AIMS For a better birth...

Who Makes Which Decision?

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Gina Lowdon talks about the realities of making birth choices

In early March 1992, a little over two weeks after I gave birth to my son at home as I had planned, the Government's Select Committee for Health launched the Winterton Report detailing the results of their enquiry and recommendations on provision of maternity services. Although this was some two decades ago it is significant because it came at the beginning of an era where official documents and general rhetoric have been characterised by the term 'informed choice'.

The in-depth inquiry involving extensive research that resulted in the Winterton Report had been instigated 'by hearing many voices saying that all is not well with the maternity services and that women have needs which are not being met.'1 Those 'many voices', AIMS among them, pleased that the Health Committee was prepared to act on its findings.

The Illusion of Choice

In due course a further report called Changing Childbirth2 was published, setting targets for implementation and recommendations for good practice. On page 1 the report said:

'The Select Committee concluded that a medical model of care should no longer drive the service and that women should be given unbiased information and an opportunity for choice in the type of maternity care they receive, including the option, previously largely denied to them, of having their babies at home or in small maternity units.'

Unfortunately the flaw in this recommendation was, and still is, that childbirth is now predominantly seen as a medical event and service provision is therefore driven by the dictates of the medical model of care. Options for birthing at home or in small maternity units where medical concerns have considerably less relevance therefore have a very low priority within the NHS which is, of course, primarily concerned with providing medical care.

Women can only readily choose from options which are made available to them and the choices available are dictated by the medical establishment which controls funding for maternity service provision and which decides which options are appropriate and will therefore be provided. The way choice is restricted was explained by Beverley Beech in her book Who's Having Your Baby?3

'Martin Richards (a psychologist) illustrated perfectly the way in which choice is restricted by describing how a woman walked into her local supermarket and asked the manager what choice of fish was available, "Well, we have whiting, herring, sole, plaice, mackerel, cod and rock salmon." She said, "How wonderful. Is it fresh fish?" "No," he replied. "We only sell frozen." The woman had a choice, either to go away empty handed or reluctantly

accept some frozen fish. To her there had been no choice, but as far as the manager was concerned he had offered her a whole range.'

Thus women's choice of care options is limited by an establishment focused on the provision of medical care. One might as well seek to buy fish from a butcher.

The idea that the NHS Maternity Services should be providing non-medical options for birth has never really been understood or taken on board by the medical establishment, which currently is the only provider of state funded maternity care. Birth is widely acknowledged as being a time of great risk, a condition requiring careful monitoring in order to catch problems early or even before they have occurred. Whilst all interventions can safeguard health or life when used judiciously, very few people are aware that many of the problems that do arise are the result of inappropriate and overuse of technological and medical treatments. Much of the damage to women is iatrogenic and evidence clearly shows that a less medicalised approach leads to better outcomes[4]

Unfortunately, the notion that the vast majority of babies (around 95%[4]) could be born without problem is inconceivable, despite research evidence that this should be achievable.

The difficulty the medical establishment has in reconciling the idea of non-medical birth with medical service provision is illustrated by the following 'Key message' from the RCOG Expert Advisory Group Report (July 2011):[5]

'While choice is supported in principle, there is a need to be mindful that choice has to be delivered in a realistic manner, balancing wants and needs with what is clinically safe and affordable and what resources can be made available without destabilising other services.'

So 'choice' is all well and good . within reason. There is the not so subtle suggestion that what some women might want may be contrary to what they need, might be deemed clinically unsafe and may be considered unreasonable in terms of service provision. Clearly there is the underlying suggestion that women may not be trusted to make responsible choices, therefore those choices must be limited to those deemed 'appropriate' and which the medical establishment, focused on pathology, consider it reasonable to provide.

This conflict is further illustrated in the RCOG Report's Introduction[5]:

'Care should be personalised, ensuring risk assessment, continuity of care and choice (this may be influenced by safety and availability of services.)'

Again there is the inference that good non-medical care can be unsafe in some way and that there are logical reasons why it might not be reasonable to make it universally available. Clearly, despite all the rhetoric, there are considerable barriers to providing women with real 'informed choice'.

Most people within our society have been convinced by the medical establishment that all improvements in outcomes are due to advances in medical care and technical developments, making it difficult to even

consider declining all that is on offer, regardless of what the research indicates about effectiveness and risks. Women who do express a preference for non-medical birth options rarely encounter a favourable response.

Define 'Informed'

The maternity services therefore, content in their mistaken conviction that all that is reasonable is being done to provide a full range of appropriate maternity care options, have a tendency to focus on the 'informed' element of 'informed choice'. Since, from their perspective, the range of choices is clearly not an issue, then surely if women were properly informed they would be choosing the form of care deemed most appropriate by knowledgeable and experienced professional health carers? After all, everyone wants the same outcome, don't they?

As far as the maternity services are concerned women making what are deemed to be inadvisable choices must therefore either be irresponsible or ill-informed.

