AIMS JOURNAL

Social Media in Pregnancy and Early Parenthood

Volume 32, Number 4,
2020

AIMS

The Association for Improvements in the Maternity Services

Registered Charity No: 1157845 2018

Contact Details

Join AIMS – www.aims.org.uk/join-us

Contact – www.aims.org.uk/contact

Donations – www.aims.org.uk/donate

Getting involved – www.aims.org.uk/volunteering

Events – www.aims.org.uk/events

Shop – www.aims.org.uk/shop

About AIMS – www.aims.org.uk/about-aims

www.aims.org.uk
Twitter @AIMS_online • Facebook www. facebook.com/AIMSUK
Helpline 0300 365 0663 • helpline@aims.org.uk

Vol:32 No4
AIMS Journal (Online)
ISSN 2516-5852

Journal Editors

Katharine Handel
Luisa Izzi
Alexandra Smith

Journal Production Team

Danielle Gilmour
Alison Melvin
Emma Ashworth
Debbie Chippington-Derrick
Nadia Higson
Jo Dagustsun
Anne Glover
Veronia Blanco
Marie Buckleygray
Bonita Khan
Maddie McMahon
Caroline Mayers
Josey Smith
Zoe Walsh

If you would like to submit articles to the AIMS Journal,we would be delighted to receive them. Please email journal@aims.org.uk

~ ~ ~

© AIMS 2020
Association for Improvements in the Maternity Services

Please credit AIMS Journal on all material reproduced from this issue.

Submissions to this Journal are the work of individual contributors and may not always reflect the opinions of AIMS.

Submissions to the AIMS Journal may also appear on our website,
www.aims.org.uk

Contents

Editorial

The Use of Social Media in Pregnancy and Early Parenthood

by Journal editors Katharine Handel, Luisa Izzi and Alex Smith

Katharine Handel

Luisa Izzi

Alex Smith

This year 2020 is drawing to a close and, for the most part of it, the Covid-19 pandemic seems to have brought almost the entirety of our lives online. But what happens when pregnancy and birth are brought online? With the pandemic, social media interactions during pregnancy and birth have become part of most people's daily experience. However, the way in which social media has a presence – or dominance – in many aspects of pregnancy and birth is not new, in terms of both information sharing and connecting with others. Therefore, the theme of this issue, "The use of social media in pregnancy and early parenthood", seemed to us new editors to be not only in need of exploring, but also extremely relevant in the present circumstances.

Interestingly enough, when we started reading around the topic, we found a really good overview in the book *Taking the Village Online. Mothers, Motherhood, and Social Media.*[1] It was fascinating to witness how the articles we commissioned and received followed very closely the same three themes illustrated in the book! Social media can often influence our ideas of parenthood, and be a place, if not **the** place, where a lot of parents find support, information, and community. Social media also has a huge potential as a place "for resistance to cultural hegemonies"[1], where we can voice our opposition to dominant ideas or practices. This seems particularly significant now, at a time when choices regarding pregnancy and birth have been severely reduced due to the Covid-19 pandemic.

I found that the following passage gives a good reflection of the findings of the stories told in this issue:

> *"Cyberfeminism's central recognition of the Internet's potential for women's positive transformation begins with individual women connecting to a community of women online. […] With this sense of community and support, mothers can develop connections rooted in authenticity because they do not feel judged."*[3]

We are grateful to the authors for their focus on the ways in which social media impacts on people's experiences at a critical time in their lives. The tension between the public and the private is addressed by Jocelyn Allen as she explores pregnancy and the transition to motherhood in her art and writing through the lens of social media. Jocelyn's personal ambiguity reflects a broader more general theme

of social media as a mixed blessing. This is illustrated by Jen Culley and Liz Skidmore's account of a very real and personal experience of regret following well-intentioned but misplaced support, sitting alongside Julie Wall's moving account of the comfort she gained through her use of social media following a miscarriage earlier this year. The weighting of opinion was that social media is a force for good, with Gemma McKenzie attesting to the way that it allows women's voices to penetrate obstetric debate more than ever before. However, Frances Attenborough tells a cautionary tale about the hidden forces at play in our use of social media, forces that may not always be to the benefit of the user. We loved the debate we enjoyed between ourselves on reading this article and we welcome your letters to the editor (editor@aims.org.uk)!

There is no debate about the way that social media has provided a lifeline for people during the Covid crisis. In her really helpful article, Jayne Joyce explains how she runs a successful closed group on Facebook that provides professional breastfeeding support, and Wendy Jones shares he experiences of supporting breastfeeding women with inflammatory bowel disease through her online forum. We must also thank Julie-Ann Crowley for bringing us up to date about the uses and benefits of the presence of AIMS on social media.

There is also a wealth of material from the AIMS Campaigns team. "Removing COVID-19-related maternity restrictions on partners" gives an update on AIMS's response to this aspect of the pandemic, while "Refocussing our attention on Better Births" marks the fifth anniversary of the Maternity Transformation Programme by restructuring the Better Births vision in poetic form to encourage reflection and reassessment. Anne Glover provides an update on a pilot scheme in Northern Ireland to implement a continuity of carer model, while in "Ideological birth wars: The academic debate goes on, but where does this leave us?", Jo Dagustun explores a recent controversial article published in the British Medical Journal about "where women should give birth" and includes a letter that she sent to the journal in response. There is an illuminating interview with Lorna Tinsley, who until recently provided a voice for midwives as a member of the Nursing & Midwifery Council, and Shane Ridley offers an analysis of "First Do No Harm," the Independent Medicines and Medical Devices Safety Review chaired by Baroness Cumberlege in July 2020. "What Has the AIMS Campaigns Team Been Doing?" gives a roundup of the Campaign team's activities over the past few months. Kay King introduces the Childbirth Choices Matter campaign, which aims to create a new insurance product for self-employed professional midwives that is not tied to the premiums set by commercial insurance companies along with an access fund that will allow pregnant women and people to access this form of care if they choose. There is a briefing for birth activists on the new role of Professional Midwifery Advocate, and finally, we have two brilliant book reviews: one of Margaret Drabble's feminist classic *The Millstone*, reviewed by Shane Ridley, and another of Mia Scotland's *Birth Shock*, a compassionate treatment of the subject of birth trauma reviewed by Anna Madeley.

We would like to thank all the Trustees and Volunteers of AIMS for their warm welcome and their support as we got to grips with producing our first issue of the journal. Also, massive thanks go to Bonita Khan, Zoe Walsh and Josey Smith, who proofread this issue, and Danielle Gilmour, who uploaded all of the material to the website.

We hope you will enjoy reading this issue! For our March 2021 issue, we have chosen the theme of salutogenesis, or the origins of health, and will be focusing on factors that support human flourishing throughout the perinatal period, and beyond.

~~~

[1] Arnold, LB & Martin, A, eds. (2016). *Taking the Village Online. Mothers, Motherhood, and Social Media*. Bradford, Ontario: Demeter Press.

[2] Arnold & Martin (2016), p.8

[3] Arnold & Martin (2016), pp.146–47


~~~

Article

A (Mother's) Visual Diary on Social Media: Pregnancy and Motherhood during the Covid-19 Pandemic

by Jocelyn Allen

When I found out I was pregnant in October 2019, I knew I was going to document my pregnancy, but it would have been weird not to considering I have been making photographic self-portraiture projects since 2009. When I could, I told friends and family the good news in person, but if this was not possible, I would share it over the phone or via WhatsApp. I was a bit nervous about something bad happening, though, and as a result I did not share it on social media until I was 20 weeks pregnant.

I have long had a love-hate relationship with social media. I see the benefits of being able to share my artwork with a wider audience and staying in touch with friends and family, but with these positives I also see negatives. Anyone can comment on what I post, and at times it can make me too accessible and I feel like I am expected to reply quickly. Posting can make me feel quite self-conscious and anxious, though I also use it to work on my confidence.

My public announcement consisted of two photographs which were taken at my very first solo exhibition and part of the caption said, 'So here are just two pictures – one of me with the entrance photo and title, and one with two members of my family who came to the show'. The two members of my family were my husband, Tiago, and the baby in my just-apparent bump.

"I Keep Looking At The Scan As I Can Not Believe It (9 and a half weeks),"
from *Waiting For Things In A Time When You Rarely Wait For Things*

My show was in Norway in February 2020. I felt a little anxious going as Covid-19 seemed to be getting closer, but I just washed my hands a lot more than normal and thought that perhaps I was being a bit paranoid. The idea of being pregnant during a pandemic seemed a bit hard to imagine.

By the time I made my pregnancy public, I had already done 34 shoots of the 84 I would eventually do for the project. I started to post the selected images online (mainly

just on my Instagram account), but I did not finish sharing them until after my baby was already over a month old. With each post, I shared a diary entry which was composed of up to 30 long hashtags. This was something I had done with my previous project in response to my awkwardness around using hashtags, but I had found it was a good way to talk about how I felt in a manner that somehow seemed less revealing. I usually wrote just before or after a shoot, so they talked about how I was feeling or anything of note that had happened. The series is called *Waiting For Things In A Time When You Rarely Wait For Things*. It seemed like such a smart title when I thought of it early on in my pregnancy, as when did you really have to wait very long for anything in 2019? Obviously by March 2020, life in the UK had really changed and soon everyone was waiting: waiting to see how long it would be until their situation changed. I felt lucky that Tiago and I had the birth of our child to count down to. We had already had our hospital appointments and as I was planning for a homebirth, the midwife came to our flat. Soon, she was the only person I was in close contact with besides Tiago, which was kind of odd.

Tiago and I met in 2015 via Tinder in London. We had both lived there for some years already, but in late 2018 we decided to move to Liverpool to be closer to his work. We did not know many people there and we had not made many new friends, so when lockdown arrived, we were quite cut off physically from people we knew. It was nice to have more time together though, especially as I was in my last trimester, and he also appeared in the project more than I thought he would have initially as he was more available.

In the end, the project became not only a diary for me, but also for family and friends who never saw me heavily pregnant in real life. I had been looking forward to seeing familiar faces during my pregnancy and letting them witness my growing bump, but instead I just saw strangers on our daily walks who I would get annoyed at for getting too close. I mostly kept in touch with people on WhatsApp and Instagram and found myself talking mainly with friends and acquaintances who were pregnant or had babies or young children, as I found they understood what I was going through more. Sometimes I find social media tiring though. I feel like with most people I watch every word I say and it can be mentally draining, as I worry about saying the wrong thing, accidentally upsetting someone or saying something which they might misinterpret. Whereas when I see someone in real life, I feel a lot freer and am less self-monitoring, perhaps as my words are not available to be looked back on again and again. As I write, a second lockdown is about to be imposed on Liverpool and I am finding myself feeling overwhelmed with having to reply to messages. I am frustrated that technology is my main way of communicating with people; it feels so demanding at times, and more energy and time consuming than talking face to face.

"2nd," from *Puke Portraits*

With my project, I was trying to censor myself less and just say what I wanted to say. I felt awkward – as I have for years – sharing my photographs and writing online. This time it felt different, though, as it seems like people have a lot of comments around what pregnant women and people should and should not do. I had morning sickness in my first trimester and I talked about it a lot in Waiting…, but I also made a separate series called Puke Portraits where I photographed myself after every time I was sick. There are 56 images in total.

I did not talk about negative aspects of my pregnancy for sympathy or advice; I just wanted to share my experiences and hoped that someone would find it useful. I knew that I was not the first or only person to feel the way I felt, so I thought it might provide some reassurance or help someone feel less alone with their thoughts. A few friends have commented on how it has been helpful to have an honest account to compare their pregnancy to, to see the similarities and differences, and to know what they might expect in weeks to come. After a while I turned off the comments on my images, as although people meant well, I found replying

to them quite stressful, particularly when I kept saying that these pictures were taken in the past so I no longer felt that way.

My work was very therapeutic for me, however, in terms of getting my head around what it meant to be pregnant and adapting to my changing body. It also helped to have existing projects in place for me to add to, as although I quite enjoy being at home, suddenly having to be there 99% of the time with no understanding of when this would change was a bit of a life shift. I get a bit stressed when I am not able to work on my personal projects, so luckily for me I have always had a 'home studio' and I could continue my work in the same way as before.

Alongside my photographic work, I was also continuing to dance on YouTube. I started a channel in 2013 and as an exercise to work on my confidence, I have made over 1,500 videos of me dancing to songs that I like. I am not a good dancer, but it is great for trying to learn not to care what people think of me – as people are less afraid to share their opinions via a screen – and I carried on dancing whilst I was pregnant. I never announced on YouTube that I was expecting, but it was getting too hot to keep wearing a big jumper when I danced, which was why I eventually decided to share my news elsewhere on the web. I used the pseudonym of Helena Teasdale for my account name, though it was not a secret that it was me, but I changed it to my real name after giving birth and felt the need to own my identity more. Just because I am now a mother, it does not mean I am just that; I am much more, and I want to show it proudly. With more responsibility and less time, parenthood also makes you realise what aspects of your old life you want to keep and make time for; making art is the biggest keeper for me.

When I was six months pregnant, I was approached by the Portuguese singer-songwriter Tiago Bettencourt to appear in a music video for his new single Dança. He had been planning to come to Liverpool so we could appear together, but the world changed quickly and he had to modify his ideas, so we recorded our parts separately in our flats. I planned to keep dancing for as long as I could and in the end, I made some videos the day before I gave birth.

I was 37+5 when my waters broke at around 1 am and I called the hospital. They said to come in for CTG monitoring and that I would be able to go home to give birth if everything was okay. It was the second week of June. I had not been in the car since March, and I had not been in any other building besides our flat since then too. Tiago had to wait in the car whilst I found out our baby was breech and that I would not be going home. A caesarean was presented as my best option, but I wanted to try for a vaginal birth; I was given a deadline of 6 pm to be in established labour (it was 9 am when I was told that turning the baby would be impossible due to lack of fluid). They said that the baby would need to be born that day and that it was better for the caesarean to be planned for early evening rather than late at night. I had done an online hypnobirthing course and knew that panicking would stop any surges, so I focused on staying positive. I was moved to a ward where there were two other women and it felt odd but quite lovely to be talking to strangers. When my surges got stronger, I danced behind my curtain to stay in a good mood, and when I was 4 cm dilated, Tiago was able to join me in the delivery suite. Two hours after a cannula had been inserted into my wrist (in case they needed to administer any drugs), our baby girl was born vaginally. Tiago had wanted to find out the gender, but she did not 'present' in scans, so I was quite happy to be surprised.

Due to restrictions, our daughter 'met' a lot of friends and family for the first time via WhatsApp video, and my parents commented on how they were sad that they would miss out on her newborn smell. Most of my family has now been able to spend some time with her, whereas we do not know when she will be able to meet any of my husband's family due to them all living outside of the UK. With social media, I decided that I did not want to show her face or reveal her full name, as though I share a lot about myself, I feel like B (as I refer to her online) deserves some privacy.

I have since started a new project called Oh Me, Oh Mãe, where I am trying to honestly share my experiences of early motherhood. Mãe is Portuguese for mother (B is half-Portuguese) and the title is a play on the phrase 'oh me, oh my'. I am mainly sharing the images through Instagram, but I have also made a blog (Jockey Greys, an autocorrect of my Instagram name Jocelynfreya) where I expand on the hashtags. Again, I am finding it awkward to share the work, particularly when I am writing about crying due to lack of sleep and feeling like a terrible mother.

"First Family Portrait Session (28th June 2020),"
from *Oh Me, Oh Mãe*

It is true that I do not have to share anything online. I did not know much about pregnancy or motherhood before it happened to me, so I hope that by sharing my experiences it can help someone else; even if it feels uneasy to disclose certain things. Knowing that there is an audience does make me think about what I choose to write or photograph, but ultimately, I am in control of its initial outing and I weigh up what I want to share with what I think is necessary and/or helpful. I know that things can be interpreted by people however they want depending on their own experiences, feelings or mood, so you can not control how people will respond. I often self-censor any nudity with white blocks, which helps my work not get taken down on social media whilst also only publicly displaying what I feel comfortable with but having the whole document for myself.

I have talked about confidence and making my work over the years has changed me. The photographs and videos have helped me (though I think it is always a work in progress) learn to accept myself and my body more, and now the hashtags are enabling me to feel more comfortable and confident with my own thoughts and opinions. The first part of the therapeutic nature of my work is making it, but the second part is sharing it and leaving myself open for more judgement than if I did not reveal much.

The most useful thing about social media for me during this time has been a WhatsApp group of seven other mums who I met through an NCT course. There is less than two months between the oldest and youngest baby, so it was really reassuring to be able to ask women who were having a similar experience during this unique time about themselves and their babies. Also, before bothering the doctors with any queries – I would worry about sounding stupid or looking like a bad mother – in the early days of panic I would often send photos of any concerns to my Mum and older sister. I stressed about leaving the house in the beginning for appointments or anything, but due to the pandemic, our doctors would ask for a photograph followed by a phone call instead, which is a service that I hope will stay forever.

Being pregnant during a pandemic was a bit of a surprise, but I feel like I handled it well. As it was my first time, I had nothing else to compare it to, though it felt odd that I never really got to say goodbye to my past life; things just changed fast and I realised that it had gone. Who knows how things will be in the future, but for now I am just grateful that I have a healthy family, and I am excited to watch my daughter grow and find her place in an uncertain world.

~~~

Jocelyn Allen is an artist who mainly works with photography, writing, video and dance. She predominantly uses herself within her personal work to explore the themes of self-confidence, hiding and revealing, body image, and motherhood.
~~~

Article

Fifteen Minutes on Social Media

by Jennifer Culley with Liz Skidmore

Editor's note: *This article features a fictionalised discussion of one woman's experience of stopping breastfeeding and her feelings of regret about doing so. AIMS knows that there are different views about breastfeeding, and the topic can arouse strong feelings. This article describes one person's perspective, and we recognise that not everyone who has stopped breastfeeding will feel this way. There will be a list of resources at the end of the article that can offer support for anyone experiencing the issues discussed here.*

Jennifer Culley and Liz Skidmore

This piece is a fictional conversation on a social media platform but is based on a real experience of a mother struggling with feelings of grief and regret. This format acknowledges the way many parents now access support. It is an example of a closed Facebook group that has a specific goal, in this case, breastfeeding support. There is a large variety of support groups, ranging from those set up by parents wanting to reach out and find informal support within an online community to groups that are run by trained professionals or volunteers who moderate posts and have rules for members to follow. The sort of online peer support modelled in this piece can be beneficial to parents who might otherwise feel isolated and unsure of where to access support or have their voice heard.

