



## The paradox of too much or too little care

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*Helen Shallow reports on the International Confederation of Midwives Congress*

I was extremely fortunate to be funded by the University of West of Scotland (UWS) recently to attend the 30th International Confederation of Midwives (ICM) Congress in Prague. As I share my reflections on the Congress I will, at the same time, include the story of what happened to a woman I know, who gave birth during my time at Congress. I believe her story is a relevant and poignant example of where contemporary UK NHS midwifery and obstetric care has failed yet another new mother and why, despite a live mother and baby, how the woman feels after the birth of her baby matters.

In the following account of key lectures from the ICM Congress and themes from the concurrent sessions on women and human rights, I have linked the story of Sarah (pseudonym) as I believe her story is a painful example of where maternity care in high-income countries causes harm to women. My thoughts about the Congress and the mother's story have created a troublesome paradox, which needs to be teased out.

### The ICM Congress

At Congress there were 3800 midwives from all round the world attending keynote lectures and a variety of workshops and concurrent sessions led by researchers and specialists in their field. Notably there were very few non-midwife delegates.

The statement that 92% of maternal deaths occur in the 73 lowest income countries with only 42% of the world's medical nursing and midwifery staff came as no surprise, but still leaves me feeling a sense of guilt and undeserved privilege, living as I do, in a high-resource country like the UK. One could question why any of us complain about maternity services in the UK when so many women in low-income countries cannot access maternity care at all with devastating consequences. However, there is a real and present issue in the UK and other high-income countries whereby valuable resources are overused due to a highly risk averse culture. Why we should question UK maternity care, was discussed by Lisa Kane Low (Associate Professor of midwifery, University of Michigan) in her keynote speech.

Lisa argued that access to health care is not just an issue confined to low-income countries. North America is one of the richest countries in the world; nevertheless there are inequities and access issues for many families who cannot afford private health care insurance. We know that in the UK there are health inequalities and women who are most disadvantaged generally have the worst maternal and neonatal outcomes. Lisa went on to say that the disparity of inequity goes further, in that two thirds of

the world's adult population control only 2% of the world's wealth.<sup>1</sup> Yet how we use those resources in maternity care in high-income countries illustrates why we do have something important to say about improving maternity care in the UK. Lisa noted that the current 'template of technology' results in increased surgical births and the 'misapplied use of technology'. Therein lies the paradox of over use in resource rich countries (such as ours) and underuse in resource poor countries where for example, the secure supply of a modicum of basic drugs such as antibiotics, a safe blood supply, and appropriate technologies such as hand-held battery-operated dopplers along with more secure employment conditions for healthcare workers, would and should save lives. However as Marjorie Tew showed in 1990, the belief that technology is the only answer is misleading.<sup>2</sup> A major theme of the conference focused on commitments to address inequalities in health caused by poverty, hunger and inadequate health and education infrastructures that we know would impact positively on overall health outcomes for women and families in resource poor countries.

## Sarah's background

Sarah is a 42 year old first time mother. I first met Sarah over 20 years ago. We had long lost touch until very recently when I received a call asking if I could keep an eye on her as she was now pregnant and living in the area where I work as a consultant midwife. Sarah had returned from London at 36 weeks, to have her baby in her home area. From the outset Sarah knew I could not commit to being her midwife as plans for the ICM and a holiday had long been made. I offered her support as a friend and in my professional capacity I helped her to communicate her place of birth intentions, as the obstetric team had challenged her decision to birth in the birth centre.

As you read Sarah's account please bear in mind that during the human rights session at the Congress, Hermine Hayes-Kleine, a human rights lawyer from the USA, noted that even though women make up over the half of the world's population and have a 'right to the highest attainable standard of health', many women do not have healthy births. Hermine concurs with the WHO definition of health, whereby women have the right to health, which is more than just a live baby but also includes physical, emotional and spiritual health. Sarah had been well throughout her pregnancy. In London at around 35 weeks her abdomen measured larger than expected and she was referred for a scan. The scan showed 'mild polyhydramnios' (extra fluid round the baby). The accuracy of amniotic fluid measurement is questioned by some authors and as a measurement alone is not sufficient evidence on which to recommend induction of labour.<sup>3</sup> Nevertheless a 'helpful' GP put the idea in Sarah's head that it would be better for her if she went into labour at 37 weeks. How, I wondered, was she supposed to do that without intervention? I talked it through with her and suggested that as the extra fluid was mild it may resolve and as she had another scan scheduled that would become evident.