Around the time that Nicholas Winterton's Health Committee was conducting its inquiry, research was becoming more accessible to lay organisations. Women became aware that many of the inadequacies they saw in maternity services provision, and their views on how these could be rectified, were, in fact, supported by medical research. The gap between the evidence base and general practice became evident and led to calls for evidence-based practice which, quite rightly, persist to this day.

This is all well and good, but there is a hierarchy when it comes to research evidence. Research results can be divided into 'quantitative' data (information that can be measured by numbers), and 'qualitative' data (information that is descriptive and therefore more difficult to measure.) Sometimes qualitative data is defined closely so that it can be converted into numbers for outcome statistics, but this often results in a loss of the nonmeasurable bits of the data.

Topping this hierarchy is the RCT (Randomised Controlled Trial), which is generally focused on outcomes in terms of numbers; the larger the number of participants the better, especially when looking at statistical differences for rare outcomes. Bringing up the rear are the case histories, which bring a richness of detail (qualitative data) but which apply to either very small groups or the lowest number possible, one.

This means that outcomes such as maternal death or length of hospital stay, which can be measured in numbers, are easier and cheaper to collect and assess and less subject to bias than qualitative data such as levels of pain or women's satisfaction with the service provided, which can be difficult and time consuming to collect reliably and are more open to biases of interpretation. For these reasons 'quantitative' data is considered to carry more weight that 'qualitative' data.

Evidence-based medical practice has now come to rely heavily on official guidelines and hospital protocols. Due to the sheer volume and complexity of research that is now currently available, guidelines and protocols tend to focus predominantly on studies from the top of the hierarchy, particularly if these

are large enough to show statistically significant differences for rare conditions relevant to planning maternity service provision for populations. This means that the experiential, qualitative evidence which is of interest to women is sidelined.

If there is a high quality, large RCT on any given issue it is likely to be considered sufficient evidence base and therefore inclusion of other studies may be considered unnecessary whether the findings of the RCT are supported or not. Also, studies further down the hierarchy may not be considered sufficiently 'robust' for inclusion, despite the often valuable insights and pause for thought that they can provide.

An additional limitation of research studies is that many are restricted to short term outcomes and tend to focus on serious adverse outcomes or benefits, either ignoring or placing less importance on more common adverse effects or benefits, some of which may have serious later consequences. Whilst the medical establishment is understandably focused on provision of maternity services for whole populations, it can be argued that the research base used is simplistic in its concentration on large numbers and rare outcomes.

In contrast, the concerns of individual women cover a much wider range of issues including common outcomes that have a much greater chance of affecting them personally. The extent to which the medical profession are prepared to subject huge numbers of women to risks of 'minor' adverse outcomes in order to save a tiny number of women and/or babies from rarer but much more serious adverse outcomes is extremely worrying.

The term 'research-based' gives the impression of being inclusive of all research on a given issue, but unfortunately in reality the research base used has become much more selective and heavily weighted towards the much narrower, predominantly quantitative and limited, range of outcomes of interest to health professionals. It is research based, but it does not take account of all the research information available on any given issue. It also ignores any common knowledge that is 'known' but unproven by robust research.

Women are rarely reliant solely on the maternity services for their information. Women share experiences and knowledge gleaned from friends, relatives, social networks and the internet and consider their personal needs in the much wider context of their whole life situation. The health of their baby is of course of paramount importance, but women also take many other aspects of birth and life into account.

Non-medical aspects of birth are of great importance to women but unfortunately the maternity services pay little more than lip service to them if they consider them at all. These include such care aspects as the benefits of home birth, the advantages of waiting for labour to start spontaneously, the reassurance of having one-to-one care from a known and trusted midwife, the comfort of being able to move freely in labour and adopt instinctive positions for birth, the care of older siblings, feelings of safety, respect and autonomy that go far beyond and yet still encompass the physical safety of the baby which can all too often seem to be the sole concern of the medical establishment.

It is clear that women do not have real freedom to make 'informed choices'. Not only are they expected to make choices from a medically controlled menu of options, they are supposed to base those choices on an artificially narrow information base deemed worthy by the medical establishment.

Just as medical influences are restricting 'choice' so too are medical opinions having an effect not only on the way women are 'informed', but also the level of respect accorded to how they are informed and the sources of their information.

Is it a Choice or a Decision?

Whilst there is no doubt that women should have a range of options, backed up with good information, from which to make informed choices regarding their maternity care, the phrase itself confers a power balance in favour of the medical establishment; it belies the legal reality that women are entitled to make autonomous decisions regarding the care they will accept or decline.

Equally women are entitled to make decisions whether they are considered by others to be 'informed' or not; to base their decisions on whatever information base they feel most relevant to their individual circumstances; or indeed, to make decisions based purely on 'gut instinct'. A woman's right to make decisions regarding her care is NOT, contrary to popular belief, affected by the existence or absence of any medical condition or obstetric history.

Women with medical conditions tend to be much less likely to question the medical advice they have been given, but their right to do so remains. Women are entitled to make decisions rather than choices and they do not have to justify those decisions.

Who makes which Decision?

