

Changing notions of trust and compliance: their implications for personalisation of eHealth systems for maternity care

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1 Introduction

The past decade or so has shown two parallel phenomena: the organic, non-planned growth of the Web and its communities, and the design of a future world of eHealth, including study of how eHealth applications aimed at the public can be personalised. We discuss the influence of the former on the latter. There is a large and lively collection of resources and online communities relating to pregnancy and birth. This is an interesting case study for issues of trust and compliance in particular because many of the issues that arise are highly controversial, with usual practices and advice differing systematically between countries (e.g. the US and the UK) and between professional groups (e.g., midwives and obstetricians), as well as unsystematically between individual practitioners.

Traditionally, both doctors and patients expect that the doctor will tell the patient what to do, and that the patient will *trust* the doctor and *comply* with instructions. Interestingly, although [3] discusses the fact that non-compliance may be a deliberate decision, it does not explicitly discuss cases where the patient may have made a judgement *about the advice itself*. For example, it mentions that a patient might take less than the prescribed dose of a drug because the patient fears side effects, but it does not mention that a patient might take a lower dose because they know that a different dose was used in a relevant clinical trial.

The UK government report *Changing Childbirth*[2] recommended that the maternity services should become more woman-centred: one result of this is the oft-occurring phrase “informed *choice*” (rather than informed consent, or compliance) to describe the ideal role to be played by the pregnant woman. In practice, however, a traditional compliance model still holds sway. For example Stapleton et al. write [4]: “We observed a strong hierarchy within the maternity services, with obstetricians at the top, midwives and health professionals other than doctors in the middle, and pregnant women at the bottom”. They conclude: “The hierarchical power structures within the maternity services, and *the framing of information in favour of particular options*, ensured compliance with the “right” choice.” (my emphasis).

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2 Nature of today's resources

Web sites range from the sites of medical research journals, to one giving the complete text of Enkin et al.'s classic book on evidence-based care, "Effective care in pregnancy and childbirth" (<http://www.maternitywise.org/guide/about.html>), to many frankly paternalistic sites ("Your doctor will decide...").

Usenet newsgroups The main relevant newsgroup is misc.kids.pregnancy (mkp). It has relatively high traffic (hundreds of messages per day). A small number (say 5-25, depending on definition) of "resident experts" (mostly not health professionals) regularly answer questions and provide references to sources of information, including abstracts of medical research papers. There are many less regular posters. The group has a US bias, but members worldwide. There is topic drift and off-topic argument, but not so much as to swamp the on-topic posts. Posts contain a mixture of support, chat and factual/scientific traffic. Any new study reported in the press is discussed (and often criticised in a scientifically literate manner) on this group. Someone who reads this group over months in preparation for and during pregnancy will be aware in advance of many of the issues on which she has to make choices, and will often be aware of controversies that she might not otherwise encounter. She is likely to recognise the fact, if a health professional gives her only one side of a story.

A typical example thread is that headed "Amniocentesis - cons/pros", which began on February 25 2005, and amassed over 60 followups in the next week. It included scientific and statistical discussion of what amniocentesis can and can't show; emotional and moral discussion of the pros and cons of choosing amniocentesis (including a subthread on whether a post-amniocentesis miscarriage should be considered murder!). It also included some information on practices in different countries concerning when amniocentesis is offered/recommended.

Mailing lists for professionals Yahoo group ukmidwifery¹ and an obstetricians' mailing list² are both available to laypeople. Comparing these two is a stark demonstration of the systematic differences in approach between obstetrics and midwifery. We may take VBAC, vaginal birth after caesarean, as an example. Some obstetricians believe that after a woman has had a caesarean section, all subsequent births should also be by caesarean section. Others (and most midwives?) vehemently disagree. Both sides claim to have studies to back up their arguments. ukmidwifery members regularly support and inform women seeking VBAC; indeed a recurring theme on the list is to bemoan the current caesarean rate, which most members of the list consider to be inexcusably high. On OBGYNL, by contrast, a typical recent post on the subject (<http://forums.obgyn.net/ob-gyn-1/OBGYNL.0503/0303.html>), in a thread entitled "Those crazy VBACs", included the phrase "If I were allowing VBACs". Awareness of such conflicts is likely to decrease a woman's trust in any single professional's unsupported opinion.