Jen: 10.00 - Is anyone there? I need to rant!

Peer supporter Liz: 10.01 - Hey Jen. What's up?

Jen: 10.02 - I've just seen a post on a local parents' Facebook group.

Peer supporter Liz: 10.02 - Go on...

Jen: 10.02 - You see, a new mother was agonising over her decision to stop breastfeeding, and it's reminded me of five years ago when my little girl was a few weeks old. I guess it's brought back some of those emotions.

Peer supporter Liz: 10.03 - I see...

Jen: 10.03 - I had really wanted to breastfeed, but it was so painful. At the time, I didn't know what to do about it or where to get support. Two friends visited me and shared that they'd struggled to breastfeed too. They described how they'd felt so much better once they stopped and that I shouldn't be putting myself through this pain at such a vulnerable time in my life. At the time, it felt so reassuring to hear that it wasn't

just me and that it was ok to stop breastfeeding. In fact, I felt that a weight had been lifted off my shoulders, and on that very same day, I went out to buy some formula.

Peer supporter Liz: 10.04 - It sounds like it was reassuring for you at the time, but like you have some regrets now?

Jen: 10.04 - Yeah, I do. I try not to think about it too often, but this post has stirred it up.

Peer supporter Liz: 10.04 - I'm sorry to hear that, it must be hard for you. So this is what you saw on Facebook this morning...people were being supportive of the mother in a similar situation to yours...is that right?

Jen: 10.05 - Yes, but no. All the comments were kind, on the whole they were saying she shouldn't feel bad about stopping breastfeeding. In one way, I agree with this, because no one should make her feel bad, but she might actually end up regretting her decision like I did, and will all those people be there to support her then?

Peer supporter Liz: 10.06 - Mmm...perhaps not.

Jen: 10.06 -That's why I'm feeling so angry. I now look back to that day with those well-meaning friends and wish I hadn't met up with them. If I had searched for a different kind of support, I might not feel the regret I still feel now at having not breastfed my first child for as long as I wanted. Everyone supported me, but I really regret my decision.

Peer supporter Liz: 10.07 - Sounds like you still have strong feelings about not continuing to breastfeed your first baby?

Jen: 10.07 - Yes, I think the fact that I was able to feed my other two children for as long as I wanted almost adds to the regret that I stopped breastfeeding my first so early on. Although I accept that others may not have the same regrets I have, I wonder if it's just me!?

Peer supporter Liz: 10.08 - No, not at all. For many mothers, stopping breastfeeding before they expected to can be devastating. It can result in feelings of grief and prolonged feelings of loss and failure, which are harmful to their emotional wellbeing. There is even some research on it. Here's a link to this research if you want to see it: https://bmjopen.bmj.com/content/9/5/e026234[1]

Jen: 10.09 - Thanks for that, that definitely resonates with me. I think my friends and the women on Facebook this morning meant well. Hearing the kind words of other women that have gone through something similar can be validating and empowering, I can see that too, but it still hits a nerve!

Peer supporter Liz: 10.10 - Social media can be a double-edged sword sometimes, can't it? The author of Informed is Best, Amy Brown, writes how social media can help reduce people's feelings of depression and anxiety by normalising and discussing these feelings, and by providing an opportunity to ask questions...but it's not always the case that the information shared is evidence-based or shared in a completely objective way. There is often unconscious persuasion hidden in the sympathy and kindness.

Jen: 10.11 - Well, it's reassuring to hear that it's not just an issue I have! I often think about coming off social media, but the benefits seem to outweigh the negatives. I had a homebirth with my third child, and the homebirth group I found on Facebook was so supportive. At the time, I didn't really know anyone that had had a homebirth, so feeling connected to a group of likeminded people made me feel less isolated. It also helped balance out the messages of 'are you allowed' and 'I don't think I could risk it' that I was getting from friends and family.

Peer supporter Liz: 10.12 - It sounds like the sense of community and support you got from that group was really beneficial to you and your home birth experience. Actually, that reminds me of a paper I looked at recently about a closed breastfeeding support group on Facebook. It reflects what you said about the sense of community and support felt by the members. The mothers involved also expressed how the group increased their confidence in their parenting decisions. Here's a link to that: http://web.a.ebscohost.com.apollo.worc.ac.uk/ehost/pdfviewer/pdfviewer?vid=1&sid=4d4e3b36-704e-467b-86e0-d407e2aa326a%40sdc-v-sessmgr01

Jen: 10.13 - Thanks, Liz. I found that with the admin-led groups (like the ones on Facebook that are moderated by professionals or volunteers with some level of training), the information seems more reliable as the admins can remove anything that's incorrect or potentially harmful. It's great that if you do something less usual, like a homebirth, there's probably a group of likeminded people out there that you

can easily access! Things have changed so much in the last six years. When I had my daughter, I wasn't really aware of these groups.

Peer supporter Liz: 10.14 - You feel you missed out on this when you had your first baby?

Jen: 10.14 - I think they might have helped me access more support. In the Facebook post this morning, there were also a few people sharing some of the support that's available, which was good. Oh, I've just noticed the time! Thanks for being around to chat, Liz, I think I just need to approach social media in a more mindful way.

Peer supporter Liz: 10.15 - No worries, there's always one of the peer supporters available to chat on this group. That's a good point: being mindful about how social media can sometimes cause negative thoughts and feelings can help us to take better care of our wellbeing. Just recognising this can enable us to take a step back and consider where these feeling are coming from.

Jen: 10.15 - Have a good week, chat soon no doubt!

Peer supporter Liz: 10.15 - You too, speak soon!

Jen Culley works as an Antenatal Teacher and a Breastfeeding Counsellor for NCT. When she's not busy looking after her three young children, Jen volunteers to support local families. Other than all things pregnancy, birth, and parenting, her interests include interior design and living a minimalist lifestyle.

Liz Skidmore is a mum of two young children and has recently qualified as a Breastfeeding Counsellor and Antenatal Teacher with the NCT. She is also a former engineer, and is passionate about making a difference to breastfeeding support locally, as well as supporting families during their transition to parenthood.

Resources for those in a similar situation

Brown, A (2019) *Informed is best: How to spot fake news about your pregnancy, birth and baby*. London: Pinter & Martin.

Brown, A (2019) *Why breastfeeding grief and trauma matter*. London: Pinter & Martin.

"Five ways to help when breastfeeding doesn't go as expected." www.laleche.org.uk/five-ways-help-breastfeeding-doesnt-go-expected/

Article

Baby loss in lockdown, the loneliest of times. Does social media help?

by Julie Wall

At 41 and with three beautiful, thriving children, I was elated if not a bit surprised to discover we were to be blessed with a fourth child. Immediately on seeing those two blue lines, I (being a meticulous planner) made head-space and grew heartroom.

I was writing a dissertation at the time on the impact of social media on the transition to becoming a mother for the first time. I now found myself looking up on blogs and social media for anonymous advice, support, and experiences on being an older mother, one that's also carrying a bit more weight!

Chalklen and Anderson suggest that mothers fall into three categories when using social media. They describe the mothers in their research as either 'advanced-active users' (those who have social media, in particular Facebook, integrated into their everyday lives: they tend to share a lot on there, be more open, and are likely to be interacting more online than the other two categories); 'closed-protective users' (these mothers are very conscious of privacy, they will look up information and 'like' it, but posted and shared information less so); finally, the 'fence-sitters' (this group are also likely to have robust privacy settings, and will view information, but are less likely to comment on posts, and more inclined not to friend work

colleagues or share photos; interestingly, the researchers found that this group might engage in certain activities on one occasion and avoid it the next). Chalklen and Anderson also observed that the mothers in their study changed how they used social media, particularly when becoming a mother for the first time. This resonates with me, and I have definitely moved through the categories during my motherhood journey, currently identifying with the 'closed-protective user' category.

Lockdown due to Covid-19 made this pregnancy experience a little different to my other pregnancies. My booking-in appointment was via telephone, with an invitation to join a closed Facebook group in order to keep up to date with Covid-19 guidelines. My first visit with the midwife was on my own, wearing a mask, then finally came the dating scan. At this point regulations were being eased a little, and my husband was also able to attend.

The drive to the hospital (with the obligatory full bladder!) was one of excitement, anticipation, and joy. We were looking forward to seeing our beautiful little surprise for the first time. We were called in (in our PPE) and I happily hopped up onto the couch, ready to enjoy the scan.

I'd had no bleeding during this pregnancy, as I had with my previous three. My pregnancy symptoms were strong and I felt contented. Therefore, as I lay there, I was pretty confident that all was fine. I'd already considered my announcement to the world via social media – what a wonderful surprise it was going to be!

The sonographer was worryingly quiet, then finally she said, 'Is there any chance your dates are wrong?' I knew 100% that they weren't. 'I'm sorry,' she said, 'There is no heartbeat.' I left the sonography room in tears and in a state of shock, that heart and headroom still gaping open, a sense of grief looming. The rest of the week went by in a blur.

Three weeks later, after expectant management of my missed miscarriage and two further scans (just to make sure), I opted for medical management. I was admitted as an in-patient due to a previous caesarean birth, and the process was as expected. I was exactly 12 weeks pregnant.

If 1 in 4 confirmed pregnancies end in miscarriage, I couldn't help wondering why I felt so incredibly alone. Again, as I did when I found out I was pregnant, I turned to the internet for support, specifically blogs, social media, and forums.

Reading other similar stories on social networking forums, such as Netmums, Mumsnet, and a private, 'safe space' on The Miscarriage Association's website, made me feel less isolated. Feeling others empathise through their written word on social media blogs, and validating my thoughts and feelings by having them affirmed by other mothers who'd experienced baby loss was invaluable to my recovery.

Evidence shows that mothers, whether they are pregnant for the first time or they have had children already, turn to social media in order to source advice and information specifically tailored to their needs. They (the mothers) report this being advantageous for the following reasons:

- It is instantly available and available 24/7.
- It can be anonymous (if required/requested).
- It gives mothers affirmation from other mothers.
- In the early days of motherhood, it makes mothers feel more connected with others, thus reducing isolation.
- Mothers do not need to leave the house to access support.
- It gives the ability to keep friends and family updated with baby news (although there is conflicting evidence about posting photos).
- It can be unbiased and mothers can receive valuable information from like-minded mothers.

I would also offer a caveat about potential bias in the private groups and forums. Just as a researcher would collate their evidence, it is important to view the 'whole picture,' not just cherry-pick the research which supports and confirms

the researcher's view. Within the private, specific groups that mothers can join, the information sharing is vital, affirmative, and powerful; however, it might leave some vulnerable members open to coercion and bias.

However, the evidence I critiqued above suggests instead the opposite. Archer and Kao state that mothers appreciate the specific groups, as it saves any 'small chatter' and allows friendships to be quickly forged through a common interest. Baker and Yang add that mothers take what they need from the groups, blogs, and forums and use the information they have learnt to their advantage.

This was certainly the case for me during my lockdown baby loss. I wanted to know exactly what to expect, and took empathy and knowledge from the lived experiences of others: even though every woman's baby loss journey is unique and individual to her and her family, reading others' stories definitely helped me, and I remain grateful to women who share their most personal thoughts.

I did read some miracle stories too, which maybe gave me some false hope along the way, but on the whole, social media supported my heart-breaking and difficult journey. When I knew medical management was the path to be taken I recalled what I had read and, although scared, I also felt prepared and less alone.

In the weeks after (and to this day) I would cry and grieve for our loss, all of a sudden there were pregnant ladies and babies everywhere. Of course they were always there, I was just noticing them now even more than normal, with pregnancy, childbirth, and babies being my passion! I kept using social media to affirm again that what I was feeling was normal, reading other experiences continued to help, and messages on forums encouraging me to be kind to myself and allow myself to grieve helped immensely.

Some friends and family knew what we were experiencing, and were incredibly supportive. However, because of Covid-19 and lockdown, they couldn't give me the hug I so needed, but were able to keep 'connected' (a theme running through all the literature I have read for my dissertation) using platforms such as Skype, WhatsApp and Zoom. This pandemic has been so hard for everyone, worldwide. Now more than ever, I believe that social media has helped friends and families stay connected and supported much of the population's mental health. People who have never used Skype or Zoom are now fluent in navigating such platforms, thus reducing some feelings of isolation.

Miscarriage, it seems, is one of the loneliest experiences you can go through. If 1 in 4 known pregnancies end in miscarriage, that's a lot of women not talking about it, and maybe that is also ok. Social media made me feel less isolated during my experience, and I aim to share it in order for other women to take comfort, support, and empathy from my story.

Julie Wall is based in Warwickshire and is the mum of three lovely children. She gained her NNEB diploma in 1997 and will finalise her BaHons in Birth and Beyond in 2021. She has worked with many wonderful families and looks forward to supporting many more in the future.

Other useful resources can be found here:

www.mumsnet.com/campaigns/miscarriage-care-campaign

www.sands.org.uk/support-you/how-we-offer-support/sands-groups

www.tommys.org/pregnancy-information/pregnancy-complications/baby-loss/miscarriage/support-after-miscarriage

References

[1] Stadlen, N. (2015) *How mothers love – And how relationships are born*. 2nd ed. London: Piatkus, pp. 10–28.

[2] Chalklen, C & Anderson, H (2017) 'Mothering on Facebook: Exploring the privacy/openness paradox.' *Social Media + Society*. doi: 10.1177/2056305117707187.

[3] Chalklen & Anderson, 2017

[4] Note from the Editor: A missed miscarriage is when the pregnancy has ended but the miscarriage has not started. 'Expectant management' means waiting for the miscarriage to happen naturally, while 'medical management' involves being given medications to begin or speed up the process of miscarriage.

[5] The Miscarriage Association (2020) *The Miscarriage Association: Pregnancy Loss Information and Support*. Available at: www.miscarriageassociation.org.uk (Accessed 15 September 2020).

[6] Chalklen & Anderson, 2017.

[7] Archer, C & Kao, K-T (2018) 'Mother, baby and Facebook makes three: Does social media provide social support for new mothers?' *Media International Australia*, 168(1): 122–139. doi: 10.1177/1329878X18783016.

[8] Baker, B & Yang I. 'Social media as social support in pregnancy and the postpartum.' Sexual & Reproductive Healthcare: *Official Journal of the Swedish Association of Midwives*, 17 (2018): 31–34.

Article

Social media and the sharing of knowledge

By Gemma McKenzie

On 10th March 1906, the British Medical Journal published an address that Dr Peter Horrocks, a senior obstetric physician at Guy's Hospital, had made to the Lambeth Division of the British Medical Association. Perhaps surprisingly, he advocated what we may now describe as a 'hands-off' labour and birth. Arguing that pregnancy and childbirth are not pathological diseases, he suggested that those practising midwifery should refrain from vaginal examinations and unnecessary interventions. He stated:

> *A woman can deliver herself safely without help of any kind in the vast majority of cases, and that the less he [doctor] interferes the better.*[1]

A slew of letters was then published from various doctors around the country both challenging and supporting Horrocks' views. Dr Mears[2] of North Shields was incensed. Apparently, he used 'chloroform and the forceps in every possible case' and 'remove[d] the placenta with [his] hand when it does not come away … within five minutes of the birth of the child' (p. 773). Dr Mears was clearly not in

favour of 'hands-off' birth, instead arguing that many women 'would only be too glad to be relieved speedily of their sufferings' by 'skilful men' (p. 773).

This debate rumbled on for weeks and I spent an afternoon reading through these letters with a mixture of horror and fascination. What struck me was the way that the male obstetricians were having this debate amongst themselves with no input from the women they were meant to be supporting. Not one woman contributed to this discussion and no doctor suggested women should be asked for their thoughts or experiences.

If we fast forward almost 120 years, we would expect that women's experiences and opinions of pregnancy and birth would have become central to maternity care. Certainly, there is rhetoric to suggest this is so.3 But the reality is that discussion around appropriate care is still very much taking place within the realms of professional academic debate. Unless invited to take part in a particular study, ordinary pregnant women and people cannot penetrate those spaces; the debates continue to take place over our heads.

There are generations of silenced women – women who were rarely permitted entry to the professions and who left little if any mark or message for the benefit of obstetric care. However, this generation could be different. Obstetric debate may still unfold in places we are not usually allowed to inhabit, but we can now more easily make our own private spaces, and this is what more women are beginning to do.

I spend too much time flicking through social media and my feeds tend to be filled with birth-related topics. What has become apparent to me is that social media has become a place where women can speak to each other about their birth experiences and plans. The Birth Trauma Association Facebook page4, for example, is populated by thousands of women who share their stories of obstetric violence and trauma. Further, when women plan to freebirth they can turn to one of several online groups for advice and support. This is the same for women having a planned caesarean for medical or personal reasons, homebirths, or any number of birthing experiences. There are now blogs and websites on all kinds of pregnancy-related topics and with some basic searching, people can watch births on YouTube in all their myriad forms. Without doubt, women are coming together online to share their birthing knowledge and experiences.

