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Just Baby, Me and Multimorbidity: Where Did All the Care Go?

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By Dr Etomby Namme

I was born with Sickle Cell Anaemia. My parents didn't know it at the time, but after a couple of years of back-and-forth hospital trips with their baby, the diagnosis came, and I have been lucky enough to grow up knowing about my condition and how to manage it. One of the things I always "knew" or thought I knew, was that people with Sickle Cell Disease aren't likely to be able to have babies successfully, if they even make it to fertile age at all. So as a young teenager turning into a young lady, talking and dreaming about her future with her friends, I asked one of my best friends to be a surrogate for me because I so badly wanted to have children and knew that I would, one way or another.

Despite the many doctors over the years as I reached the age of fertility, who warned me of the dangers of getting pregnant with Sickle Cell Disease; despite their many lectures about needing to stop Hydroxyurea (the only drug that brought me some symptomatic stability from the age of 14); despite the risks, I felt in my heart a yearning to be pregnant and carry my own child.

That yearning became a reality, and aside from my Booking Visit, when the Maternity Nurse asked me how long I have had this genetic condition that I was born with… I was swiftly transferred to consultant led care and managed very closely. I was fortunate enough to live right next to a tertiary hospital that had both my haematology services and Obstetric services as well as the other speciality services which monitor me for other conditions. They quickly formed a Multidisciplinary team (MDT) that met regularly to review my case and scheduled my appointments on the same day as much as possible to reduce the burden of frequent hospital visits not only for monitoring the pregnancy but managing the effects of my condition. They kept a close eye on my health and managed my numerous hospital admissions whether for a Sickle Cell Crisis, respiratory review for asthma or for overnight monitoring due to reduced foetal movement. I had heard so many harrowing stories that I was so grateful to be in this supportive environment. The Specialist Sickle Cell nurses were my point of contact, and they did a phenomenal job of liaising with the other specialist teams, including maternity services, whenever I called them with issues.

Unfortunately, my little boy was born prematurely at 35 weeks via emergency caesarean, but I truly believe the reason we got as far as 35 weeks is because of the great work done by the MDT and the way they were able to communicate and liaise with each other to devise a comprehensive care plan.

After the birth, he was whisked off to the Neonatal intensive Care unit (NICU) and I still required blood transfusions and IV morphine, fluids and oxygen to manage the Sickle Cell crisis that had led to his early appearance. Eventually I was wheeled down on my bed to the NICU to hold my baby for the first time and could not stop crying as I was wheeled back up to my own hospital bed where I somehow had to start expressing colostrum and begin a milk expression routine. This ultimately hampered my own recovery as it meant I had to refuse opiate, and being on a 4 hourly expression routine was of course not conducive for sleep and healing. I also had the added stress of trying to express while separated from my baby with nothing but the blanket he was first wrapped in and a picture to try and trigger the natural hormones that would facilitate the milk letdown and engorge my breasts. Suffice to say the engorgement never came. I was nevertheless determined to give him the 2 ml of milk I could express to be added to his tube feed.

While in hospital, I would organise with family to take me down to the NICU in a wheelchair or beg any member of staff who was free to wheel me down to the NICU so I could try to start breastfeeding, which I so desperately wanted to do. He was being tube fed, so had no drive to feed and hadn't developed a good suckle so it was not going well. I looked to the NICU nurses for advice and was met with responses of "try not to stress, fed is best". Not satisfied with that, I managed to search for breastfeeding support services in the local area and to my surprise found there was a service in the very same maternity hospital just 4 floors up from the NICU. I made arrangements myself and went to seek their advice and thankfully they had some for me which very much helped. It left me wondering however, why I wasn't signposted to them by the NICU nurses. Did they not know about them?