Karen Guilliland, ICM board member and Chair of the Human Rights session, noted that we have become a 'fetus centric' world that compels us to see through the woman to the baby and, as a result, we are not putting mothers first. When society does not put mothers at the centre, we as midwives will (and do) also find it difficult to be woman centred. As soon as we cast doubt on the wellbeing of her baby a woman

finds herself trapped in the web of 'what ifs' even when there is no immediate threat requiring action.

Everything else about Sarah was normal except, according to NICE criteria, her age.<sup>4</sup> Sarah commented that she knew at some point she would *'have to have the age debate with the doctors'*. Sarah was well and her baby's growth was fine and yet the obstetrician in London had already undermined her confidence by talking about the *'age issue'* and *'need'* for induction at 38 weeks.

Sarah deferred the decision in the hope that the local obstetricians would be more enlightened. In the event, at the next scan at just over 37 weeks, the fluid levels were back to normal, however, the sonographer noticed an anomaly with baby that could not be fully explained until after her baby was born. Sarah was again advised she should go to the labour ward, and again induction was recommended. The conversation went something like this: *'Was this due to the anomaly seen in baby?' No it wasn't. 'So why then?' ... 'Well, just in case, your age, your history of increased fluid...' ... 'but that's resolved', 'yes', 'so I would still like go to the birth centre'. 'Well, we'll just do a stretch and sweep today' her reply being 'no thanks'. Later Sarah described how the offer of a cervical stretch and membrane sweep sounded like she was being 'offered a cup of tea' and the doctor appeared confused when she declined.*

In the Human Rights lectures, Hermine Hayes-Klein outlined a legal definition of informed choice. The woman is informed of all of her options. She can be advised by the professional what he/she thinks she should do and why. Then the professional must support the woman even if she goes against their view. If a professional does not support in this way it is not choice. Health care professionals cannot say *'I'm the expert and you cannot decide'*. Choice goes beyond clinical evidence. No-one but the woman has all the information in the context of her life and family.

Sarah was well informed and had confidence in her ability to birth her own baby and yet it was becoming clear to me that she was facing the oh-so-familiar and difficult obstacle course that has an incremental demoralising effect on a woman's confidence, as of course, her baby comes first.

paediatrician and was assured that the anomaly may well resolve and that the only plan would be to scan the baby six weeks after the birth. I communicated with the birth centre manager and Sarah's consultant obstetrician that Sarah would be going to the birth centre when her labour started. She planned to await spontaneous labour and she fully understood the indications which could lead to transfer to labour ward. As Sarah's story unfolded we kept in touch via email intermittently as reception was not always possible.

Speaker after speaker at Congress talked about putting women at the centre of care. *'Women', they said, 'need to be key decision makers as it is they who take their children into adulthood'* (Professor Lesley Page). Irrespective of country or level of income the rights of women to sexual and reproductive health and self-determination are seen as paramount. That every pregnant woman should have care by a trained and skilled midwife was seen not only as the *'best value for money'* (Frances Day-Stirk, President of ICM), but as the best option for women in terms of outcomes. It would appear that government and nongovernment organisations are no longer advocating that all women must birth on an obstetric labour ward and yet for many complex reasons, including the fear engendered in women, midwives and doctors,

this continues apace. Whilst in Prague I continued communication with Sarah as and when I could. She had reached her due date and all was fine. The plans were going well and she was just waiting in happy anticipation. At the end of the Congress, we all went our separate ways, my husband met me in a rented camper van and we drove off quite literally into the sunset.

Email communication became more erratic but Sarah remained on my mind. I sent reassuring emails not knowing if she would receive them, in a long distance attempt to keep her confidence up, knowing the pressures she had been facing. Then when she was just five days past her estimated due date her waters broke.

She emailed:

*'Things have taken an unexpected turn! Waters broke last Thurs eve so I was then on the clock in terms of being able to have natural labour at the birth centre. Went in to birth centre on Friday was having regular contractions and the view of the doula and midwife was that I was in labour. I got into the pool and continued having contractions through the night - pretty strong and regular. But then seemed to slacken off and VE at 4am showed I was only 2cm dilated!!! Was then given 'til 11 to see if more progress could be made. Increased by 1cm so decision to transfer to labour ward.'*

Sarah wrote this email after transfer and an epidural had been sited and she said she was waiting... My spirits sank as I read Sarah's email. Fresh out of Congress with renewed hope, to hear that Sarah was 'on the clock' and the race was on to see if she could get into labour within the prescribed timeframe, was disheartening and reaffirmed all that is wrong in contemporary maternity care. No surprise when I read that, exhausted, she had 'succumbed' to the epidural and was waiting, and I knew what she was awaiting, but hoped against hope that I was wrong. Nevertheless I sent a resoundingly positive message of affirmation and support from us both and we anxiously awaited news knowing that her baby's birth was imminent.