The question then arises as to whether this form of knowledge sharing creates any power or force in challenging the existing dominant narratives around childbirth. Personally, I think it can. About a year ago I watched with curiosity as an obstetrician put a post on an online maternity group with a link to an opinion piece he had written for a well-known medical journal. Reams of comments suddenly appeared on the group. Women challenged him directly; they spoke up and many openly disagreed with his views using their personal experience of birth as ammunition. It was both refreshing and intriguing to watch, and the discussion continued until quite suddenly the comments were turned off. I like to think that the obstetrician in question experienced a moment of clarity or at the very least a sense of confusion.

The knowledge deemed important to women may be different to the type of knowledge maternity professionals believe is authoritative. Lived experiences are often labelled as anecdotes and emphasis is placed on numbers and statistics. However, pregnant women's use of social media suggests that there is a deeper level of knowledge that they crave, which is often satisfied through shared storytelling, in finding people like themselves who share their views and in creating spaces that challenge dominant narratives around pregnancy and childbirth.

I wanted to find out more about Drs Horrocks and Mears, but they seemed to have slipped away into history. Remnants of both types of practice continue to exist in twenty-first century maternity care and the debate around 'hands-off' midwifery has still not been resolved. What has changed, though, is that women's voices are increasingly penetrating that debate. Continuing to share knowledge and experience is a powerful tool and social media has become a key way to do that.

Gemma McKenzie is an AIMS volunteer and is currently undertaking doctoral research at King's College, London on women's experiences of freebirth

References

1 Horrocks, P (1906) 'The midwifery of the present day.' *British Medical Journal,* March 10: 542.

2 Mears, FC (1906) 'Correspondence.' *British Medical Journal*, March 31: 773.

3 National Maternity Review (2016) Better Births. https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf *(Accessed 10 September 2020).*

4 Birth Trauma Association – UK www.facebook.com/Birth-Trauma-Association-UK-496299280533226/

Article

Pregnancy apps and social media – are we being watched?

by Frances Attenborough

Editor's note: *We are all to a greater or lesser extent, wittingly or unwittingly shaped by the society in which we live, and when society moves online, this continues to be true. In her potentially controversial article, Frances Attenborough gives an account of what the literature has to say about the hidden forces at play in our use of social media, forces that may not always be to the benefit of the user. With more awareness of these issues, Frances believes that women, as they become mothers, can experience increased agency and satisfaction in their online lives.*

Pregnancy apps and social media – are we being watched?

Pregnancy is a time of change for many women. McMahon describes it as a process of *becoming*, of exploration into and trying on of motherhood. Whereas previously pregnant women might have turned to others around them for support and information, nowadays many women turn to apps and social media for these things and to help with decision-making. In this article, I'm considering both apps specifically targeted at women as 'pregnancy apps' and social media apps that pregnant women happen to use. This is a world of convenient, reassuring information and easy connection with others, which has real importance for maternal well-being, particularly in times of a pandemic. Just as Das argues that there are potential downsides to the social networking side of app use in the perinatal period, are there other potential hazards that women might want to be aware of? In this article I shall be considering the potential surveillance concerns around app use and what the consequences might be.

As John Donne wrote, '*no man is an island*'; we are all of us products of our culture. Social learning theories postulate that as a social species, we learn by observing and imitating those around us. As Yate describes, 'we […] copy those around us and seek their approval, even if it costs us our health.' Thus, as we spend more time using social media, we become more absorbed into the culture that is there. What is more, this is a world that we are increasingly comfortable with, as it becomes the new normal. For example, pregnancy apps frame it as normal to track every aspect of a pregnancy and to share this with others. In the world of social media, we are encouraged to share our personal stories and feelings; they are meant to be viewed. We become 'object[s] of surveillance.' Furthermore, the observers are invisible, with no way of knowing who is watching. Parallels can be drawn with Bentham's Panopticon.

The Panopticon was originally a theoretical prison constructed so that one person (the guard) could see all the prisoners without the prisoners knowing whether or not they were being watched. As a result, the prisoners would change their behaviour. Michel Foucault identified that all hierarchical systems follow this power structure; those with lower status conform through self-policing just in case they are being watched by those with power. Elmer explores how this theory can be applied to an online world with surveillance at its heart. Couch *et al.* suggest that the panopticon works in a symbiotic relationship with the synopticon, where the many gaze upon the few, such as when we read or watch media stories about celebrities or reality TV programmes. This becomes a form of social control because it is those with power that are presenting stories to be consumed by the masses that fit with their agenda. The spectacle inherent in these stories (to make them entertaining) warps what could be considered normal. For example, consider how childbirth is portrayed in reality TV shows such as '*One born every minute,*' with its bias towards the normalisation of medicalised birth and lack of

consent. Mitrou *et al.* use the term 'omniopticon,' in which the many watch the many, to describe social media. We are all expected to watch and comment on each other, to judge others and to be judged.

These three systems are able to work together to maintain a hegemony because humans are a social species. Our place in the hierarchy is determined by how popular we are. When our social status decreases, our cortisol levels go up; the reverse is also true. Now we can quantify exactly what our social status is by how many 'likes' we get. As more and more gets shared, it becomes necessary to provide ever more 'spectacle' to keep getting noticed and liked. Not only can we create an online identity that is more than ourselves, the ourselves we aspire to, but it becomes necessary to do so, in order to fit in.

I have chosen to concentrate on how apps and social media change women's expectations because our society is both patriarchal and misogynistic. Women are constantly judged from a young age, usually as wanting. This judgement continues when a woman becomes a mother. Taylor describes the 'Madonna-whore complex' through which women are either considered as 'mothers' (nurturing and selfless) or 'whores' (promiscuous and sexual). Yate places Western society's image of motherhood in a historical context, explaining how the 'cult of maternity' developed in the 18th century. In the cult of maternity, a mother's primary concern should be to nurture her child, and thus all her needs are met through this act. A mother's love is absolute and seen as the 'highest form of love'. This ideal of motherhood puts mothers on a pedestal and yet at the same time all of society's ills are laid at their door. Our culture presents it as a pregnant woman's duty to protect her baby at all costs and woe betide her if she gets something wrong – that makes her a 'bad mother.' It is seen as a citizen's duty to criticise a pregnant woman in public, thereby enabling the mother to become a better mother. Various authors noted that pregnancy apps reinforce cultural stereotypes (for example, finances are covered much more in pregnancy apps targeted at fathers) and pregnancy and birth are portrayed in a way that reinforces the cultural view that they are risky processes. Furthermore, they depict as essential that a woman achieves a perfect pregnancy. Thomas and Lupton argue that whilst using apps can be beneficial for pregnant women, being a source of support and information, they can also increase anxiety and feelings of self-responsibility and blame.

As a result, a pregnant woman will then strive to do things 'right', to be a 'good mother'. The literature describes a pregnant woman as being considered a 'good mother' if she is seen to: comply with and submit to doctors, accept that her body will not be enough, always put the baby (and others) first no matter what the cost to her, be solely responsibility for the baby's safety, and accept that she will always be watched and judged by others. If she does not display how good she is, she will be judged to be irresponsible and neglectful. These issues have been further exacerbated during Covid-19 restrictions. Apps situate themselves as providing 'the answer', helping a woman to be a 'good mother' yet all the while reinforcing the status quo and gendered stereotypes because it helps to increase in-app purchases or advertising revenue. It is in the interest of an app developer to make their app appealing and addictive, and for users to be compliant and willing.

Whilst it can be argued that posting on social media can be empowering as the user controls what is posted, the panopticon / omniopticon theory reminds us that posts are always subject to self-monitoring because if something isn't liked, the user's status is lowered. Social media is creating a world that has the appearance of being a place of freedom and self-expression, yet it is really reinforcing the existing hegemony. Thus, whilst birth is generally celebrated, women are shut down by others for having the 'wrong' birth. The effects are toxic; for example, as more dramatic births get shared and seen as normal, tokophobia increases.

Apps are big business, despite users being unwilling to pay much for them upfront. The majority of apps (including those targeted at pregnant families) are owned by commercial companies, which includes breastmilk substitute manufacturers. Users state that they would rather avoid such apps; however, Haddad *et al.* found that apps developed by health care providers tended to have unfriendly user interfaces and to have ignored the complex systems and work processes that they are trying to ease.

Some apps have been developed either by or to be used in conjunction with health care professionals and providers. It is noticeable that the benefits of these apps are given in terms of benefits to health care professionals and providers, such as how well women conform to the system, not in

terms of outcomes for mothers and babies. Looked at through the lens of the panopticon, it is a clear example of how apps reinforce the current hegemony, with little regard to the mother.

As internet use has increased, so too has awareness of the dangers of sharing information online. App developers make money by selling on harvested data; the user **is** the commodity. Research by Zimmeck *et al*. demonstrates that a significant proportion of apps do not have privacy policies, and of those that do, when the code was scrutinized it was found that many of the apps did not follow them. Liao *et al.* suggest that there may be similar issues with voice-operated apps. It is not easy to opt out of sharing data without compromising the functionality of the app, something Barassi describes as coercion. Risks can also come from family and friends unthinkingly sharing information without permission. Hargittai and Marwick found that users are aware of these risks and how hard it is to avoid them. During pregnancy, parents not only share their own data, but also that of the baby. The baby has been forced into having an online presence before they are even born.

What we see in apps and on social media feeds is controlled by algorithms created by app developers, as per the synopticon. Furthermore, the data we share affects these algorithms, potentially forming a feedback loop of what we share being influenced by what we have seen, and in turn influencing what we will see.

The friend in your phone is always there, always watching, and as Lyons points out, it fits in around your daily life. The friend in your phone pushes notifications at you, encouraging you to share more, to personalise more, to develop reliance upon it. Users prefer apps that are personalised, even though this comes from sharing more with them.

App users are often aware that their data will be shared with all and sundry. Women report feeling 'used' by apps. As Sacacas observes, app users balance the gains they make from the app against the privacy risks, with users being more likely to share data when it is seen as being socially relevant. The only alternatives to sharing are to try to circumnavigate the app settings or to not use the app at all. Not using an app comes with its own problems, however. Withdrawal / non-use can be seen as being selfish or a bad mother, because the woman is opting out of what is seen as the best possible care. During lockdown, social media has become a literal lifeline for some. Contributing on a social forum can enhance a person's reputation and increase their feelings of personal satisfaction because they have helped someone else. Johnson points out that mothers can gain self-worth through their virtual, shared pregnancy. Those seen to be paying close attention to the development of their baby and to be sharing this are seen as being an appropriately caring and responsible mother.

On the other hand some argue that sharing information about the baby is problematic, in part because the baby has not consented. By suggesting to a mother that she not use an app because it may put her unborn baby's data at risk, I may be contributing to the societal norm that puts her baby's needs above her own, when I hold strongly that this is her decision, and hers alone. However, it can only be a conscious decision, when the mother is aware of the debate

So what conclusions can we draw? No app is neutral; there is always an agenda behind the development of an app. Whilst some apps are purely commercial, others are developed to meet a need that someone thinks women have; for example, those developed by health care providers, ostensibly to reduce inequality. All involve monitoring the woman in some way. Using the lens of the panopticon, it becomes clear how observation changes the way people behave: they comply with the societal norms in order to be liked, to feel good about themselves and because they see the benefits as outweighing the risks. The consequences for pregnant women around consent, informed decision-making, expectations of birth, and mental health have the potential to be detrimental, but so does not joining in. Acknowledgement of the hidden forces at play within social media, is not to frame women as victims. Increased awareness strengthens women's agency and enables them to navigate those forces to their own good. It seems to me the way forward may be in creating spaces where realism flourishes and where women can 'build their village', communicating together through social media with an even greater sense of control, autonomy and satisfaction.

Frances Attenborough lives in the North West of England and originally pursued a career in Materials Science before having children and realising that supporting mothers was much more worthwhile.

References

1. McMahon, M (2018) *Why mothering matters*. London: Pinter & Martin, p. 11.
2. Moon, RY, Mathews, A, Oden, R & Carlin, R (2019) 'Mothers' perceptions of the internet and social media as sources of parenting and health information: Qualitative study.' *J Med Internet Res*, 21(7): e14289. doi:10.2196/14289.
3. Lyons, A (2020) 'Negotiating the expertise paradox in new mothers' WhatsApp group interactions.' *Discourse, Context & Media*, 37: 100427. doi:10.1016/j.dcm.2020.100427; Sanders, RA & Crozier, K (2018) 'How do informal information sources influence women's decision-making for birth? A meta-synthesis of qualitative studies.' *BMC Pregnancy and Childbirth*, 18: 21. doi:10.1186/s12884-017-1648-2.
4. Das, R (2020) COVID-19, *perinatal mental health and the digital pivot*. Available at: http://epubs.surrey.ac.uk/857117/1/COVID-19%2C%20Perinatal%20Mental%20Health%20and%20the%20Digital%20Pivot.pdf (Accessed 29 September 2020).
5. Yate, Z (2020) *When breastfeeding sucks: What you need to know about nursing aversion and agitation*. London: Pinter & Martin, p. 108.
6. Sacacas, LM (2018) 'Personal panopticons: A key produce of ubiquitous surveillance is people who are comfortable with it.' Real Life, 5 Nov. Available at: https://reallifemag.com/personal-panopticons/ (Accessed: 18 August 2020).
7. Thomas, GM & Lupton, D (2015) 'Threats and thrills: Pregnancy apps, risk and consumption.' *Health, Risk & Society*, 17(7–8): 495–509. doi:10.1080/13698575.2015.1127333.
8. Mitrou, L, Kandias, M, Stavrou, V & Gritzalis, D (2014) 'Social media profiling: A panopticon or omniopticon tool?' *Proceedings of the 6th conference of the surveillance studies network*, Barcelona, 24–25 April, pp. 1–15.
9. Kandias, M, Mitrou, L, Stavrou, V & Gritzalis, D (2013) 'Which side are you on? A new panopticon vs privacy.' *Proceedings of the 10th International Conference on Security & Cryptography* (SECRYPT), Reykjavik, Iceland, 29–31 July.
10. Foucault, M (1977) *Discipline and punish: The birth of the prison,* trans. A Sheridan. New York: Pantheon Books.
11. Elmer, G (2003) 'A Diagram of Panoptic Surveillance.' *New Media Society*, 5: 231–247. doi:10.1177/1461444803005002005.
12. Couch, D, Han, G-S, Robinson, P & Komesaroff, P (2015) 'Public health surveillance and the media: A dyad of panoptic and synoptic social control.' *Health Psychology and Behavioural Medicine*, 3(1): 128–141. doi:10.1080/21642850.2015.1049539.
13. De Benedictis, S, Johnson, C, Roberts, J & Spiby, H (2019) 'Quantitative insights into televised birth: A content analysis of One Born Every Minute.' *Critical Studies In Media Communication,* 36(1): 1–17. doi:10.1080/15295036.2018.1516046
14. Mitrou *et al.*, 2014.
15. Lupton, D & Williamson, B (2017) 'The datafied child: The dataveillance of children and implications for their rights.' *New Media & Society*, 19(5): 780–794. doi:10.1177/1461444816686328.
16. Gerhardt, S (2015) *Why love matters: How affection shapes a baby's brain*. 2nd ed. London: Routledge.
17. Couch *et al.*, 2015.
18. Perez, CC (2019) *Invisible women: Exposing data bias in a world designed for men*. London: Chatto & Windus; Taylor, J (2020) *Why women are blamed for everything: Exposing the culture of victim-blaming*. London: Constable.
19. Taylor, 2020, p. 28.
20. Yate, 2020, p. 28.
21. Richardson, SS, et al. (2014) 'Society: Don't blame the mothers.' *Nature,* 512(7513): 131–132. Available at: www.nature.com/news/society-don-t-blame-the-mothers-1.15693 (Accessed: 25 October 2020).
22. McMahon, 2018, p. 113.
23. Thomas & Lupton, 2015.
24. Hughson, JP et al. (2018) 'The rise of pregnancy apps and the implications for culturally and linguistically diverse women: Narrative review.' *JMIR Mhealth Uhealth*, 6(11): e189. doi:10.2196/mhealth.9119; Lupton & Williamson, 2017; Thomas & Lupton, 2015. J
25. ohnson, SA (2014) '"Maternal devices," social media and the self-management of pregnancy, mothering and child health.' *Societies*, 4(2): 330–350. doi:10.3390/soc4020330; Thomas & Lupton, 2015.
26. Thomas & Lupton, 2015.
27. Cummins, MW (2014) 'Reproductive surveillance: The making of pregnant docile bodies.' *Kaleidoscope,* 13: 33–51; Lupton & Williamson, 2017; Thomas & Lupton, 2015; Couch et al., 2015.
28. Das, 2020.

