AIMS For a better birth...

Editorial - When the mother is unwell

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Christian Krohg (1852–1925)

By Alex Smith

Welcome to the June 2024 issue of the AIMS journal. The theme for this issue focuses on the experience of maternity care for those who embark on pregnancy already unwell or who become unwell at some point before or after their baby is born.

Pregnancy is often portrayed as a time of wellness and indeed, pregnancy and childbirth is, according to the World Health Organisation:

> a *physiological process that can be accomplished without complications for the majority of women and babies.*[1]

Yet, according to a Danish study published in 2016[2], the overall prevalence of maternal chronic disease increased from 3.71% in 1989 to 15.76% in 2013, and a more recent study proposal[3] puts the figure for those in the UK having multiple pre-existing long-term conditions (two or more) at 20%. While the researchers acknowledge that the average age and weight of mothers has also increased during this time, and that this is associated with increasing incidences of chronic disease, age and size in themselves have not been counted as morbidities. The researchers also acknowledge that increasing awareness and recording of chronic disease, especially mental health conditions, may have some part to play in what amounts to a fivefold increase in the number of people who come to pregnancy already 'unwell'.

Another way of looking at those figures though is that four in five people (80%) embark on pregnancy free from any pre-existing illness, and should perhaps expect a far smoother experience of birth than the majority do.

Chronic health conditions are those that have lasted at least one year and require on-going medical care. They include asthma, heart disease, blood clotting disorders, thyroid conditions, autoimmune diseases such as various types of arthritis and inflammatory bowel disease, diabetes, high blood pressure, HIV, epilepsy and mental health conditions - all associated with a higher incidence of adverse pregnancy outcomes. In times gone by, a person with one or other of these conditions may have been advised not to marry or to have children, but that is not so often the case today and many can and do have healthy pregnancies and healthy babies.

In addition to those who enter pregnancy already being treated for a chronic condition, the normal physiological changes of pregnancy can unmask conditions for the first time.[4] For example, in pregnancy the blood clots more easily to reduce the risk of heavy bleeding during and after the birth, and this tendency can reveal conditions like hereditary thrombophilia[5] or antiphospholipid syndrome.[6] Another example would be related to the fifty percent increase in plasma volume during pregnancy. This increase is required in order to support the pregnancy and meet the needs of the growing baby, but it can unmask cardiovascular conditions in the mother, including arteriovenous malformations.[7] Symptoms of such a condition can be confused with those of pregnancy and consequently, a proper diagnosis seriously delayed.[8] A third example is related to the physiological increase in insulin resistance during pregnancy.[9] This clever adaptive mechanism ensures an adequate supply of glucose to the rapidly growing baby, but in people who are already insulin resistant (and many people are without knowing) this can manifest in pregnancy as gestational diabetes, with an increased chance of developing type 2 diabetes in the future.

Unwellness can also be experienced after the birth, either as an acute situation such as a blood clot or infection, or as the emergence of chronic conditions such as pain, incontinence or mental health conditions. It is hard to find research showing the extent of postnatal maternal morbidity (unwellness), but a study from 1995 found it to be “extensive and under-recognised”[10] and a 2023 report looking at the issue for women globally describes it as, “prevalent, enduring, and neglected”.[11] An NCT study found that many mothers felt, “left to their own devices”.[12] The focus of maternity care seems to be on ensuring a live mother and baby; postnatal morbidity, and especially iatrogenic morbidity (unwellness arising from medical treatment or mistreatment) is under-recognised and under-prioritised both by the cash-strapped NHS and by a society that no longer affords the mother a proper period of recovery.