At Congress one of the overwhelming messages was that midwives need to act autonomously and that women should be key decision makers, but here we had a woman with a midwife and her doula in attendance, who all appeared unable to protect Sarah by challenging a seemingly intractable system that does not allow for professional autonomy or individual decision making. The utilitarian one size fits all model was well into play.

Despite the rhetoric of choice and empowerment, noone was empowered in this account, least of all Sarah. A tense 24 hours passed before we could access our email again. I sent my husband to retrieve it, as I could not bear to, fearing what I anticipated but hoping to be wrong. The look on his face said it all on his return. This is what Sarah wrote:

*'Hi Helen baby was born at 10.23 this morning. 8lbs 4ozs. Had to have a caesarean, as despite being in a perfect position and me pushing effectively she would not come out fast enough. There have been so many timeframes in this pregnancy that I appreciate are about reducing risk but have made things stressful. Forceps didn't work so I had to have a section. Am disappointed that I had almost every intervention but realise how unpredictable birth is...'*

So how was it then that I could predict it, even though I hoped so much to be wrong? So the baby could not come out fast enough. Fast enough for whom? Sarah felt she understood that the actions taken were all about reducing risk but reducing risk to whom? Her baby was in a *'perfect position'*.

No one could have done more than Sarah to ensure she and her baby remained healthy throughout her pregnancy. As soon as her waters broke naturally she was virtually destined towards caesarean section due to the time constraints placed upon her to perform accordingly. Where were her advocates when she needed them most? Sarah thanked me for my support, but I was not able to be there when she needed that support the most.

The evidence around spontaneous rupture of membranes and risk of infection has changed over the years and the NICE intrapartum guideline currently recommends 'offering' immediate augmentation or after 24 hours after ruptured membranes; and yet the NICE guideline on antenatal care used to state that there was no increase of infection up to 96 hours after ruptured membranes. I cannot see where and how this evidence was superseded by newer evidence that shows expectant management to be more risky.<sup>4</sup> So where was Sarah's right to base a decision on this somewhat conflicting information when her labour started to be managed? I am not inferring that anyone deliberately set out to cause harm. On the contrary, I am sure everyone felt they were doing their very best for Sarah under the circumstances. Unfortunately the prevailing circumstances are those described by Lisa Kane Low and so many others at Congress, when she described the alignment of high income to increased technological know how and over use, linked with fear of litigation, and underuse where it may be needed but is not available or easily accessed in low income countries.

*'However, in most cases, there is no absolute indication. The decision to perform a caesarean section involves balancing multiple risks: short- and long-term, maternal and foetal, for and against performing the procedure. Judging the balance of these risks for an individual woman in many ways requires more skill than performing the procedure.'* (Editor's emphasis) Smith GCS (2014) Variation in Caesarean Section Rates in the US: Outliers, Damned Outliers, and Statistics. PLoS Med 11(10): e1001746.  
doi:10.1371/journal.pmed.1001746

So, surely, in order to support healthier births and improved outcomes in all settings, we need to look beyond the rhetoric of risk, which stifles women's potential, and implement known solutions to improving women's health while at the same time providing more honest education that strengthens self efficacy and empowerment. All women have the right to be properly equipped both mentally and physically to play an active key role in self determination that impacts on improved health both physically

and emotionally as well as spiritually; not just for her but for the wellbeing of her whole family.

In Elizabeth Prochaska's (English barrister and a founder of the organisation birthrights) lecture on human rights violations I would suggest that several of Sarah's human rights had been violated as follows:

- Non consented care - what is consent when fear is engendered by non compliance
- Misinformed care - not outlining risks of augmentation after ruptured membranes or risks of time constraints
- [possible] Discriminatory care - 'She's done all the classes and you should see her birth plan!'
- Abandonment - epidural sited and waiting.....

## In conclusion

Sarah's story parallels some of the themes that came from the ICM Congress. It painfully demonstrates the contrast between the reality and the rhetoric. I know without a shadow of a doubt that it could have been very different for Sarah. She may have had a caesarean anyway but she may well have not. We will never know that. What we do know is that she stood little chance against the hegemony of risk averse management of labour that puts the needs of the professional and the organisation before the needs of women '*just in case*'. She wasn't given the time to enable her body to continue to do what her body had already started to do after her membranes ruptured spontaneously. The hormone drip and the epidural, the stress and the feeling of disempowerment ultimately led to her not being able to birth her baby unaided. In short, we have a live mother and baby but we also have a new but 'disappointed' mother who will need time and support to assimilate what has just happened to her and to know that she is not to blame.

Helen is currently registered at UWS for her PhD study exploring what happens to women when their labour starts.

## References

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