29. Cummins, 2014; Sacacas, 2018.
30. Kedzior, R & Allen, DE (2016) 'From liberation to control: Understanding the selfie experience.' *European Journal of Marketing*, 50(9/10): 1893–1902. doi:10.1108/EJM-07-2015-0512.
31. Das, R (2017) 'Speaking about birth: Visible and silenced narratives in online discussions of childbirth.' Social Media + Society, Oct. doi:10.1177/2056305117735753.
32. Wang, N et al. (2019) 'Understanding the use of smartphone apps for health information among pregnant Chinese women: Mixed methods.' *JMIR Mhealth Uhealth*, 7(6): e12631. doi:10.2196/12631.
33. Szinay, D *et al*. (2020) 'Influences on the uptake of and engagement with health and well-being smartphone apps: Systematic review.' *J Med Internet Res*, 22(5): e17572. doi:10.2196/17572.
34. Hastings, G, Angus, K, Eadie, D & Hunt, K (2020) 'Selling second best: How infant formula marketing works.' *Globalization and Health*, 16(77). doi:10.1186/s12992-020-00597-w.
35. Hughson *et al*., 2018.
36. Haddad, SM, Souza, RT & Cecatti, JG (2019) 'Mobile technology in health (mHealth) and antenatal care – searching for apps and available solutions: A systematic review.' *International Journal of Medical Informatics*, 127(July): 1–8. doi:10.1016/j.ijmedinf.2019.04.008.
37. Carter, J, Sandall, J, Shennan, AH & Tribe, RM (2019) 'Mobile phone apps for clinical decision support in pregnancy: A scoping review.' *BMC Medical Informatics and Decision Making*, 19: 219. doi:10.1186/s12911-019-0954-1; Haddad *et al*., 2019.
38. Yao, MK, Rice, RE & Wallis, K (2007) 'Predicting user concerns about online privacy.' *Journal of the American Society for Information Science and Technology*, 58(5): 710–722. doi:10.1002/asi.20530.
39. Haddad *et al*., 2019.
40. Zimmeck, S *et al*. (2019) 'MAPS: Scaling privacy compliance analysis to a million apps.' *Proceedings on Privacy Enhancing Technologies*, 2019(3): 66–86. doi:10.2478/popets-2019-0037.
41. Liao, S *et al*. (2020) 'Measuring the effectiveness of privacy policies for voice assistant applications.' arXiv:2007.14570v [cs.CR], 29 July.
42. Barassi, V (2017) 'BabyVeillance? Expecting parents, online surveillance and the cultural specificity of pregnancy apps.' *Social Media + Society,* April. doi:10.1177/2056305117707188.
43. Hargittai, E & Marwick, A (2016) '"What can I really do?" Explaining the privacy paradox with online apathy.' *International Journal of Communications,* 10: 21.
44. Barassi, 2017; Johnson, 2014.
45. Lupton & Williamson, 2017.
46. Lyons, 2020.
47. Johnson, 2014.
48. Szinay *et al*., 2020; Wang *et al*., 2019.
49. Wang *et al*., 2019.
50. Sacacas, 2018.
51. Hargittai & Marwick, 2016.
52. Hargittai & Marwick, 2016.
53. Johnson, 2014.
54. Das, 2020.
55. Lyons, 2020.
56. Johnson, 2014.
57. Thomas & Lupton, 2015.
58. Johnson, 2014; Thomas & Lupton, 2015.

Article

Oxfordshire Breastfeeding Support & Social Media

by Jayne Joyce, IBLC, Project Lead

The OBS facilitators: Charlotte Gilman, Julie Gallegos, Lisa Mansour and Jayne Joyce (left to right)

Online feeding support is not for the faintheartedIf we'd known back in 2012 what would be involved in running our brand-new Facebook group – the sheer hard work, occasional panic, and frequent frustration – would we still have done it? We were fortunate not to have walked into it blindly, but with experience and guidelines from La Leche League. Over the last eight years, Oxfordshire Breastfeeding Support (OBS) has given high quality feeding help via Facebook to thousands of women and has fostered a virtual community that has proven especially invaluable during the pandemic. I hope that by sharing some of our learning, we can, in turn, help others to count the cost and provide excellent support.

OBS is a small independent charity that provides feeding support to any family resident in Oxfordshire or whose baby was born here.[1] We have a team of self-employed facilitators (three of whom are IBCLCs), a superb Board of Trustees, and two dozen or so volunteers: peer supporters, breastfeeding counsellors, and health professionals who volunteer their time. Funding comes from a range of sources including trusts, grants, donations from service users, fundraising events, and major donors. In 2019, we were awarded the largest ever grant to an infant feeding organisation by the National Lottery Community Fund, which will enable us to develop our service over the next five years. Pre-Covid, we ran six drop-ins per week around the county and offered support via our private Facebook group.

It's easy to set up a Facebook group with a few clicks, but running one responsibly – ensuring quality of care and a safe, supportive environment – takes considerable effort. Ours has very high levels of user satisfaction (based on two independent impact assessments)[2] and an excellent local reputation. So, what works in online support?

Decide the parameters

Successful Facebook groups will grow. Our current membership is approximately 2200 (up from 1700 at the start of the pandemic). Decide from the outset what your boundaries are. Who is the group for? Can partners and co-parents join? How about health professionals, relevant private practitioners, students, or academic researchers? *We limit our membership to "anyone in Oxfordshire who is pregnant, breastfeeding/providing their own milk for their baby, or who is not currently breastfeeding/providing their own milk but is aiming to do so."* We allow health and allied professionals and students to join as observers, but not to post or respond in their professional capacity. We don't include fathers, non-lactating co-parents, or researchers in our Facebook support group, but have started a second "Friends of OBS" group where they are welcome, and we have a public

1 For our full Mission and Vision, see www.oxbreastfeedingsupport.org/index.php/aboutus/mission

2 www.oxbreastfeedingsupport.org/images/OBS_ImpactAnalysisReport_2020.pdf and www.oxbreastfeedingsupport.org/images/OBS-Impact-Report_full.pdf

Facebook page they can follow. It is tempting to allow people beyond our remit to join because they are friends of current members, or because they need help and we like to be helpful. But we do not have time or funding to provide breastfeeding support to the entire planet (we signpost to La Leche League for that). Agree your boundaries and stick to them.

Set clear ground rules

Facebook has functionality for setting group rules and requiring prospective members to agree to them. Think carefully about what you will and won't allow in your group and write it down: in the rules, in the group description, and in a pinned post at the top of the group. Bullying, discrimination, and antisocial behaviour will not be permitted, of course. How about advertising? Will you allow mothers to name, tag, or criticise health professionals or other individuals, or professionals to post or respond with their work "hats" on? How about diluting the focus of the group: Can members give away or request equipment, feeding-related or otherwise? Recommend specific products? Go off on tangents unrelated to the group's purpose? We don't permit any of these in our group and have developed Conflict of Interest and Commercial Activities policies to strengthen our commitment to keeping our service a space that is free of any commercial influence.[3] Members who have been in our group for a while know the rules and often report breaches before admins are aware. You can fine-tune your rules as you go along in response to common issues. If there is a clear rule with a sanction, you can deal with any breaches. If there is no rule, you are not in a position to act, even if you don't like the behaviour.

Put the hours in

Facebook groups look superficially attractive as a low-energy support option which "runs itself". They don't. Beneath the calm surface of an effective Facebook group, admins are paddling vigorously. If you set up a group and leave it, you are likely to end up with members giving inaccurate information and unhelpful advice, being targeted by advertising, being shamed for their feeding stories and, at worst, getting badly hurt (and blaming you).[4] The stakes are high. Infant feeding is – partly due to sophisticated strategy on the part of the formula industry[5] – a deeply contentious subject which can leave feelings running high. If you want your group to provide good care, someone has to be responsible for making sure that it is provided, that the group stays focused, and that group rules and ethos are respected. Admins set the tone in how they respond to posts. We train our volunteers to "provide emotional care first", rather than simply replying at the informational level. Inaccurate information needs to be challenged, or at least, accurate information needs to be provided – you don't want families saying, "but I heard it on X group….". Some groups delete inaccurate posts or responses. We prefer a gentler approach, ensuring that every post receives an empathic response and evidence-based information from our team, without shaming members who have posted incorrect information or unhelpful suggestions. Things can go wrong quickly on Facebook. An unkind or careless comment can escalate into an incident which damages everyone, including your reputation. Feeding support groups need to be closely monitored, with admins available to deal promptly with any issues. This is not realistic without a reliable team. Facebook has options for admins to pre-approve all posts before they are made public. If capacity to monitor the group is limited, this is a safe option. It is your group – you are responsible for its quality and content.

Share the load

One person cannot manage a Facebook group, unless all posts and responses are pre-approved and the pace is very slow. Feeding is a very time-sensitive business; mothers need responses quickly. Our team ideally has two IBCLCs sharing responsibility, with one being "on duty" on any given day. This means keeping an eye on the group from first thing in the morning until bedtime. In the evenings Facebook is typically busiest, and new parents at their most desperate. Most posts receive a direct response from one of the IBCLC facilitators. Increasingly, as their skills and confidence grow, our volunteers turn into "first responders", with facilitators being tagged by volunteers for additional help with more complex queries. We support our volunteers to develop their online helping skills and we encourage all who are confident in this format to do as much as they can. Facilitators check

3 www.oxbreastfeedingsupport.org/index.php/aboutus/policies

4 Regan S & Brown A (2019) "Experiences of online breastfeeding support: Support and reassurance versus judgement and misinformation." *Maternal & Child Nutrition*, 15(4), pubmed.ncbi.nlm.nih.gov/31299699/

5 globalizationandhealth.biomedcentral.com/articles/10.1186/s12992-020-00597-w

and add new members and deal with misinformation or infringement of group rules. If necessary, we delete posts or responses and contact the poster by private message (PM) to explain why this action was taken. The ultimate sanction is to remove a member from the group – we have only resorted to this a couple of times. "Facebook burnout" is a well-known risk in the lay breastfeeding support organisations, who have blazed the trail in online support. For the first time this year, after five months of intense Facebook activity triggered by lockdown, we "archived" (temporarily closed) our Facebook group for a fortnight, to give the team a complete break. In the long term, we need more of our team to step up and share the supervisory load, which is mostly carried by one person, or perhaps to bring in another IBCLC specifically to help with Facebook.

What do mothers say? – Voices of OBS Facebook group members

"It's given a sense of community at a time when we can't see our support network face to face".

"You have helped me keep my sanity during the trickier times when no one else was available to help".

"Everything I know about breastfeeding I know from here :) all the problems I ever had were solved quickly thanks to advice I got here."

"The Facebook support from the OBS team and the members of the group were indispensable in a time of full lockdown, no relatives in this country, no breastfeeding friends and no other peer support. It was a reliable community I could turn to at ANY time during the day and night!"

"There is always someone awake, no matter what time at night, the OBS Facebook support has meant that I am never alone. I have never had a message from anybody, facilitator or other group member, that didn't make me feel connected, cared for and supported. I am grateful for the expert support and advice always delivered with love and I will be breastfeeding to one year and beyond because of it."

"It's meant [that] throughout lockdown and when I've been unable to go out with a vulnerable premature baby, I've felt connected with other women, mothering alongside me, providing solidarity and understanding, caring support, and wisdom. It's meant [that] when exclusively feeding from the breast felt impossible, there were people encouraging me... It's meant having a place to celebrate highs and lows".

"*At the moments of total parenting and breastfeeding despair, fear, frustration, exhaustion and burnout there was someone at the other end nurturing and soothing... It showed the best of local people and I felt connected and belonging."*

Conclusion

Mothers enjoy the sense of connection with a virtual community, particularly at a time when other supports, both informal and professional, may be difficult to access. They value the immediacy, the quick responses round the clock. They appreciate the emotional care given by the team and other mothers, beyond factual information. All of these take thought, skill, and time – lots of time, often at hours when we might rather not be working. It isn't an easy option, but it is a useful strand in feeding support, for a generation who have grown up with mobile phones. Our next challenge will be to figure out how to reach the next generation of younger mothers. They are opting for more visual, transient platforms like Instagram or Snapchat, which don't lend themselves to text-based large group conversation.

Jayne Joyce

Jayne has a MSc in Applied Social Studies from the University of Oxford and began her professional life as a social worker, with a particular interest in adoption.

She has been a La Leche League International Leader since 2003 and an IBCLC since 2011.

She is Project Lead at Oxfordshire Breastfeeding Support (OBS).

OBS
OXFORDSHIRE BREASTFEEDING SUPPORT
Supporting your family from pregnancy to weaning

Article

My experiences of supporting breastfeeding women with inflammatory bowel disease (IBD) via social media

by Wendy Jones,
PhD MRPharmS MBE

'Scientific, evidence-led information which is very up to date and relevant, and … better informed than some doctors'

(Member of 'Breastfeeding with IBD' Facebook group)

For the last 40 years, I have had a passion for breastfeeding, and as a pharmacist, I first began looking more closely at the safety of drugs in breastmilk 25 years ago. I began writing about the topic in 1995, when the internet was in its infancy and finding data was difficult. I also began a PhD looking at the experiences of mothers, pharmacists, and doctors in a matched area. Not totally unsurprisingly, there was little agreement. Professionals lacked – and to a large extent still do lack – training on this topic. They based answers on their personal experience – good, bad, or indifferent. I had comments like 'I couldn't possibly ask a mother about breastfeeding; it's far too personal,' or 'if a mother insisted on breastfeeding on medication, I'd report her to social services.' It worried me a lot.

Whilst I was conducting my research and writing my thesis, the Breastfeeding Network (BfN) was formed and I became a founder member of it, leaving the National Childbirth Trust with whom I had trained. One of the first things the BfN did was to fund a telephone line for me to take questions about drugs in breastmilk (up until then, they had come in on my home telephone, so they were often answered by other members of my family). That line continued until about five years ago, and it has now been replaced by social media and emails. Over the last two years, there have been around 10,000 contacts a year handled by me and another pharmacist who supports me one day a week.

'This group offers support & ladies that just "get it" ... especially at times when I have needed it the most'
Member of 'Breastfeeding with IBD' Facebook group

I began to recognise that there were a lot of contacts about inflammatory bowel disease – ulcerative colitis (UC) and Crohn's disease. This echoed in my head because I was diagnosed with Crohn's back in 1976, when I was just 22 years old. I have subsequently had three daughters and have never been healthier than when I was pregnant or breastfeeding – hence the passion for breastfeeding. I was lucky enough not to need medication when I was breastfeeding. However, I have had to have three bowel resections over the years. This is where a surgeon removes an affected segment of gut and then re-joins it again. Each time, I had to sign an agreement to have a stoma if necessary, something which terrified me in my younger age. It is major surgery, and I needed a lot of support from my husband and my mother.

So, in 2016, I set up a Facebook page called 'Breastfeeding with IBD (UC and Crohn's)' and invited people who messaged me with questions about drugs in breastmilk to join. It has grown and grown beyond my wildest imagination. As of this month, we have over 1,200 members from across the world, with the age range predominantly from 25 to 44 and 99% female.

'The opportunity to ask questions about practical, day-to-day issues is invaluable'
(Member of 'Breastfeeding with IBD' Facebook group)

In my mind, when I set up the group, it was somewhere to talk about poo! Those of us with IBD frequently suffer from urgency, so our babies and toddlers get used to having to come with us. One of the topics discussed has been having a bouncy chair ready in the loo 'just in case.' However, it has developed into so much more. It is a place where people ask for suggestions for food to tolerate when ill and encouragement when they feel they need it, but above all (and I guess because of me) a place to seek information on the compatibility of drugs and investigations with breastfeeding. Many health professionals have also joined in order to access the information, although they rarely post!

'A great mix of personal experience and scientific data'
(Member of 'Breastfeeding with IBD' Facebook group)

When I was asked to write this, I turned the question to the group and felt very humbled by the responses:

'I have found this group immensely helpful. I only wish I had found it a lot earlier. For me it is not usual to know other people who suffer from IBD, so the opportunity to ask questions about practical, day-to-day issues is invaluable and doesn't occur anywhere else for me. This group provides scientific, evidence-led information which is very up to date and relevant, and, I have found, better informed than some doctors, who do not always know or understand intricacies of breastfeeding and use of prescription medications.'

'This group helps me feel supported and less alone. The chance of me finding another pregnant or breastfeeding mum with IBD in my local area seems quite slim, especially without social media, so this group makes me feel less alone with that. I also feel that if I needed to increase my medication or go for a colonoscopy etc. I would feel so much more confident challenging any advice to not breastfeed that I was given.'

'This group and the advice and information you have provided, Wendy, is invaluable. I don't think I would have breastfed for as long as I have (eldest daughter 14 months & currently youngest daughter still breastfeeding at 12 months) without it. Definitely more knowledge in terms of IBD & breastfeeding & medication etc. than the health care professionals that I have seen – from nurses to GPs to consultants. All my friends that have breastfed or are going to breastfeed (IBD or not) I have pointed in the direction of your drugs factsheet, along with said professionals. I feel that this group offers support & ladies that just "get it" ... especially at times when I have needed it the most & would have otherwise felt lost & alone.'

'It's a safe haven to ask questions and get answers from people's experience. No one judges. It's good to know there are people who are sailing in the same boat and some have sailed safely when you are feeling the journey is rough. Gives hope and positivity to get through difficult times we have with the disease.'

'It's a Godsend group. Extremely helpful.'

'This group is amazing. Everyone is always so helpful. … It's a great mix of personal experience and scientific data. My old GI [gastroenterologist] was so misinformed on medications while breastfeeding. … I was told I couldn't breastfeed on prednisolone; I was told I couldn't breastfeed on my drugs. I was told I had to pump and dump through my entire colonoscopy prep and for 24–48 hours after the procedure. I was so fortunate to have this group as a resource. I truly feel I never would have achieved 14 months of breastfeeding if I hadn't found this group.'

'The support of online groups is invaluable. It's very useful having people who have been through similar experiences give advice especially when doctors often don't have enough specialist knowledge about certain conditions and medications and breastfeeding.'

These are the words that probably sum up what I had hoped for initially:

'I have never really been able to connect to anyone in person with IBD except in passing. In social media groups I am able to speak openly about struggles, fun yet gross moments that are relatable to others, and ask for valuable support and advice. I find not only support, but community!'

'This group helps me feel supported and less alone'

Social media puts us together in a place with other like-minded people – if you are in the right group! As one comment said, breastfeeding can make you feel alone. Having IBD definitely makes you alone, as no one can see that you have a chronic medical condition, but it affects every bit of your life.

The role of social media and chronic medical conditions

Since I was first diagnosed 44 years ago, because of my resections, my tummy is not pretty! My resections also caused me to develop peripheral vascular disease, which normally only occurs in elderly, overweight people who have smoked and who have therefore laid down cholesterol in their legs. At one stage, I couldn't walk 50 yards, and my consultant told me I would lose a limb within five years and be dead within ten. I can now walk long distances (though only slowly uphill) by opening up small blood vessels to bypass the blocked ones. I bought two Border Collies who needed exercise and they saved my life. Three years ago, I was diagnosed with a melanoma on my heel – not from sunburn, but due to my medication. I had major surgery and have a large hole where the mole was removed, but a six-month delay might have meant a spread and a less positive outlook. In the current pandemic, my medication meant I was in the shielding population, so I missed seeing my daughters and grandchildren from March to August. This is a disease with so many ramifications; we need each other in the special place that our group provides.