Unfortunately the Maternity Services are operating on the basis that obstetricians make decisions and women make choices.

Obstetricians do have decisions to make of course; they have an obligation to assess evidence and use their professional experience to make carefully considered Clinical Decisions over what forms of treatment or care should be offered to pregnant and birthing women.

However, having come to a Clinical Decision, and having advised the woman accordingly, it is then

entirely up to the woman to make a Personal Autonomous Decision to either accept or decline what has been advised, regardless of the potential consequences

The majority of women, however, are unaware that they have a decision to make. This is clearly illustrated by women with a history of caesarean section who want to give birth vaginally to their next baby; many are under the mistaken impression that they need the permission of an obstetrician to labour and give birth to the baby they are carrying - is it not ludicrous to make women feel they require permission to give birth?

Indeed, when a woman is healthy and has enjoyed a problem-free pregnancy it can be argued that there is no clinical decision to be made. However, since most women tend to go with the flow of medical advice, albeit in many instances much against their better judgement, those few women who do make Personal Decisions that are not in line with medical opinion are more often than not met with perplexity, incredulity and pressure to conform.

The Validity of Consent

The aforementioned issues concerning 'choice', 'informed', and 'who makes which decision' impact very seriously on the validity of 'Informed Consent' and it is clear that the understanding of many health professionals leaves a lot to be desired.

The NHS Maternity Services, in common with all areas of the NHS, has a legal obligation to offer patients what is considered to be appropriate medical care. Patients then have the legal right to either accept or decline the treatment or care that has been offered. Where the vast majority of cases are concerned, patients are ill or are suffering from some medical problem, so consent issues are possibly less controversial since patients are generally anxious to recover good health, have consulted their doctor in the hope of a remedy and are keen to try any treatments offered, and the sooner the better.

The Maternity Services present a slightly different scenario, since for the most part women are healthy and most pregnancies are straightforward showing no signs of medical problems. Many of the treatments that are commonplace do not deal with ill health, since normal pregnancy is a sign of good health, not ill heath, and generally consist of monitoring procedures which are not designed to safeguard health but to detect ill health or deviation from what is considered to be the norm.

Valid consent is therefore particularly important within the Maternity Services since women have firstly not approached their doctor with a medical condition and secondly are usually healthy individuals who are being 'offered' treatments and forms of care which may not be clearly indicated by a currently presenting problem and therefore carry the risk of adverse effects without any compensating benefits to the individual. This was further illustrated by the recent Birthplace Study[6] the latest in a long line of research indicating the increased risks to women and babies of birth in hospital.

Women making valid decisions to either decline professionally recommended care or who require access to birth options not 'on offer' through their local maternity services, especially if they are basing those

decisions on valid grounds albeit not grounds considered worthy, are increasingly finding themselves the subject of harassment, bullying tactics, and accusations that they are putting their babies at risk to the extent that in an increasing number of cases inappropriate and damaging referrals to Social Services are being made.

We are now at the point where:

- non-medical options for birth are thin on the ground within the medically-oriented NHS,
- women are being pressured to 'choose' between limited care options which are medically-managed and therefore inappropriate for predominantly healthy women,
- birthing decisions are expected to be based on narrow, carefully selected research focused mainly on short-term medical outcomes which may or may not be relevant to the woman's individual case,
- refusal of consent is not considered valid if it is not in line with medical expectations,
- birthing decisions are seen as the domain of obstetricians, not women.

The consequences are dire: high rates of intervention, high rates of avoidable caesarean sections, higher costs to the NHS,[6] high rates of post birth trauma, suicide now a leading cause of maternal death, low rates of 'normal' physiological birth, low rates of breastfeeding, adverse effects on bonding and parenting skills to list but a few. And yet the evidence is clear about what needs to be done, so why are we no further forward two decades on from Changing Childbirth?[2]

Who is making the decisions? In theory women have the right to make decisions or at the very least informed choices from a full range of birthing options. In practice decisions are dictated by an obstetric-led maternity service that limits options available and controls freedom of choice. Women, even healthy women, are captive patients who must either comply or fight a continual battle throughout their pregnancy in order to retain any semblance of autonomy.

It is not good, and it is getting worse.

References

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3. Beech, BAL (1991) Who's Having Your Baby? Bedford Square Press: London.
4. Lowdon, G (2010) All on the same side, AIMS Journal, Vol. 22 No. 2, p4-11.
5. RCOG (2011) Expert Advisory Group Report. High Quality Women's Health Care: a proposal for change. Available at www.rcog.org.uk/high-quality-womens-health-care/.
6. Birthplace in England Collaborative Group (2011) Perinatal and maternal outcomes by planned place of birth for healthy women with low risk pregnancies: the Birthplace in England national prospective cohort study. British Medical Journal, 343:d7400 doi:10.1136/bmj.d7400. A

summary and further information is available at www.npeu.ox.ac.uk/birthplace.

Further reading

- www.kingsfund.org.uk/blog/decisionmaking.html Please stop muddling shared decision-making and provide choice by Angela Coulter, 1 June 2012, with interesting following comments.