The problem is exacerbated by the reduction in home visits from a midwife after the birth, and by the sense of being ‘signed off’ at the six-week check-up with the doctor. More historically, any collective knowledge and skills regarding postnatal recovery and the management of the long-term consequences of childbirth, ‘devices’ women may have shared and valued, were eroded by the advent of the professional midwife, and later by the NHS, when the message that ‘the doctor knows best’ could be taken to heart by rich and poor alike. In some other countries the grandmothers and aunties still offer

care based on rest, nutrition, herbs, massage and belly binding.[13,14] We had similar practices in the UK, which have largely been forgotten, but not quite. Perhaps drawn by an ancient calling, and definitely through actual need, the grandmothers and aunties are re-grouping in the form of the postnatal doula and her like. If only their services could be free at the point of contact. A recent study from Ireland[15] found that new mothers would value extended professional support, but especially if this was personalised, skilled and respectful of the mother as the decision-maker. For many new mothers, a skilled postnatal doula would fit the bill exactly.

The combination of pregnancy and illness is an unusual one for the AIMS journal. While it is easy to understand why some people believe that all pregnancies and births should be medically managed -*just in case* - this actually turns out to be counter-productive. Disturbing the normal physiological process always comes at a price. When medical procedures and technologies are used routinely or without need, they do more harm than good - even for people with a pre-existing chronic condition. The two extremes of maternal health care, *too little too late* and *too much too soon*, have been discussed in the Lancet series of that name.[16] In summary it recommends that for *all* women:

> *The right amount of care needs to be offered at the right time, and delivered in a manner that respects, protects, and promotes human rights.*

Perhaps with this balance in mind, Dutch doctors Paul Reuwer, Arie Franx and Hein Bruinse, have proposed a resurrection of O'Driscoll's 'active management of labour' in their book entitled, 'Proactive Support of Labor: The Challenge of Normal Childbirth'.[17] While ringing old alarm bells,[18] they have a lot to say about the harm caused by the overuse of some birth practices and from misplaced faith in birth technology, going as far to stress that:

> *For women with a complicated pregnancy (the minority) there is no better place to give birth than a hospital. For healthy women with a normal pregnancy (the majority) hospitals can be very dangerous.* (Page 27)

They propose an approach to care that respects the physiological process of labour and, refreshingly, one that enhances women's satisfaction with childbirth. However, when a labour is regarded as being too slow, they very naturally apply their medical minds to the situation resorting to the oxytocin drip without consideration of non-medical techniques first. That said, for those who want or need to give birth in the hospital setting, their thinking is in line with the AIMS campaign for a 'physiology-informed' approach to care that benefits birth however and wherever it takes place.[19,20]

This brings us back to the care of women who are approaching or recovering from the birth of their baby while managing a medical condition of one kind or another. They too benefit from just the right amount of care, and care that respects, protects, and promotes their human rights.

> ***A heavy handed, insensitive or unresponsive approach to care risks adding trauma to***

complexity.

A care plan for more complex situations must involve communication *between* the specialists involved as well as between each specialist and the mother. Without good interprofessional collaboration, misguided assumptions on the part of one practitioner or the other can result in advice that leads to poorer outcomes. When the medical condition is under good control, an attentive, responsive but low-key and gentle approach to care may be as safe or safer as routine intervention, when this is what the mother prefers.

What is certain is that in both complex and straightforward pregnancies, the mother has 'inside information'. Just as with any other aspect of our physiological functioning, we sense when something is awry and when medical intervention feels welcome and appropriate. Bizarrely, given how frequently medical intervention is offered in the normal course of events, when women actually ask for an investigation or treatment, or when they tell a practitioner what they think may be wrong, they are often met with casual reassurance, resistance or delay. This can also lead to poorer outcomes.This lovely video reminds doctors to listen to women in these circumstances.[21] If *all* mothers (before, during and after their babies are born) were listened to and responded to with genuine warmth and respect, and if their care decisions were supported, outcomes would improve in every way and litigation cases would plummet.