I set up the group to help others in the place I had been, but now I get support from them. It feels like they are all my daughters, and I do tend to respond as such! That the group has spread across the continents is amazing: the problems are just the same.

'I find not only support, but community'
Member of 'Breastfeeding with IBD' Facebook group

A few years ago now, several of us were interviewed by *Connect*, the magazine of the Crohns and Colitis Association (https://www.crohnsandcolitis.org.uk/)[2]. An amazing report resulted, and we were all proud. We were over the moon when the magazine won Member Magazine of the Year and Cover of the Year at the PPA Scottish Magazine Awards against competition from the *Beano* and the *Big Issue*. The cover normalised not just breastfeeding and IBD, but long-term breastfeeding and IBD. What more could I have ever asked?

A member commented: 'I just wanted to say how uplifted I was to open the envelope containing Connect magazine and see the feature on breastfeeding and IBD on the cover. There is so much misunderstanding about medication and breastfeeding so it's just great to see this.

If you know someone who has Crohn's disease or colitis, please signpost them to us: https://www.facebook.com/groups/BreastfeedingIBD.

If you know an interested professional, they are welcome to join, but they will need to explain why when applying so that I can keep the group safe.

I am very proud of what we have achieved together in four years. I wish I could set up groups for everyone with a chronic condition to provide information about medication and breastfeeding, but I can't, which is why the title of my latest book reflects that, Breastfeeding and Chronic Medical Conditions.

Thank you for listening to my thoughts about IBD and I hope you have learned just a little more. Thank you too for the members of the group whose words I have used.

Countries with the most members of the 'Breastfeeding with IBD' Facebook group:

United Kingdom	695
USA	283
Ireland	58
Australia	47
Canada	39
Belgium	17
Slovakia	15
New Zealand	11
Germany	5
Romania	3

Age range of members (%):

18-24	5
25-34	50
35-44	40
45-54	3
55-64	2
65+	1

References

1 Jones, W & Brown, D (2000) 'The pharmacist's contribution to primary care support for lactating mothers requiring medication.' Journal of Social and Administrative Pharmacy, 17(2). Available at: www.researchgate.net/publication/289301609.

2 www.crohnsandcolitis.org.uk

Wendy was one of the founder members of the Breastfeeding Network. In her employed life, she was a community pharmacist and also worked in doctors' surgeries supporting cost-effective, evidence-based prescribing. Wendy left paid work to concentrate on writing her book Breastfeeding and medication (Routledge 2013, 2nd edition 2018), developing information and training material on drugs in breastmilk as well as setting up her own website, www.breastfeeding-and-medication.co.uk. She has also published Breastfeeding for dads and grandmas (Praeclarus Press, 2016), Why mothers' medication matters (Pinter and Martin, 2017), and most recently A guide to supporting breastfeeding for the medical profession (Routledge, 2020), co-authored with Professor Amy Brown. She was awarded a Points of Light award in May 2018 and was delighted to be nominated for an MBE in the New Year's Honours List 2018 for services to mothers and babies, receiving her award in May 2019.

Article

AIMS and Social Media

by Julie Ann Crowley

Long gone are the days when AIMS relied on people stumbling across our website online through search engine queries, or word-of-mouth between birth workers at a recent birth or antenatal event. Although these routes continue to contribute to our reach, AIMS is seeing great exposure and engagement as a result of having a dedicated social media team. Our creative minds and the fantastic software at our fingertips allow us to create really attractive and engaging posts, using images of women and birthing people from all walks of life.

This year started off with a heavy focus on recruitment. In order to achieve the maximum reach across social media, we required more volunteer team members. Our plans to expand the team got off to a great start, with the help of social media itself! Instead of relying on word-of-mouth and advertisements on the website alone, we used our platforms to advertise volunteer posts across the whole of Facebook and Instagram. We found that groups that already have a personal interest in maternity services, such as student midwife communities and Maternity Partnership Voices groups around the country, have been the best breeding grounds for recruits of late. New volunteers Lizzie and Ellie joined us in September and you will see their personal touches on AIMS posts from now on.

Volunteering for the AIMS Social Media team requires a set number of hours dedicated to administering requests, analysing responses, and retrieving information from a variety of resources in the fields of medicine, NHS policies, and personal experiences in maternity services. Since we are all people with young and older families and other jobs and responsibilities, the only way to ensure that the team can commit to a set number of hours is to increase the headcount. Personally, as a single mother with a baby son and an 8-year-old daughter, coupled with my passion for attending to absolutely anything and everything AIMS-related, I find it helpful to know that I have a team of volunteers who are always there to support each other when it comes to keeping our accounts active and engaging. On average, each of us contributes about 3–6 hours per week to AIMS, in a team of three members. Our work has inevitably increased this year due to the reports of Covid-19 affecting women and birthing people's rights and experiences, as we really need to keep our finger on the pulse and try to include all announcements and any progress on the topic, in order to keep our followers and the public updated. During these busier times, I have found myself working in excess of 16 hours per week for AIMS, but I know that it is all work that goes towards benefitting the public.

Working with the social media team is easy to fall in love with! Every time that a person clicks 'like' on a post that you created yourself, feels like a virtual little pat on the back and a massive boost for the profile of AIMS. Personally, I am also finding it easier to explain to my family and friends what I do and what I stand for just by sharing AIMS social media posts with them. It's easy to see what we stand for and what we continue to work for, just by viewing AIMS's profile on social media and all of our previous posts.

Social media has also been an important medium in our calls for help and support with campaigns. Recently, we put out a request for women and birthing people to consider contacting us privately with their stories of maternity care during the pandemic. Although painful to read at times, the response has been amazing and is helping AIMS with research around the disparities between trusts in the UK and their policies surrounding birth partners and their presence.

In some of our social media posts, we also ask for people to engage in a way that directly helps some of our authors and our campaigns group. In June, we asked our followers for their thoughts on the third stage of labour and birthing the placenta. Our AIMS community did not disappoint! Suggestions for inclusion in the next AIMS book on the third stage of labour ranged from the benefits of consuming one's placenta to creating memorable art with it. In addition to this, important points were raised for women and birthing people to remember their choices and rights when it comes to delivering the placenta and their entitlement to view it and keep it, as opposed to the common assumption of some practitioners that one would not like to see it. Some people shared pictures of their placentas on the conversation thread about the third stage of labour. I found it amazing that people were willing to share such a personal thing online for all to see, in what we hope was a helpful way to remove the stigma around this most valuable organ being seen as 'gross' or inappropriate. Facebook stats informed us that almost 6,000 different people viewed this post on Facebook alone, and we like to think that this was perhaps the first time that some of them had ever seen pictures of real-life placentas.

Another aspect in which our presence on social media platforms has been invaluable is the impact it has had on book sales! Recently, it was shared with me that — immediately after our Facebook post advertising the AIMS online bookshop went live — book sales took off massively. We believe the engagement with the original post also increased after we shared it onto other notice boards and groups which our target followers are members of. Another 'win' for book sales and fundraising for the charity was our completely sold out Zoom workshop in November, which saw attendees receiving a copy of our new book, The AIMS Guide to Your Rights in Pregnancy & Birth (principal author Emma Ashworth).[1] Over 20,500 people viewed this post and it was shared 179 times by people to other pages, groups, and via private message on Facebook. With a follower base of 9,000, this is pretty impressive!

By far, our highest performing post published so far this year has been the one in July about updates to the NHS guidelines on birth partners being present in maternity care.A massive 74,000 people viewed this post on Facebook, which really illustrates how important this issue has been for maternity service users this year. On average, our posts prior

to that reached around 1,000 people. The cascade effect of having someone click like, comment on our posts, or share them across the platform really does make an impact to our reach.

We have a great responsibility to ensure that AIMS's professionalism is consistently maintained online. Information is shared left, right, and centre on social media around the topics of pregnancy and birth, and what we are seeing with the number of people sharing our posts and tagging us in their own posts is that AIMS is widely trusted as one of the most reliable resources out there. The content of posts is curated and approved by a select few trustees, which ensures that any statements made online are backed-up with evidence and the correct referencing of sources.

AIMS has been campaigning for a long time: 60 years this year! But all of a sudden, we have seen a massive surge in followers, due to various campaigns pushing to try and get access back for women and birthing people within NHS trusts across the UK, as a result of the Covid-19 pandemic. Before a group of doulas came up with the catchy #ButNotMaternity hashtag, doulas and birth-workers across the nation had been posting publicly about the very sad situations that people were finding themselves in and tagging AIMS in their posts. This has meant that our letter templates, evidence-based guides, and birth information pages have been pushed into the limelight not only by the social media team, but by our followers clicking the share button or creating short social media 'stories' that feature our posts. We have also seen the beginning of a coalition of charities and organisations with AIMS, including Birthrights, Pregnant Then Screwed, Make Birth Better, Birth Trauma Association, the Fatherhood Institute, and But Not Maternity. Originating from a clear pattern in the public tagging us all alongside each other in social media announcements, personal stories, and pleas for action, this coalition brings our followers together, creating exposure for both this campaign and for AIMS's work beyond the pandemic.

In a world where convenience and speed seem paramount, AIMS needs to be present on social media given that it is a place where a multitude of interested audiences are found. Businesses and individuals trawl social media and subscribe to certain buzz-words and hashtags in order to be alerted when a topic of interest is discussed. Platforms softwares are also becoming more intuitive — you may love it or hate it — when it comes to 'pushing' certain posts into the limelight using algorithms. This allows them to recognise what else a particular user may be interested in when they look at a post from AIMS. This happens even when we log in as AIMS admins rather than users! Therefore, it makes sense to subscribe to certain buzz-words and pages in order to see updates as and when they happen. In turn, these enable us to stay in touch with events occurring in the world that we otherwise wouldn't have been able to see. And it is all free! As a charity, AIMS needs to utilise the free tools available to us to get our work out there. Through social media, with a small team of dedicated volunteers, we can reach 74,000 people in an instant, for free, with invaluable information regarding their maternity care![2]

With the Covid-19 pandemic bringing injustices in the maternity services into the limelight, we hope that people will continue to follow us for decades to come. The issues that existed long before the present circumstance will invariably still remain in our futures. We urge our followers to keep sharing and re-tweeting our information and, most importantly, to remember that in a room full of a buzz about pregnancy and birth: mention AIMS.

(Note of the Editor): If you are interested in volunteering with the AIMS Social Media team, or in other AIMS volunteering opportunities, please contact enquiries@aims.org.uk.

References

1 www.aims.org.uk/shop/item/aims-guide-to-your-rights-in-pregnancy-and-birth

2 www.facebook.com/AIMSUK/photos/a.392070900861830/3058774174191476/?type=3

Julie Ann Crowley is a Birth & Postnatal Doula in Northamptonshire, a former student midwife, and IT systems analyst, from Ireland. She runs various local groups on a voluntary basis such as Positive Baby Family, Northamptonshire Birth Voices and, more recently, the national group But Not Maternity.

Campaign update

Removing COVID-19-related maternity restrictions on partners

by the AIMS Campaigns Team

Since the start of the pandemic, the AIMS Helpline has been receiving calls from women who are deeply distressed by the restrictions that their local Trusts have placed on their ability to have a partner or other supporter of their choice with them in hospital. You can read some similar stories in our previous AIMS Journal "Pandemic Birth", www.aims.org.uk/journal/index/32/2. In this article, we update you on what AIMS has been doing to address this issue.

Many of the calls to our helpline were heart-rending. We heard from women who had previously suffered a miscarriage or termination of pregnancy and were now having to face potentially devastating news from antenatal scans and tests with no-one to support them. We heard from many who were worried that they would have to go through the early stages of an induction, or wait in triage whilst already in labour, without the birth supporters they needed – even if they suffered from severe anxiety, had a disability, or their first language was not English. We also heard from women worrying how they would cope alone if they had to stay on a postnatal ward for any length of time and fathers upset that they would be unable to be with their babies and support their partners in the hours or days following the birth. A common theme to these calls was a lack of flexibility on the part of maternity service providers to respond to individual needs or to have any consideration for the mental health impact that these restrictions were having.

Our immediate response was to put in place resources for self-advocacy, including our Birth Information page "Coronavirus and your maternity care" which informs maternity service users about the latest guidance and what we feel it should mean for their care, and a set of template letters for people to send if they are struggling to get their support needs met. We asked people to copy us in, so we know that these templates are being well used, and it is encouraging that at least in some cases, they have met with a positive response. In others, however, Trusts and Boards continued to show a distressing lack of understanding and flexibility. One interesting learning point was that sometimes, when people contacted their Head/Director of Midwifery, they found that options which their own midwife had been saying were not allowed could in fact be made available on a case-by-case basis.

Meanwhile, AIMS Volunteers continued to campaign for the needs of maternity service users to be considered in national guidance. We submitted responses and queries to the NHS, RCOG and RCM over issues in their guidance and to the Health & Social Care Select Committee inquiry on "Delivering Core NHS and Care Services during the Pandemic and Beyond." You can find all of these on our Campaigns webpage: Campaigns Page 1 of 2 | AIMS.

The publication of new guidance by NHS England [1] in September led us to hope that the restrictions would be eased, but it soon became clear that this was not the case in many areas.

AIMS was then approached by a group of Public Health Registrars to help them publicise their findings from a Freedom of Information request[2](FOI) sent to all Trusts in England with maternity services. This showed that not only were 43% of the Trusts who replied yet to reverse their restrictions in line with the NHS England guidance, but also that 24% intended to reinstate them unchanged in the event of a local or national rise in infections. We jointly created a press release to draw attention to the story, illustrated with a case study from a woman who had contacted the AIMS Helpline and was happy to share her story. We were very pleased that this resulted in stories being published in the Evening Standard, the Mail on Sunday and the Observer.

Meanwhile, several other campaigning groups have also been working to highlight the issue, including the #butnotmaternity social media campaign. AIMS joined with a coalition of these groups (Birthrights, Pregnant Then Screwed, Make Birth Better, the Fatherhood Institute, and the Birth Bliss Academy) to send a letter to NHS England,[3] calling for them, as a matter of urgency, to issue clearer guidance to Trusts on removing restrictions on partners or

other supporters attending maternity services. The letter calls for Trusts to be advised that "A partner of choice should be seen as an 'essential visitor' and should be permitted to attend all scans, antenatal appointments, induction of labour, assessment (triage) of labour, a significant number of hours per day on inpatient wards and in neonatal units, and that a second birth partner should be accommodated where possible."

The same group (now also including the Birth Trauma Association) has also signed a letter (drafted by AIMS) to the Society and College of Radiographers asking them to review their guidance on partners and supporters attending antenatal scans and an open letter to the Chief Executive of NHS England.[4]

At the time of writing, in the midst of a new national lockdown, we are continuing to work with this coalition to emphasise the need for all maternity services to recognise the needs of women and birthing people and their partners and to learn from those Trusts that have found effective ways to lift the restrictions while mitigating the risk of infection for staff, service users, and their supporters. Trusts need to be looking at what they can do safely, rather than what they can't do easily.

References

1 www.england.nhs.uk/coronavirus/publication/visitor-guidance/

2 www.bmj.com/content/370/bmj.m3483/rr-1

3 www.birthrights.org.uk/wp-content/uploads/2020/10/Final-letter-to-NHSE-from-coalition-re-visiting-restrictions.pdf

4 pregnantthenscrewed.com/but-not-maternity

Article

Refocussing our attention on Better Births: The poetry of scrutinising policy implementation

by the AIMS Campaigns Team

The AIMS Campaigns Team has previously promoted the Better Births vision[1] as a key tool for birth activists in England. In this article, we encourage our readers to re-engage with the vision in preparation for a conversation to mark the fifth anniversary of the Maternity Transformation Programme.

Published in February 2016 as the culmination of the National Maternity Review report[2], the Better Births vision underpins the ongoing Maternity Transformation Programme in England alongside 28 specific recommendations.

Our vision for **maternity services across England** is for them to
become
safer,
more personalised,
kinder,
professional and
more family friendly;

where **every woman**
has access to
information to enable her to make decisions about her care;

and **where she and her baby**
can access
support that is centred around their individual needs and circumstances.

And for **all staff**
to be supported to
deliver care which is women centred,
working in high-performing teams,

in **organisations**
which are well led and

in **cultures**
which *promote*
innovation,
continuous learning, and
break down organisational and professional boundaries.

February 2021 marks the fifth anniversary of the Better Births report. This anniversary offers a useful opportunity, as a time to take stock and a time for us to reflect together both on what has been achieved since 2016 and on what remains undone. Over the next few months, AIMS will be asking you to join us in these reflections as the #BetterBirths5YearsOn conversation commences. Whether you are someone who is using or has recently used the maternity services, a supporter of service users, or someone who works in the maternity services, we'd encourage you to keep this "poem" close at hand over the next few weeks and months and to use it to reflect on the maternity services as you experience them. In what ways do your experiences align with this vision? In what ways do they diverge?

Please then follow us on Facebook, Twitter, and Instagram to join the conversation, which we'll be launching in the New Year. We look forward to seeing you there! And if you can't wait to have your say, please feel free to email us now with your reflections, via betterbirthsfiveyearson@aims.org.uk.

References

1 "Better Births Basics #1: The Better Births vision | AIMS." 1 August 2018, www.aims.org.uk/journal/item/better-births-vision (Accessed 23 October 2020).

2 "Better Births – NHS England." www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf (Accessed 23 October 2020).

Campaign update

Continuity of Carer, Northern Ireland - trying to do it properly!

by Anne Glover, AIMS Volunteer

What is it?