¹ <http://health.groups.yahoo.com/group/ukmidwifery/>

² <http://forums.obgyn.net/ob-gyn-1/>

3 Effects on trust and compliance

The Web has made access to research and pedagogical information dramatically easier. It has also made available qualitatively new sources of information. People can now hear about the advice given by other people's healthcare providers worldwide, share experiences, and even eavesdrop on heated discussion among health care professionals. Moreover, the large membership of the available fora makes it possible to form an impression of the consensus or lack of it on an issue.

In this context trust in any one practitioner is likely to be provisional. Compliance is also at issue. For example, screening for gestational diabetes is routine in the USA, but there is a controversy over whether this is appropriate: one school of thought is that gestational diabetes is a misnomer. Misc.kids.pregnancy regularly hears from people about to undergo this screening who are advised on how to "beat the test". Inevitably, some posters exclaim that it would be better to refuse consent to the test than to subvert it, and others explain that their providers are so insistent that they should have the screening that to refuse would be intolerably awkward, so that they prefer to take the test and pass by hook or by crook! That is, a woman makes her own choice of what to comply with, *resting on the authority of what other practitioners advise in similar circumstances*. This has obvious risks and benefits.

Health practitioners' attitudes to people seeking health information online can be instructive. Almost all profess to believe that people should take responsibility for their own health. Nevertheless, there is a stereotype of the informed patient as a non-compliant hypochondriac nuisance. For example, Harris Interactive's Healthcare News [5] characterises all those who ever go online for health information as "cyberchondriacs". ([5] reports that 74% of all those online have at some point looked for healthcare information online, and that most of those do so using a portal or search engine, not by starting at a specialist site.)

4 Implications for eHealth systems

In the light of access to this conflicting information, it is unlikely that the internet literate user of an eHealth system can be given one viewpoint and expected to trust it implicitly, even if it is backed up with argument. EHealth systems will need to acknowledge opposing viewpoints and explain explicitly why a conclusion has been reached. This has been done to a limited extent: [1] is a good example.

Will a system ever be able to credibly claim to be viewpoint-free: will obstetricians and (radical) midwives ever be able to agree on the information and advice presented? Certain documents (NICE guidelines (<http://www.nice.org.uk>), MIDIRS Informed Choice leaflets (<http://www.midirs.org>) are already developed with this aim: however, anecdotally their development tends to be fraught.

Personalisation How may relevant eHealth systems be personalised? Most obviously, by taking account of previous medical and obstetric history, such as parity. However, we have already mentioned the VBAC controversy. If space permitted, we could cite many more, such as whether to intervene in a longer-than-average pregnancy, or when to encourage home birth.

A more ambitious use of personalisation might be to start by getting a general picture of someone's ideal birth, and use that to give tailored relevant information. For example, someone whose ideal birth is in hospital with as little pain as possible might be given different advice to someone who prefers to avoid drugs and sees pain as positive. Exactly how to do this would need to be carefully considered, because naturally any system would have to present the risks and benefits of any given option honestly. A different slant on the same information might be justified, however. For example, one might offer information on labour positions that are often found helpful to both groups, but introduce the information differently. The potential drug-free home-birther might be told:

"People who prefer to avoid using drugs for pain control often say that finding good positions for labour is important to them. Some positions which are often found helpful are ..."

whereas the hospital pain-minimiser might be told:

"Even people who plan to use epidural anaesthesia should consider alternative methods of pain control, because there are many reasons why an epidural might not be available immediately. [link: What reasons are there?] What position you are in can make a big difference to how much pain you perceive. Some positions which are often found helpful are ..."

Possibly such matters, having more to do with the mother's comfort than with life and death, would be less daunting to address initially.

5 Conclusion

This short, preliminary paper has aimed to open debate on trust and compliance in situations where people have easy access to information about controversies and different viewpoints. eHealth systems aimed at pregnant women need to co-exist with online resources and communities and elicit trust in this environment.

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