The journal this quarter opens with Jane Furness's wonderful account of self-efficacy in ensuring the best possible birth experience for her and her baby. Jane has type 1 diabetes but knows that, unless things change, a low-key home birth is the way to go. Jane is followed by Rebecca Jarman who explains about peripartum cardiomyopathy (PPCM), a rare form of heart failure in women that only occurs just before or after childbirth. Rebecca's mission is to raise awareness of the symptoms so that treatment can be started as early as possible. If more midwives and doctors were alert to the symptoms of PPCM, Claire Sheppard may have had a different story to tell. When Claire became ill after the birth of her baby, nobody really listened until it was nearly too late - even when she said that it might be PPCM.

Phoebe Howe also felt a surprising lack of support from her maternity care, both before and after the birth. When she found herself unexpectedly pregnant, support and treatment for her serious mental health condition just stopped. Emma Dickinson felt similarly disrespected. When she told the midwives that she couldn't walk or move easily, no one listened. When she told them she was in labour, she wasn't believed. Their stories illustrate the importance of listening, and of responsive, kind and compassionate care.

Insensitive care, fear mongering and mixed messages can be traumatising and cause lasting harm. Victoria Rixon, a midwife herself at the time, shares her diabetes and pregnancy story. Both she and Jane

experienced a profound loss of confidence because of fear-driven care. One has to wonder whether confidence is intentionally undermined in order to gain the person's compliance.

Victoria is followed by Catharine Hart who shares her experience of pre-eclampsia and the subsequent care of a premature baby. She looks forward to a time when mothers and babies remain together throughout any hospital stay. Victoria Hilton from the Marfan Trust explains about Marfan Syndrome and about the very specialised care that people with this condition require throughout pregnancy and birth, and Kim Morley, a specialist nurse, explains the complex care required to ensure the safest possible pregnancy outcomes for people with epilepsy. Rounding up our section of themed articles,Lara Wilson, a specialist physiotherapist, explains about the impact of pregnancy and birth on the pelvic floor and all of the things that can be done to put that right.

Moving on to the AIMS Campaigns Team section,Anne Glover reports on an interesting and packed three days at the Doula UK online Conference 2024: Inspire & Connect. Members of the Team bring us up to date with two campaigns that are close to AIMS heart in their newContinuity of Carer Corner and in a report on their work related to the AIMS campaign forphysiology-informed maternity services, and last but never least, we share what the AIMS Campaigns Team has been up to this quarter.

We are very grateful to all the volunteers who help in the production of our Journal: our authors, peer reviewers, proofreaders, website uploaders and, of course, our readers and supporters. This edition especially benefited from the help of Anne Glover, Katherine Revell, Grace Hall, Danielle Gilmore, and Josey Smith.

The theme for the September issue of the AIMS journal is*Trust*. If you have an experience or insight relating to this concept and would like to write about it for the journal - I would love to hear from you. Please email: alex.smith@aims.org.uk

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https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7401936/

6 Tommy's - Antiphospholipid syndrome. https://www.tommys.org/pregnancy-information/pregnancy-complications/antiphospholipid-syndrome-aps

7 Editor's note: An arteriovenous malformation (AVM) is a specific term used to describe a tangle of blood vessels with abnormal connections between arteries and veins. These are usually present at birth though may not be obvious.

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https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10072959/

9 Editor's note: Insulin is the hormone that enables glucose in the blood to enter cells where it is needed. Insulin resistance is when this process has become less efficient and the body needs to make higher levels of insulin to do the same job. If the point is reached when not enough insulin can be made, blood glucose levels rise.

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19 Warrington C (2022) Physiology-informed maternity care. BJM https://www.britishjournalofmidwifery.com/content/charity-spotlight/physiology-informed-maternity-care/

20 AIMS (2021) Position Paper: Physiology-Informed Maternity Services https://www.aims.org.uk/assets/media/730/aims-position-paper-physiology-informed-maternity-

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21 Preventing maternal mortality: It's ok to ask - Royal College of Physicians and Surgeons of Glasgow and the Royal College of Obstetricians and Gynaecologists.

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