This pilot Continuity of Carer[1] scheme, called the Lotus Midwifery Team, is being implemented at the Causeway Maternity Unit in Coleraine. The scheme was launched only in August 2020, but already it is receiving excellent feedback from women, especially from those experiencing previous birth trauma. There are currently 7 dedicated midwives working with the Lotus Team and their primary focus is to give mothers a positive maternity experience, irrespective of their choice of where or how to birth their baby. The vision of the team is to provide individualised care during pregnancy, birth and the postnatal period with the focus being on building a trusting, interpersonal relationship.

How does it work?

The aim is for each woman to see the same midwife at each appointment throughout her pregnancy, her labour and birth, and to be visited by her at home postnatally, until care is handed over to the health visitor when baby is 2 weeks old. Any woman planning to birth in the Causeway Maternity Unit can self-refer to the Lotus Midwifery Team. She then meets her named midwife and buddy midwife at the booking-in appointment who are responsible for her entire birthing journey, along with an extra midwife who joins her team at 36 weeks. This enables the mother to have access to one of her three midwives 24/7. During labour, the midwife will also accompany the woman to another hospital if required. The team has so far supported 12 women during their pregnancy, birth and postnatal period and all of them have reported a positive birth experience, which they state is due to the trusting relationship they have built with their Lotus Team Midwife.

What difference does it make to mothers?

The clinical outcomes of the Continuity of Carer model have shown that mothers are less likely to experience preterm births, still birth, episiotomies, intervention, and are more likely to know the midwife at birth, feel satisfied with their experience, have a normal birth and are more likely to breastfeed. The Lotus Team has been collecting data from women on a monthly basis, but as the team is still in its infancy, it cannot demonstrate statistically significant outcomes as yet. However feedback so far has been very encouraging and positive, with women who have had previous birth trauma expressing how their recent births with the Lotus Team have healed them, and some even saying they would have paid privately to have the experience. It is also worth noting that with the current COVID restrictions, women have said they feel safer because they meet the same midwife at each appointment, which reduces and helps to alleviate their anxiety.

First-time mum, Bevin, self-referred to the Lotus Team:

"From the day I opted into the care of the Lotus Team at 8 months pregnant, one primary midwife was with me for all appointments and the birth of my baby. Even though I was quite far along my pregnancy, this enabled me to quickly develop a strong, trusting relationship with one healthcare provider. I was also able to meet with my midwife, doula and partner all together on several occasions to discuss our birth preferences, concerns, etc. My midwife and doula were both fantastic throughout my pregnancy, birth and postnatal experience; I felt they worked really well together, communicating throughout to help ensure I got the best support possible.

Throughout my care, I felt I was the primary decision maker as I was able to fully discuss my choices and preferences with people who were very respectful of these, offering me helpful advice and information as appropriate. During labour my midwife ensured my partner and I were fully informed about potential procedures and their risks/benefits. This helped me feel in control at an extremely vulnerable time. Overall, I would highly recommend the continuity of care model. I think it leads to safer care, and more woman-centred care that helps empower parents. I think it is a fantastic service that should be the norm for all maternity care."

What does it mean for midwives?

Midwives were initially asked to express their interest in working on this pilot scheme two years ago as a result of the implementation of Better Births[2]. Paula Morrison is a Lotus Team Midwife:

"From a personal perspective I was lucky enough to be cared for by continuity midwives when I had my own children. It was the care and support I received from them that inspired me to retrain as a midwife. I am so passionate about providing this model of care for women as I know first-hand the positive impact this can have on a new mother and her family. From a professional perspective the level of job satisfaction providing a positive maternity experience is incredible. Hopefully in the future this model of care will be available to all women requiring maternity care."

Caroline Diamond is Head of Midwifery and Gynaecology in the Northern Health and Social Care Trust:

"Having worked in a Continuity of Carer team in the 1990s as a young midwife, I can personally attest to the real benefits this way of working offers both the woman and the midwife, and it is the reason I am so passionate about this model of care. The evidence is clear around the clinical outcomes for women, but it is the sense of empowerment, control of her body and her birth, and confidence in the information and decisions she makes when supported by a known and trusted midwife which underwrites a positive experience of pregnancy and birth.

This model of care gives midwives the opportunity to

develop that 'professional friendship' and a trusting reciprocal relationship with women throughout the childbirth continuum which the traditional model does not provide. Whilst all midwives are advocates for women, that advocacy role is acutely focused when the midwife has nurtured a bond with the women and is personally invested in her experience. The autonomy and flexibility, the ability to achieve a good work life balance, and the personal job satisfaction is an additional bonus that Continuity of Carer midwives experience. As Head of Midwifery, I am extremely proud of our Lotus team who have worked so hard and tirelessly to commence this model of care, despite being in the midst of an unprecedented global pandemic".

Looking to the Future – how to sustain this programme:

The implementation of the Lotus Midwifery Team at Causeway Maternity Unit is proving to be a great success, and there are already plans to expand the service in the new year. Resources are key, and more midwives are needed to not only cover the vast geographical area in this Trust, but to accommodate increasing demand for individualised care. There is a cultural shift from how midwives provide maternity services traditionally to this working model which changes to a more flexible, being on-call, self-managing model. It is important to acknowledge that this change can be challenging for some midwives and they need to try it out and see if it works with their own family and life pattern.

The Continuity of Carer maternity model is now embedded in student midwives' teaching[3] so it will soon be the norm when they qualify as registered midwives. It is the foundation of maternity care, improving quality and safety and promoting positive birthing experiences. AIMS looks forward to the time when this model of care will be available to all.

References

1 www.rcm.org.uk/promoting/professional-practice/continuity-of-carer/

2 NHS England (2016) National Maternity Review: Better Births – Improving outcomes of maternity services in England – A Five Year Forward View for maternity care. www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf

3 www.rcm.org.uk/news-views/rcm-opinion/2020/getting-it-right-from-the-start-implementing-midwifery-continuity-of-carer/?fbclid=IwAR0AhGmzQ0P35aV6NY-S5LjqirQdx3wCzW34HCb6SK0pIXl04-9jp_tfzRE

Ideological birth wars: The academic debate goes on, but where does this leave us?

by Jo Dagustun

A recent article published in the British Medical Journal[1] provoked quite some controversy in maternity circles, and the ensuing debate[2] highlighted a continued and unsettled controversy about "where women should give birth." Here, AIMS Volunteer Jo Dagustun seeks to unpick the arguments and explore what this all means for the maternity services and their users. In summary, Jo suggests that this latest debate demonstrates that maternity service transformation into a service that BOTH supports women well via the provision of high-quality information AND improves maternity care for all is still some way off. Nothing new there then…

The original BMJ article – via some seemingly straightforward analysis of existing maternity statistics – wades into the vexed issue of "risk stratification." On the basis of their data work, the authors suggest some major changes to the way in which maternity services declare who

is "low risk" and who is "high risk." (Yes, we know: this sort of label can be deeply unproductive. But let's go with it for a bit, on the basis that such labels might at least be helpful for service organisation…)

These changes – if adopted as the authors envisage – would potentially raise barriers, and certainly "raise eyebrows," if, for example, a first-time mother wanted support to birth at home or at a birth centre not co-located with obstetric services. This is because from the authors' perspective, all first-time mothers who are not already in line for a planned caesarean would now be classed as "high risk'." They reason this because the figures show that nearly half of these women will end up with a "complicated birth."

The definition of complicated birth used by the authors is in itself quite controversial, mainly because it includes both medical interventions and health outcomes (apples and pears, you could say). It also excludes a consideration of long-term mental health outcomes; this is surely quite an omission. We are clearly still awaiting the day when all players in the healthcare system truly support an understanding of health as including both physical and mental health, and also one in which the longer-term effects of birth are properly taken into account.

The key, and strikingly familiar, point of contention is between different understandings of the nature of the risks of childbirth. For sure, the risks are various and highly personal to each individual. But is the key reason that problems arise because women are fundamentally flawed, that our bodies are flawed, that the physiological process of birth cannot be trusted and should be put "on trial," under close supervision and in a place where medics are close to hand, especially for first-time mums? Or are many of the problems related to the fact that our maternity services just aren't adequately focussed on understanding and supporting both the needs of the individual service user and the physiological process of birth?

In general, most people would agree that "more information is good," but this is true only if the information is accurate and its biases are clearly identified. Although the article purports to offer more information – to aid women's decision-making – we would ask readers to take care. The detail is important and not all information is as politically neutral as it seems. AIMS is passionately keen to ensure that women are not misled about the birth-related risks they are likely to face when they make decisions about their maternity care. As such, we would hope to see more methodological sophistication when reports on such data are published.

I wrote a response to the article. Whilst it wasn't selected for publication by the BMJ, AIMS colleagues thought that readers might be interested to see it, so it is reproduced in full below.

Reference

1 Jardine, J, Blotkamp, A, Gurol-Urganci, I, Knight, H, Harris, T, Hawdon, J, van der Meulen, J, Walker, K & Pasupathy, D (2020) "Risk of complicated birth at term in nulliparous and multiparous women using routinely collected maternity data in England: Cohort study." *British Medical Journal* 371: m3377.

2 Demonstrated by the rapid responses to the article and by the discussion on social media - www.bmj.com/rapid-responses

~~~

An open letter to the Editor of the BMJ on behalf of AIMS, 6 October 2020

Risk of complicated birth at term in nulliparous and multiparous women using routinely collected maternity data in England: cohort study

I am grateful to the authors for their careful work in bringing this quantitative analysis to publication. They present here thought-provoking statistics indeed. Just why is it, for example, that nearly half of all women traditionally categorised as 'low risk' (excluding those undergoing a planned caesarean), and giving birth for the first time at term, experience such high levels of the interventions and poor outcomes selected by this team?

I fear, however, that this paper provides a stunning example of authors offering implications and conclusions that barely relate either to the preceding results and analysis or to the current policy context. Before jumping to policy recommendations based on the notion that certain levels of birth outcomes, within certain populations, are inevitable,
~~~

and that first-time mums ought to be advised to birth 'in a setting that enables rapid access to care by an obstetric or neonatal team, including midwife led units', I'd strongly advise the authors – and readers - to pause for thought.

This is because this line of argument curiously and unacceptably ignores the broader ecology of birth. We surely cannot simply assume that the physiological process of birth inevitably fails so frequently, absent a close examination of the context in which such complications occur?

I would suggest that a more productive line of enquiry – and basis for policy recommendations in this area, which the authors seem curiously keen to make – might have been to contemplate *what it is about the way in which our maternity services provide support to maternity service users that leads to such outcomes*?

So, what are the issues related to the delivery of maternity services that urgently need to be addressed, to support better outcomes? Here, I'd recommend a close examination of the Better Births (2016) report, alongside the related and ongoing Maternity Transformation Programme. There is an existing rich seam of policy work underpinning this Programme, and it is disappointing that this is not reflected here. Indeed whilst an intellectual enquiry into risk stratification for operational purposes may serve some purpose, this goal seems fairly obscure given the nationally agreed policy shift towards (a) a stronger focus on a woman's right to make decisions about her care (on the basis of balanced, evidence-based information to support her in making an informed decision), (b) service provision which is increasingly able to support personalised care (shifting away from the conveyor belt approach to 'care' which is sadly all too common still), and (c) a new transformational model of relationship-based care that is firmly rooted in an evidence-base of improved outcomes (continuity of carer).

I appreciate that it might be difficult for some hard-working and well-intentioned healthcare professionals to even contemplate the line of enquiry I suggest here. But it is equally difficult for me to accept that the authoritative platform of the BMJ is being used to platform such ill-informed, misleading and potentially dangerous policy recommendations as are presented in this paper. Reviewing the open access peer review papers associated with this article, I would also suggest that the BMJ looks urgently at the diversity (especially methodological) of those involved in that process.

For future reference, I'd also strongly recommend that the term 'women with a singleton birth at term after a trial of labour' is not accepted for use in the BMJ. It is not the physiological process of labour that is, or should be, on trial in this situation, and I cannot think of any other physiological process that would be conceptualised in this way. This terminology is inappropriate in this context, and – in this case – worryingly suggests an underlying but undiscussed set of beliefs on the part of the author team, the non-disclosure of which does not sit well with the scientific rigour that your readers have come to expect. Nor, I suggest, is it suitable to refer to women as 'candidates' for a certain type of birth setting.

Yours
Jo Dagustun
Volunteer, AIMS

Interview

An Interview with Lorna Tinsley

Rachel Boldero

AIMS believes that an effective Nursing and Midwifery Council (NMC) is crucial for a well-functioning maternity service. In this interview, we take the opportunity to speak to Lorna Tinsley, an NMC Council member between 2013 and 2020. When Lorna's term was coming to an end earlier this year, there was much concern across the maternity services improvement community that there were no plans to replace Lorna's midwifery expertise on the Council. Responding to this concern, Philip Graf, Chair of the NMC, moved quickly to reassure us that midwifery expertise on the Council was indeed a priority and explained the NMC's plans to make this happen. In that context, we thought that it would be interesting to find out from Lorna how she came to be an NMC Council member and more about that role, as well as Lorna's thoughts about what we can all do to ensure that the NMC is as effective as we need it to be.

Thank you for agreeing to be interviewed by AIMS, Lorna. To start, can you tell us about your passion for midwifery, what first attracted you to the idea of being a midwife, and your midwifery journey?

I began my career as a nurse and was working on the Poisons Unit at Llandough. I loved it – it was a great job as a nurse, but I found I was getting much more involved in the wellbeing side of things, and considered psychiatric training. However, they were building a maternity unit right next to our building, which caught my attention. I hadn't actually enjoyed my obstetrics experience in training, but two things triggered my interest: my focus on wellbeing; and I had then had a little girl (my first child). I had a fabulous birth experience at what was at the time quite a run-down inner-city unit in Cardiff. The midwives paid so much attention to my mental wellbeing in addition to my physical health. They were absolutely fantastic, so I decided to do my midwifery training.

I started off working in the same unit where I had my daughter – the placement was 9 months there and then 9 months in a bigger hospital in Cardiff. I enjoyed the training very much and had another baby – a boy. I was working as a clinical midwife and a job opportunity came up in parent education for midwives, combined with health promotion. I had my third baby (another boy) and kept working on mental health, wellbeing, and health promotion. I had a fabulous time promoting yoga, aquanatal, and couple classes.

How did you get involved beyond the local level?

I was approached by the Royal College of Midwives (RCM) whilst I was on maternity leave with my fourth baby (a third son) – I'd been a rep for them for a while. At the time I was doing a Masters with four young children and was also the RCM National Officer for Wales. It was great fun! I travelled across Wales and met wonderful midwives. Every time I was out and about, the sense of family among midwives was always reinforced. The midwives I met wanted the women in their care to be looked after properly, they were passionate about the women's physical and mental wellbeing, they were kind, and I was so proud to be one of them.

As I travelled across Wales, I met with the Chief Executives, HR Directors, and got to know some senior people in organisations (such as Local Health Boards, Community Health Councils, Welsh Government, Health Inspectorate Wales). The Heads of Midwifery were amongst my main contacts, as were the Directors of Nursing. Over the years I saw excellent examples of succession planning and midwives I had met are now Heads of Midwifery, Directors of Nursing and Chief Executives.

On my travels in Powys (a rural part of Wales), someone approached me at the Trust board and asked if I had considered working for the Employment Appeal Tribunal (EAT). They were looking for more diversity, a Welsh speaker, and someone with a Trade Union background, so I applied and got that job. The EAT work was wider than midwifery: it was employment law across the spectrum. I was exposed again to a wider field of people and interestingly, the judges were fascinated about midwifery as, at that time, the media focused on some real hot topics, such as home births and midwifery-led units.

I then came to a point where I was interested in doing something a bit different. I had been working with the Welsh government on an all-Wales payment system for supervisors of midwives. As part of this work, we had been looking into a career framework for maternity support workers. I wanted to take my role a bit further, and someone in the Welsh government suggested that I apply for the National Leadership and Innovation Agency for Healthcare post. This was an arms-length government role looking at the commissioning of NHS education, career planning, etc.

When the secondment came to an end, my supervisor of midwives asked what I'd do next. I wasn't sure, and she said 'why don't you apply for the Nursing and Midwifery Council (NMC)?', as they were looking for a midwife to join them. I didn't think there was any way I would get the role, but off I went for the interview. I was absolutely delighted when the letter arrived on the mat that confirmed I had been offered the position. I had no idea what I was letting myself in for! So then, I was doing some teaching at Cardiff University, I had the EAT role going, and I was an associate for Skills for Health.

Lorna also shared that she had three home births and some interesting experiences. My daughter was born at St. David's in Cardiff and I had three home births after that. With my first home birth, the GP tried to have me kicked off their GP list. It went to the General Medical Council and I had a lovely letter back which I treasured for many years confirming that they wouldn't take me off the list, but I decided I would come off it anyway due to the treatment I had received. I went to my husband's GP, who promptly told me that I had 'got a boy and a girl now so no more silly nonsense about home births.' I quickly found a new GP, who I am still with, and she actually attended my last birth as she had never been to a home birth – this was the only one I had in the bedroom – I had one of my sons in the kitchen and one in the living room!

Since you were appointed in 2013, what are you most proud of achieving in your role as Council member?
I am most proud of the fact that I have brought a real view of midwifery to a council that is made up of lay members and other registrants, because it's very difficult to articulate what it is that makes a midwife and what a midwife is. My own belief is that a midwife is an advocate for women and their families, helping them navigate a life experience and supporting them in the transition from pregnancy to motherhood.

Many of the group had their own personal experiences, e.g. they may have had traumatic incidents or heard their parents' stories – there were so many experiences they were bringing to the table, and it was good to be able to sort through these and reinforce what a midwife is, how important the role is and how to differentiate it from a nurse's role. This came up many times in conversations, even where we were discussing things like accountability or re-designing the code. We saw this in the revalidation process and in the education standards, as the approach for nurses was not the right fit for midwives, and we have ended up with some fabulous future midwife standards as a result. Every time, I was able to be the voice for midwives and to bring the real picture back to people so they could understand that some of the recommendations wouldn't necessarily fit for midwives.

