely excluded from clinical trials by the manufacturers of drugs, antibiotics and vaccines on precautionary grounds, and on the grounds that inclusion would be "unethical". This begs the question of why it is then both "safe" and "ethical" for these pharmaceutical products to then be approved for general use in these untested populations.

[8] There is a significant body of literature raising questions about the quality and reliability of medical research, including the manipulation of data and research designs, the misrepresentation of statistics, conflicts of interest and flaws in the system of peer review. In an article provocatively titled 'Why most published research findings are false' (PloS Medicine, August 2005, 2 (8)) John Ioannidis states that "for many current scientific fields, claimed research findings may often be simply accurate measures of the prevailing bias". See also articles by the former editor of the British Medical Journal Dr Richard Smith,

'Classical peer review: an empty gun' (Breast Cancer Research, 2010, (12)), and Drs John Abramson and Barbara Starfield, 'The Effect of Conflict of Interest on Biomedical Research and Clinical Practice Guidelines: Can We Trust the Evidence in Evidence-Based Medicine? (Journal of the American Board of Family Practitioners, 7 September, 2005).

[9] Benson and Doubilet (2014) '*The History of Imaging in Obstetrics*', Radiology, (273) 2

[10] The precautionary principle means that, "...if there is the possibility that a given policy or action might cause harm to the public or the environment and if there is still no scientific consensus on the issue, the policy or action in question should not be pursued." eur-lex.europa.eu/summary/glossary/precautionary_principle.html

[11] The Covid-19 vaccinations are a case in point. Although pregnant women have not been included in the trials and general safety and efficacy trials are ongoing, the JCVI has advised that pregnant women should be offered the jab: www.gov.uk/government/publications/safety-of-covid-19-vaccines-when-given-in-pregnancy/the-safety-of-covid-19-vaccines-when-given-in-pregnancy

[12] General Medical Council, *Decision Making and Consent* (2020): www.gmc-uk.org/-/media/documents/updated-decision-making-and-consent-guidance_pdf-84160128.pdf

[13] RCOG (2015) Obtaining Valid Consent - www.rcog.org.uk/globalassets/documents/guidelines/clinical-governance-advice/cga6.pdf

[14] GMC (2020) Guidance on professional standards and ethics for doctors - Decision making and consent. (page 12) Available at: www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---decision-making-and-consent-english_pdf-84191055.pdf. Accessed: 15th June 2021

[15] This raises further questions which are beyond the scope of this article. Why is this happening? If women were given complete and impartial information, would this change their decisions, and if so, what would be the implications of this?

[16] The fact that how long it is considered "safe" to continue a pregnancy or where a woman is "allowed" to labour may differ from hospital to hospital, region to region, is testament to the fact that it is not science but policy which determines these choices.

[17]See Institute for Government and the Cabinet Office, *Influencing behaviour through public policy*: www.instituteforgovernment.org.uk/sites/default/files/publications/MINDSPACE.pdf. During the Covid-19 pandemic, for instance, a government advisory group stated: "The perceived level of personal threat needs to be increased among those who are complacent, using hard-hitting emotional messaging. To be

effective this must also empower people by making clear the actions they can take to reduce the threat." assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/882722/25-options-for-increasing-adherence-to-social-distancing-measures-22032020.pdf