How do you think you have been able to make a difference to maternity services and ultimately the experience of maternity service users?
One really good example of this was the development of the midwifery committee into the midwifery panel. Following the King's Fund review of supervision recommendations, the midwifery committee was going to be removed from statute.[1] It was a challenging and threatening time, and we were really concerned about what the future would look like. We grieved the loss of this, but embraced the different structure – we could bring in more women's voices, more lay people, and stakeholders who were so critical in enabling us to move forward with a number of vital midwifery agendas.

We had observers on the committee, but their role was simply observing. One of the observers (Louise Silverton) was crucial to us, and the thought that we wouldn't have her voice was a challenge. So when we came to undertaking the work on the standards, we had such a fabulous group we could call upon and be certain that decisions that were being taken were the right ones. We had women and families at the heart of this – the purpose of the NMC is public protection at the end of the day.

Another area where I have played a significant role is in the drive to identify and disaggregate midwifery data. It had been the practice to combine midwifery and nursing data simply because some registrants were dual qualified and there was no system other than manually working through thousands of data sets to identify if the individual was practising as a nurse or a midwife. From the very beginning, I raised this as an essential issue with the Council. The development of the revalidation processes and improvements in IT enabled the disaggregation, and this can be seen in the annual reporting.

The Black Lives Matter movement is obviously a huge (and welcome) focus currently. What positive action have you observed in maternity services in recent times to improve BAME outcomes and where do you most believe there is most work to be done?

I think to start with, it is the focus which is positive. Before, it was something that people were aware of, but it wasn't in the conversation, people were nervous to broach it, whereas now there is an energy about this topic and people are not frightened to talk about it. I hear pride associated with the topic now as people take their unconscious bias training, which wasn't as commonplace before. I hear midwives talking about this much more now. There are extensive resources online to really focus in on what we are doing, how we can improve, what the real life stories are, where we have got it wrong, and where we can put it right.

In terms of how cases involving BAME communities are dealt with by the NMC, within the NMC there is real focus on this. When we reviewed this issue, we didn't believe there was a problem in terms of the way we are dealing with individual cases, but we are mindful that we seem to receive more referrals from BAME communities than we would expect, so we are trying to unpick why that is.

By law, the Council can include just 6 registrant members. How important do you think it is for the Council to include a midwife member?

This is the law, but it doesn't state what experience the registrant members have to have, so they could have no health visitor experience, psychiatric nursing experience, etc. When the Council is looking for new members, it's about looking for people with diverse experiences and the right skills mix.

It is vital to have a midwife voice, but it is not enough for them to be just a midwife. What is really important is having someone with relevant midwifery experience who has networks across the UK, because this enables you to be that voice all over, pulling in the strength of midwives from all around the UK. Our practice is developing all the time, and a registrant member needs to be involved in this, in addition to being politically aware. It is a fine balance to be the voice of midwives without being their representation, as this is the RCM's job.

The Council is also obliged to include members from each of the UK countries. As the council member for Wales, do you think this is important, and can you tell us how you have been able to ensure that the NMC properly takes Welsh needs into account?

There has to be a registrant from each of the countries and where you have a registrant on their own, it can be quite lonely. I've been really lucky as there was a registrant for Wales when I came on board, but during a short gap where there wasn't, I found it challenging. It is absolutely key that we have these registrants from each of the countries. It would be lovely if lay members came from the different countries as well, but that doesn't always happen.

The network is vital, you have to have registrants who have the right networks. You need relationships with senior bodies, and political awareness, to be able to be the voice of the country.

What are your observations about the impact of COVID-19 on maternity services currently, and what focus would you suggest to overcome any of the negative effects we are experiencing?

It's tragic, and an awful time. I am very grieved for women and families whose experiences during this time have been affected by the pandemic. Having had two new grandchildren

during this time (just as we went into lockdown, my daughter and daughter-in-law each had a baby within a week of each other), I've experienced the effort made to make the journey a positive one. Their labours were just before lockdown, and the postnatal support was incredible: the use of technology was brilliant and it had a positive impact on breastfeeding. There was a tremendous effort to give support in a different way.

I am sure, however, and have read in the media, that people have had negative experiences; going for a scan and getting bad, confusing, or good news on your own, for instance; it's a sad time for people. But the efforts being made to make this the best service possible at this time are commendable.

Having said all of that, as soon as we can get back to a situation where people can have more family and midwifery support both antenatally and postnatally, the better. Roll on the end of the pandemic!

AIMS is celebrating its 60th birthday this year, and now as much as ever we're keen to ensure that the professional regulatory system works effectively. Looking forward, what do you think AIMS should focus on to help ensure that the work of the NMC improves maternity services for all service users?

My family loves the quote "Always watching" from the Monsters, Inc. film, and I believe that that should be the focus. Always watching, constructively challenging and ensuring that the NMC is kept up to date on maternity services so that they can continue to effectively regulate midwives across the four countries of the UK.

~~~

For background on the NMC's position regarding midwifery expertise on the NMC Council, please see here: [An update from the NMC Chair on recent Council member recruitment.]

Reference

1. www.nmc.org.uk/globalassets/sitedocuments/councilpapersanddocuments/council-2015/kings-fund-review.pdf Statutory supervision of midwifery was in place in the UK for 113 years (from 1902). Following the Morecombe Bay Investigation, the Nursing and Midwifery Council (NMC, 2015) voted to accept the recommendations of the King's fund review (2015) into midwifery regulation, which saw the end of the statutory supervision of midwifery. (Note of the Editor)

The AIMS Guide to

Your Rights in Pregnancy & Birth

How many times during pregnancy and birth do you hear the phrase 'am I allowed to…?'

How often do you think that you must be given 'permission' by the maternity services?

You don't have to ask permission.
You have the legal right to decide what happens to your body.

And you have always been allowed!

Available in paperback (£8)
and kindle format
from
the AIMS shop

www.aims.org.uk/shop
~~~

Article

A short analysis on First Do No Harm the Independent Medicines and Medical Devices Safety Review chaired by Baroness Cumberlege, July 2020

by Shane Ridley, AIMS Trustee

Follow this link for the report:
www.immdsreview.org.uk/downloads/IMMDSReview_Web.pdf

Introduction

> *This report deals in the shame felt by women and the currency of silence. It deals in misogyny, in paternalism, in arrogance and in the imbalances of power – both individual and systemic.'*
>
> *Kate Jarman, Health and Care Women Leaders Network, 14/7/20.*

The review is 'about people who have suffered avoidable harm' specifically the use of two medications and one medical device. It examined Primodos which was a hormone pregnancy test (HPT) used between the 1950s and 1978; Sodium Valproate which is an anti-epileptic drug taken by women during pregnancy and pelvic mesh implants used for treating vaginal prolapse, the latter two are still used today. The HPT and Sodium Valproate are known to be teratogenic, i.e. capable of causing malformation of the embryo.

The review found that the healthcare system, which in this definition means the NHS, private providers, the regulators and professional bodies, pharmaceutical and device manufacturers and policymakers, '**is disjointed, siloed, unresponsive and defensive. It does not recognise that patients are its raison d'etre'** and that **'the system is not good enough at spotting trends in practice and outcomes that give rise to safety concerns'.**

The review document is very long (268 pages), detailed and complex - so for the purposes of this article I will highlight areas which are relevant to the maternity services and those who are pregnant or intend to be. For a quick read you will find that Chapter 1 is a summary of findings and recommendations and Chapter 2 considers the overarching themes found; other chapters consider the detail and implementation of the recommendations. Chapter 6 considers the role of public inquiries.

The new 'AIMS Guide to Resolution After Birth' describes in detail the issues surrounding complaining about care. This review serves as a stark reminder that it certainly isn't easy to **complain** and be heard. The review clearly states that improvements must take place in relation to **informed consent**, again a constant theme in the new

series of AIMS Guides. Together with these issues and many others, AIMS looks forward to hearing how the recommendations from the review will be taken forward.

Patient involvement

In setting the review in place, it had been recognised that legitimate concerns of patients, families and campaigners had not been heard, not just for a year, a decade, but for 40 years. The patients' concerns, which make harrowing reading, were '**dismissed, overlooked, and ignored for far too long'** (1.10). There is a list in 1.12 of the review highlighting the sixteen common themes found by the teams, amongst them **'the lack of information to make informed choices', 'the struggle to be heard'** and **'not being believed'** – words often heard in relation to the maternity services.

Descriptions of the clinicians include **'defensive', 'dismissive'** and **'arrogant'** (2.3) and patients spoke of being **'gaslighted'** – a really serious accusation which means 'to manipulate (a person) by psychological means into questioning his or her own sanity.' Oxford English Dictionary (p17 ref).

Consent and Risk

> *'It is the patient's right to be told whatever information they need and in a manner that they understand – not what the reasonable clinician chooses to say – to make a decision on whether or not to proceed with a particular procedure or medication.' (2.14)*

Some women did not know they had had mesh inserted, some who agreed to full removal were never told that not all of it had been removed. Some women were never told of the effect their medication for epilepsy **could** have on their unborn children. Some women were given the HPT pills from their GPs' desk drawers – samples from drug companies – no prescription.

The new series of AIMS Guides highlights the complexity of reporting complaints, giving consent and understanding risk. The review examines the general level of dissatisfaction with all the bodies who receive complaints and recommends more changes to the system. The review recommends that 'More thought needs to be given to help patients conceptualise risk.' (2.21) There is mention of the GMC recommendation that every patient conversation with a clinician about consent will be documented with both parties' views being noted, perhaps with the use of audio or video (2.24).

The review is recommending the appointment of a Patient Safety Commissioner to champion the value of listening to patients and promoting users' perspectives in seeking improvements to patient safety around the use of medicines and medical devices, and a new independent 'Redress Agency' for those harmed by medicines and medical devices.

Medications and Devices

The frightening bigger picture found by this review is that it is not just the three chosen subjects, but there is another long list patients have been complaining about for years, including Essure (a contraceptive device), Roaccutane (a treatment for severe acne that can cause birth defects if used in pregnancy), Poly Implant Prostheses (PIP) breast implants, cervical cancer vaccination, in utero exposure to hormones, Valproate use in children and other mesh procedures.

The review highlights major flaws in innovation in medical care – lost opportunities to learn the efficacy of products, and a lack of comprehensive pre- and post-market testing and long term monitoring. The Medicines and Healthcare products Regulatory Agency (MHRA) does not have the same high profile as similar agencies in other countries, but it will have to change post-Brexit, as it will be the UK's standalone medicines and medical devices regulator, taking over from the EU regulatory function. It needs far more robust surveillance post-marketing of medicine and devices, but unbelievably they are not involved in the pre-market development of medical devices.

The system doesn't know what works and what doesn't (1.16)

- The system doesn't know how many women were treated with the mesh, how many were cured and how many had life-changing conditions because of the mesh.
- The system doesn't know how many women took Sodium Valproate who then went on to become pregnant. It is a very effective treatment for managing epilepsy BUT it is known to be a teratogenic medication. It doesn't know where children/adults

affected by Sodium Valproate are or how many there are.

- The system doesn't know how to ensure women who take Sodium Valproate are monitored, advised and aware of the Pregnancy Prevention Programme.
- The system doesn't know how many women took a HPT, how many miscarriages were caused, how many children may have been malformed, or how many are still alive.

The review heard that **'crucial research evidence that should help to shine a light on what are safe and effective interventions is neither prioritised nor funded'** and importantly, they heard that research funded by manufacturers **'never sees the light of day because it is negative or inconclusive'** (1.22).

The vital information for AIMS and the people we care about is that:

' … the system is not safe enough for those taking medications in pregnancy or being treated using new devices and techniques.'

'… we have heard nothing that would lead us to believe that things are different for other surgical procedures and devices or other medications.' (1.23)

This means that the healthcare system is not robust and safe enough and healthcare providers are not informed well enough, to know **fully** about the safety of **any** medication or procedure used in a pregnancy.

Duty of Candour is also discussed in the AIMS Guide to Resolution After Birth; it is the requirement for health and social care professionals and to be open and honest with patients if things go wrong, but the review found that there is still a 'persistent culture of reluctance to speak out'. During the pandemic, there have been disturbing headlines such as 'Coronavirus: NHS whistleblowers 'threatened with job loss' for speaking out on PPE'. (Independent 15 May 2020)

Conflicts of interest have the potential to arise in the complex financial links between drugs and medical device companies AND doctors, hospitals and other health organisations and private practice. Currently there is **no centrally mandated register** for healthcare professions to hold information about actual and potential conflicts of interest. This applies in maternity services as well as anywhere else in healthcare.

The Royal College of Obstetricians and Gynaecologists (RCOG) has highlighted an issue that 'the same procedure may be carried out by both accredited sub-specialists and by those who have done general training and developed an interest in specific interventions who, necessarily, will not have the same level of skill'. (2.57) Patients have no access to any information which will tell them the competencies of their doctor.

Most importantly there appears to be no requirement to declare conflict of interest when doctors sit as experts on working groups, advisory committees or to agree guidelines. For example, the review found that clinical members of such groups were being paid by pharmaceutical companies. The review says that reliance on voluntary, self-declaration of conflict of interest must cease.

Guidelines

Guidelines are advisory. All AIMS information states this but we have a long-held belief that often guidelines are, on one hand, out of date and on the other not followed when they do have good evidenced-based information. The healthcare system has a responsibility to ensure common practice is in line with recommendations, but the review found this does not always follow, despite it being a requirement in annual appraisals, clinical audit and monitoring quality. An additional comment was in relation to Fitness to Practice investigations where guidance has not been followed "**appropriately"** (2.70). In the maternity services, AIMS often finds staff slavishly following guidance to the detriment of their clients but not reporting out of date or inappropriate guidance to their Trust.

Databases

Despite all the information in patients' individual records, 'they' still don't know who has what! This is in relation to medical devices, such as the mesh, and to those women of child-bearing age who are taking Sodium Valproate. The review has called for a more complex system, including evaluation of long term outcomes and patient safety. (See above Medications and Devices.)

Patient Safety

Risk profiles for medicines used in pregnancy and identifying teratogens

The risk of teratogenicity has meant women are largely excluded from clinical trials; as a result, only a handful of

medicines are licensed for use in pregnancy and the safety profiles of newer medicines in pregnancy are initially unknown. Indeed, the whole pharmaceutical and devices regulatory systems have been criticised as being sub-optimal for women[1,2,3]. There are moves to change this nationally and internationally. (2.122)

The review found that all the professional and systems regulators including the MHRA, NICE, Care Quality Commission, NHS England and NHS Improvement and the Department of Health and Social Care worked only within their own remits – there were no effective linkages between them and no oversight of the system as a whole. The review supports much of the work being done by these bodies, but highlights their failures, hence their call for a new Patient Safety Commissioner – independent, proactive, having statutory authority, accountable to Parliament directly. Read Theme 12: Patient safety – doing it better, starting at page 55, for an in-depth insight into the plan. It cannot be worse than we have now.

Challenges for healthcare professionals

- Listen to the patients and clients, listen carefully. Show that you've heard.
- If you are responsible for the maternal postnatal check at 6-8 weeks and your client has a pelvic floor disorder, search for evidence-based nonsurgical options, including that of specialist physiotherapy.
- If you have a patient to whom you are prescribing Sodium Valproate, check if she is of child-bearing age and ask her if it is possible she could get pregnant.
- Are you up-to-date with any alerts about a pharmaceutical drug, medical device, treatment or procedure you are prescribing or recommending?

If you are a birth worker, help your clients to be aware of these issues.

A lesson for us all

Anecdotal patients' evidence is too often disregarded. Evidence-based medicine is all very well and should be used when it is available. However anecdotal evidence should always be listened to and not dismissed and as this review shows, it may be the only evidence we have on side effects and issues. The pharmaceutical industry must not be allowed to dominate the evidence base, and independent research needs to be undertaken, along with long term review.

Conclusions

The review is comprehensive in explaining the history of pregnancy testing with Primodos, Sodium Valproate use in pregnancy and pelvic mesh and the regulatory background of how we have got to where we are today – it is worth the long read, although much of it is heart-rending and may leave you feeling angry and upset.

There is a systematic problem within healthcare provision and it needs everyone – clinicians, other professionals and managers - to face up to this truth and for pregnant women and people to understand the implications.

References

1 John Naish 'The everyday medicines that make women ill because they have only been tested on MEN' *Daily Mail* 5 November 2012

2 Amy Westerveldt 'The medical research gender gap: how excluding women from clinical trials is hurting our health' *The Guardian* 30 April 2015

3 Simon Crompton 'Why the drugs don't work for women and what to do about it' *The Times* 2 July 2019. (ref p53)

Article

What has the AIMS campaigns team been doing?

By the AIMS Campaigns team

- We have continued to review and update the AIMS Birth Information page, "Coronavirus and your maternity care," and our template letters for maternity service users and campaigners in line with the latest guidance from the NHS and the Royal Colleges. This includes the new guidance to Trusts from NHS England[1] on lifting the restrictions on partners/ supporters' presence at antenatal appointments and scans, during labour, and on antenatal and postnatal wards. For details of AIMS' response to this new guidance, see www.aims.org.uk/campaigning/item/latest-guidance-birth-partner. We also welcomed the efforts being made by NHS England to strongly encourage and support maternity services to re-open access to partners. Their letter to Directors of Nursing and Heads of Midwifery[2] (dated September 19) is well worth a read to support your local activity in scrutinising – and challenging, where necessary – the basis for local arrangements.
- For more details of AIMS campaigning on the issue of maternity service restrictions, see the AIMS Campaign report, "Removing Covid 19-related restrictions on partners".
- We welcomed the relaunch of NHS Resolution's maternity incentive scheme and the tightening up of the scheme to make it less open to abuse. Safety Action 9 supports the ongoing implementation of Continuity of Carer, which AIMS wrote about back in June. Although the relaunched scheme has been updated since we wrote about it, our article still offers useful background: www.aims.org.uk/journal/item/continuity-of-carer-incentives.
- We responded to a NICE consultation on a draft quality standard relating to FASD (Fetal Alcohol Spectrum Disorder). We argued that the maternity-related elements of the proposed standard demand further consideration and have been pleased to note that NICE is now taking its time in processing the consultation responses. Find our response here: www.aims.org.uk/campaigning/item/fasd-quality-standard.
- We have submitted comments on two draft NICE guidelines on Caesareans and Postnatal Care.
- We noted the publication of two open access papers evaluating the controversial "Obstetric Anal Sphincter Injury Care Bundle," obgyn.onlinelibrary.wiley.com/doi/10.1111/1471-0528.16396 and bmjopen.bmj.com/content/10/9/e035674.
- We submitted evidence to the Health and Social Care Select Committee enquiry on the safety of maternity services in England. You can read our submission here.
- We made a submission to the NHS-commissioned independent investigation into the issues and sequence of events which led to the cessation of community maternity services provided by One to One Midwives: www.aims.org.uk/campaigning/item/statement-one-to-one-investigation.
- We welcomed the appointment of Professor Trixie McAree as the national midwifery lead (England) for Continuity of Carer and we are in contact with herto ensure that AIMS continues to play an effective role in this policy area. AIMS looks forward to a time when we no longer talk much about a continuity of carer model of care because this will be the standard model of care offered to all women and families. See AIMS campaign update here: www.aims.org.uk/journal/item/coc-campaign-update.
- We were pleased to note that the "fresh ears" policy has now been deleted from the Saving Babies' Lives Care Bundle (SBLCB), following some effective collaborative feedback in which AIMS participated. Find the updated SBLCB document here: https://www.england.nhs.uk/publication/saving-babies-lives-version-two-a-care-bundle-for-reducing-perinatal-mortality/.
- We welcomed the scrutiny of health and social care services reported by the Care Quality Commission

(CQC) in their State of Care report 2019/2020: https://www.cqc.org.uk/publications/major-report/state-care. The report notes that at least a quarter of core maternity services were rated as "requires improvement overall" at the end of March 2020. Whilst risk-based inspections and enforcement action have taken place during the pandemic, AIMS is keen for routine inspections to recommence as soon as possible.

- We read the BMJ article on "Risk of complicated birth at term," which is discussed in "Ideological birth wars" on page 35 by Jo Dagustun.
- We read a new book from the Pinter and Martin publishing house, Amity Reed's Overdue: Birth, Burnout and a Blueprint for the NHS. This part memoir/part manifesto for change, and others like it in this growing genre (accounts of the maternity services told from the perspective of healthcare practitioners), provides an important and highly accessible reminder of why we campaign for maternity service improvement. The AIMS Campaigns Team highly recommends this genre to the maternity improvement community, especially those not working with birth and the maternity services on a daily basis. This book is a great up-to-date example of the genre.
- Our Volunteer Gemma McKenzie presented her AIMS-supported research as part of the 2020 Festival of Social Sciences. This included an early showing of a film that Gemma has created to communicate some of her early research material. Whilst Gemma's research focus is decision-making around unassisted birth, we would recommend her short (9-minute) film to everyone interested in improving maternity services, as it offers an excellent – if heart-wrenching – commentary on the impact of our contemporary encounters with the maternity services, both positive and negative. We look forward to seeing more of Gemma's authentic and co-created exploration of women's narratives of freebirthing in the UK. Find Gemma's film here: https://youtu.be/P38mvu9tlME.

Meetings attendance:

- We participated in the annual meeting of ENCA (European Network of Childbirth Associations), of which AIMS was a founding member: www.facebook.com/encaeurope/.
- We participated in the September and November meetings of the Maternity Transformation Stakeholder Council: www.england.nhs.uk/mat-transformation/council. Jo Dagustun has now taken over as the AIMS representative at these meetings, following in the very capable footsteps of Debbie Chippington Derrick.
- We attended (as an observer) the first ever National Maternity Voices' AGM: http://nationalmaternityvoices.org.uk.
- We attended an Oxford Brookes University webinar on "Challenges and Opportunities in Implementing and Embedding Change in Maternity Services."
- We attended the International Maternity Experience 2020 conference.
- We attended #MidwiferyHour Facebook live events, including one focussed on "Building Continuity of Care in COVID-19" and "Educating Future Midwives."
- We participated in the #ContinuityofCarer Zoom group.
- We attended the Association of Radical Midwives annual conference, "How Birth Works."
- We attended the Virtual British Intrapartum Care Society annual conference.
- We attended the Cardiff Midwifery Society conference "Beyond the Bump; how ethnic minority families are failed in maternity services."

References:

1 http://web.archive.org/web/20201105154603/https://www.england.nhs.uk/coronavirus/publication/framework-to-assist-nhs-trusts-to-reintroduce-access-for-partners-visitors-and-other-supporters-of-pregnant-women-in-english-maternity-services/

2 http://web.archive.org/web/20201102164954/https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/09/letter-to-directors-of-nursing-and-heads-of-midwifery-19-september-2020.pdf

3 www.bmj.com/content/371/bmj.m3377/

Article

Introducing the Childbirth Choices Matter Campaign

By Kay King

The UK-based Childbirth Choices Matter campaign has a vision to create a new insurance product for self-employed professional midwives, without being tied to the premiums set by commercial insurance companies, together with an access fund which will allow women and birthing people to access this form of care if they choose.

Self-employed midwives are fully qualified professionals who are registered with the Nursing and Midwifery Council (the NMC), the regulator for midwifery practice in the UK. Point 12 of the NMC Code of practice states that midwives must "have in place an indemnity arrangement which provides appropriate cover for any practice you take on as a nurse, midwife or nursing associate in the United Kingdom. To achieve this, you must make sure that you have an appropriate indemnity arrangement in place relevant to your scope of practice."

We started our campaign because we saw the need for an indemnity product that didn't fluctuate with the mood of the commercial insurance market. Since launching the campaign, the premiums required for the indemnity insurance on offer from the commercial market have become so high there is simply no affordable indemnity option available for self-employed midwives. Subsequently, many find themselves unable to practice legally in the UK. This made our aim of launching our own product, independent of the commercial insurance market, even more urgent.

We understand that insurance is absolutely necessary for practising midwives and that the cover should be at a level that represents the claims that could potentially be made. Such an indemnity product obviously requires a significant amount of upfront investment. Our key task at the moment is therefore fundraising, across many streams of income, to support this fully independent insurance product as soon as possible.

Another part of the vision of the campaign was to establish a network that supports midwives wishing to transition into working in a self-employed capacity by choosing to step away from the NHS. It is our belief that midwifery expertise should be grounded in a social model of care, with an emphasis on advocacy, supporting well-being, and protecting public health, and that women and birthing people should be able to choose the model of care that suits their needs.

Some NHS Trusts can make it difficult for midwives to support women in the way they need to be supported and cared for, and having midwives working outside the NHS system has been crucial in enabling some women to make informed decisions about their care when the NHS services have failed to support them. The threat to individualised care has been increased during COVID-19, when women and birthing people's choices for care within the NHS have been withdrawn or dramatically limited due to fear of infection and a perceived need to centralise resources. This has presented many midwives with a barrier to providing personalised care and has caused upset amongst the midwifery profession.

Similarly, women and birthing people may find it very difficult to have decisions about their care respected by NHS staff, especially if they wish to have care that is not recommended in hospital guidelines. Employing an independent midwife can provide these people with the chance to have the birth they want – but currently this option is beyond the financial reach of many. This is why we saw a need for an access fund for families to use, if they needed it, when they are making choices about their birth care.

So, to sum up, we need a lot of money to achieve this, and we have a team of fundraisers working tirelessly to make it a reality. Over the coming months, we will have lots of different ways in which people can join in to make this long-term vision a reality. We are extremely grateful to everyone who is supporting our campaign.

At its heart this campaign is about feminism. With the creation of a women-led, women-run indemnity product that

cannot vanish overnight, as commercial products are wont to do, alongside an access fund to ensure equity, we are committed to working towards returning the choice of caregiver to the options available for all women and birthing people.

You can read more about the campaign here: www.childbirthchoicesmatter.co.uk. Follow us on Instagram @childbirthchoicesmatter.

Kay King is the Executive Director for White Ribbon Alliance UK. She is a birth activist, doula, and fundraiser.

Birth Activists Briefing

What is a Professional Midwifery Advocate (PMA)?

by the AIMS Campaigns team

The Professional Midwifery Advocate (PMA) is a role which has replaced the Supervisor of Midwives (SOM) in England. PMAs should now have been appointed in all NHS Trusts in England. This is part of the new model of midwifery supervision, A-EQUIP, which was published in 2017. A-EQUIP stands for Advocating and Educating for Quality Improvement.

PMAs should be experienced registered midwives who have undergone specific training in the role. In Scotland, Wales, and Northern Ireland, there is a similar role for "supervisors." Both supervisors and PMAs in all four nations have to follow an education programme based on the same key principles.

The following document details the A-EQUIP model and the role that PMAs should have in supporting women: www.england.nhs.uk/wp-content/uploads/2017/04/a-equip-midwifery-supervision-model.pdf

It states "The PMA is a new and fundamental leadership and advocacy role designed to deploy the A-EQUIP model. The role supports staff through a continuous improvement process that aims to build personal and professional resilience, enhance quality of care and support preparedness for professional revalidation."

Trusts can decide whether to employ someone in this role full time or to appoint someone to do it in addition to another role in the maternity service.

The A-EQUIP model is intended to work for women in three ways:

- Advocating for women
- Providing direct support for women within a restorative approach
- Undertaking quality improvement in collaboration with women.

PMAs should be ensuring that all midwives are equipped "with the skills and knowledge to be able to advocate confidently for women". In some cases, the PMA will offer direct support to women, but the maternity service provider can decide whether they should have this direct role or not. From what AIMS has heard, they do have this role in many Trusts, but not all.

It is well worth reading the section of the document entitled "How A-EQUIP and the PMA role works for women" which explains in detail how PMAs should train and support midwives to advocate for women. It makes clear that "Part of the PMA's role is to support midwives to support women whose care choices they do not necessarily agree with and may find distressing" and to "help colleagues to recognise that a woman's view of benefit and risk is subjective and may differ from that of the healthcare professional, but nonetheless needs to be respected and advocated for, as long as the woman has been given all the information required to make an informed choice."

Other aspects of the PMA's role which are particularly relevant to women and pregnant people are supporting the provision of listening services and consulting with them "when initiating service improvement initiatives."

Action for Birth Activists:

If you are someone who supports maternity service users to escalate concerns about their care needs when their named midwife is unable or unwilling to advocate for them, find out whether PMAs are available to directly advocate for women in your Trust. If not, then find out what alternative form of advocacy the Trust is providing to consider individual needs, such as a discussion with the Head of Midwifery or the local consultant midwife or midwives.

Whatever the advocacy process is, the relevant contact details should be easily accessible to service users on the Trust's website, and also provided at the first midwife appointment and included in the maternity notes. If the details are not easy for service users to find, then you may want to raise this issue with the Trust and the local MVP (Maternity Voices Partnership)/ Maternity Service Liaison Committee (MSLC).

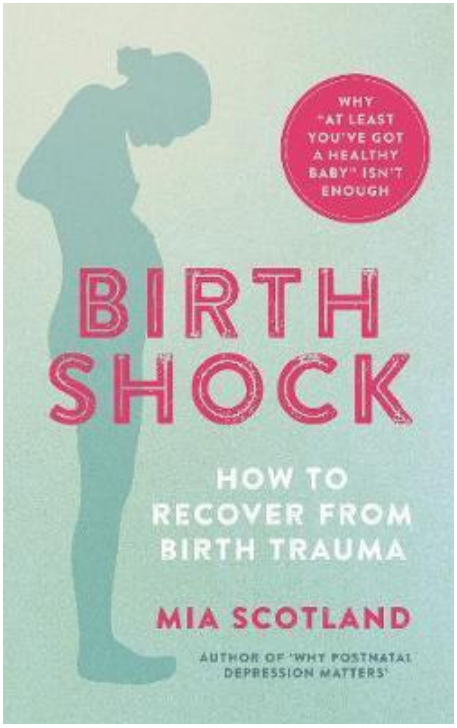
Book Review

How to recover from Birth Trauma

by Mia Scotland

ISBN: 9781780664958
224 pages
Published by Pinter & Martin (2020)
List price: £12.99

Find this book on Waterstones



This new book by Mia Scotland is a perfect read for women, and their families, who suspect that they have suffered trauma in connection with giving birth. Mia is a perinatal clinical psychologist, specializing in birth trauma and perinatal mental health issues. Mia's care about this subject - and her kind and patient support for women and families - is evident in every page.

Focussing not only on the 'whats and ifs' of birth trauma, this text lays foundations and contextualises, by taking the reader on an easily readable and accessible journey through the history of birthing and the maternity services in the UK, including an examination of how people might be affected by different ways of birthing and of organising care. By people, I include partners, since this book also encompasses the trauma that can be experienced by those witnessing trauma and being involved in that journey alongside their loved ones. In later chapters, there is also a focus on trauma experienced by those in the wider birthing community: midwives, doctors, doulas and allied health professionals. As a midwife, I felt that the book did a good job in highlighting that all birth professionals are human and therefore can experience vicariously the trauma of others. This is such an important subject, not only for women and their families to recognise, but birth professionals too. It was an 'I hear you' moment and I applaud the author for this.

One of the real strengths of this book is how it moves away from the perception that trauma is caused alone by labour and birth, discussing how events surrounding birth, for example having children in special or intensive care, breastfeeding experiences and experiences of postnatal care, can have an equally devastating and long-term effect on women and their families. The inclusion of discussion around trauma in babies is an angle that I have rarely considered in this context, and was highly thought-provoking. Additionally, the gently presented differences between anxiety, depression and PTSD was highly effective, and should be of real practical help.

Whilst this book's target audience is women and their families, I'd also recommend it to birth professionals, and indeed anyone seeking a starting point for exploring some of the main issues around birth trauma and resolution. The text is sensitively written, mindful of the reader who might find some of the book emotionally difficult to read, and each chapter is accessible, clear and simply presented. The chapter that delves into the psychology of birth trauma is very interesting indeed, and I'd say succeeds where many texts fail, in simplifying the psychological processes involved in trauma without 'dumbing down'.

To sum up, I think that this book would be helpful for anyone wondering if they are suffering trauma, including when planning for a future pregnancy. The book treats those living with birth trauma respectfully, as people with agency: it describes a range of helpful techniques and routes for support (not just NHS) as well as plenty of friendly and accessible tips for reflection and planning. I would predict that this book - as well as being helpful in its own right - will nudge some readers to seek the further support and help they deserve.

Reviewed for AIMS by Anna Madeley

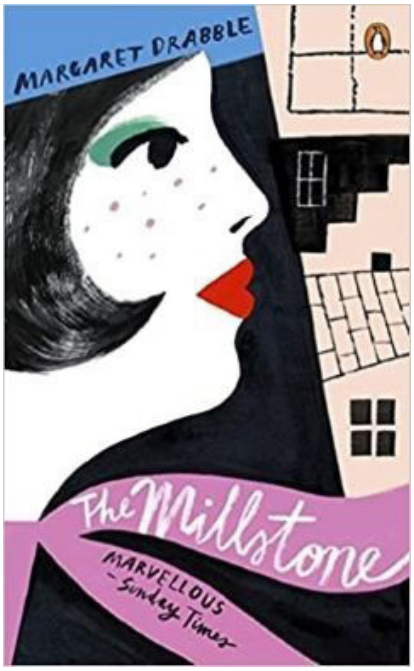
Book Review

The Millstone

by Margaret Drabble

Various editions of this 1965 classic are available. The cover below is the Penguin Essential version,
176 pages
List price: £8.99

Find this book on Waterstones



I was given this book during lockdown and although it is unusual for AIMS to review fiction books I realised that it was an interesting book to review given this is AIMS' 60th Anniversary year. It was first published in 1965 so not quite as old as us!

It tells the story of a young woman in the 60s. Rosamund is a well-educated, well brought-up, daughter of middle-class socialists living in London in her parent's flat whilst they are out of the country. She has a few issues with the new freedom of sexual encounters, but eventually finds herself pregnant after a one-night stand. She tries the 'usual ways' of losing the baby, but soon realises that she really wants to be a single mother.

There follows the most delightful story of Rosamund's experience of pregnancy and birth. The medical students who probe her fundus, listening to the horror stories about birth and getting to hold a baby for the first time and realising they are quite heavy, warm and damp. Then waiting for labour to progress, listening to the chatter of five nurses in the corridor and then … I won't spoil the story, but it's one we still hear today! She enjoyed her stay in hospital 'fortified by the superior beauty and intelligence' of her child.

She takes her baby, Octavia, home and is doing well. But when the baby is a few months old Octavia needs a life-saving heart operation. After the operation, the matron says she can't see her for a fortnight and our heroine reacts ...

This novel is set in a decade long gone, but I would recommend the book as it will remind us of how far we have come in terms of maternity services and how far we have not. It is an incredible feminist novel too, one which I think should be on young people's reading lists, as it is as good and relevant as when it was first published.

I nearly didn't read it because of the title as I don't think of a baby as a 'millstone'. However I'm very pleased I did, as it reminded me of the joy of pregnancy, birth and motherhood. There are, apparently, reasons for the title that I will pass to English graduates to explain!

Reviewed for AIMS by Shane Ridley

There for your mother

Here for you

Help us to be there for your daughters

www.aims.org.uk

Twitter – @AIMS_online

Facebook – www.facebook.com/AIMSUK

Helpline

helpline@aims.org.uk

0300 365 0663