I began to wonder why I felt so alone and overwhelmed. Why did I have to ask if the hospital had a breastfeeding pump I could borrow? Why did I have to beg to be wheeled down to the NICU? Why couldn't my baby be brought up to my room since he wasn't on any ventilation? Why did I feel like I had to figure it all out by myself? I was in the maternity hospital so I wasn't getting the regular review and care I would get for my Sickle Cell Crisis on the Haematology ward, but because I was being treated for a Sickle Cell crisis in a side room with the advice provided to the postnatal ward by the Haematology team, I wasn't being treated like a postnatal mother either. What happened to that wonderful MDT management? What happened to all the support? Where did that feeling of being cared for go?

When I was finally discharged and my baby and I were home, I was contacted by our local health visitor for our first visit and looked forward to getting some advice and support with managing my health conditions along with now being a single mother. The health visitor showed up for our first visit with her trainee in tow and I was happy to see them and go through things with them. But it very quickly became obvious that she knew nothing about my underlying health conditions as she asked nothing about my physical recovery or pain management and when I offered this information, she had little advice but lots of sympathy.

I had been given no advice as to when to restart my regular medications and didn't have a Haematology follow up booked for 3 months so as I was breastfeeding, I chose to stay off medications. Thankfully I had family support, but they also had other responsibilities, and I didn't want to be a burden on anyone. My mum stayed for the first couple of months and was a Godsend but after she left, I wondered every time I gritted through the pain of a crisis, whether I should go into hospital; what would happen to my baby if I was admitted urgently and no family members could get to me in time? Would the baby stay with me? Would we be separated? Would people think I was an unfit parent being a single mother constantly going into hospital and not being able to look after him? I cried as he cried for milk and my stressed, in-pain body gave him none, and finally gave in to formula feeding though he suckled constantly for comfort (both mine and his). In those 3 months before my first postnatal Haematology review, I felt I had been abandoned. The birth had taken place, the MDT disbanded and I was on my own, with a community team that was ill equipped to support me. How did all that good, coordinated care dissolve so quickly?

The reality is my experience is only a small part of a much wider problem of disjointed care for many women with multimorbidity, particularly as they go through maternity care. *“Lost in the System: Responsibilisation and Burden for Women With Multiple Long-Term Health Conditions During Pregnancy”*by Stephanie J.Hanley, *et al*[1]; is a compilation of qualitative data collected from women with multiple health conditions about their perinatal experience, and from the healthcare providers who manage them. Many of the women spoke about a deterioration in their own care and a much greater focus on the baby, describing exactly the burden of responsibility I myself went through and speaking to the desperate need for more cohesive care:

“Once you have a baby the focus completely shifts, it's like you're love-bombed when you're pregnant, and then when the baby comes it just drops like a hot rock.”- (W26, Ankylosing spondylitis, fibromyalgia, 5 months postpartum)

Another participant; a health visitor herself, described how a 6-week routine postnatal check with her general practitioner was focused solely on the baby with no attention towards her health conditions or birth experience.

“They checked baby, but … not me. So, from my experience as a health visitor, I know most mothers receive phone calls anyway, but I just thought maybe for me it will be different because of my health conditions and how much blood I had lost. But the fact that they didn't was quite poor.”- (W10, Endometriosis, polycystic ovary syndrome, anaemia, 5 months postpartum)

Healthcare providers themselves recognise the gaping hole in maternal care when it comes to the postnatal period, with some on the study describing it as, “falling off a conveyer belt”. Like many other women, I experienced a stark difference between the excellent coordinated antenatal care and what felt like crash landing in a nowhere zone of care. This highlighted to me, not just the fact that good multidisciplinary care is highly effective, necessary and entirely possible, but also that simple policies and multiagency communications need to be put in place to make this a reality in the postnatal period.

One healthcare provider in the study described a lack of postnatal care funding as an issue where the ‘job is done’ if the mother and baby simply survive. Another shared concerns about a lack of specialist postnatal follow up:

“I guess the intensity through pregnancy is probably quite high, and then I think they fall off the conveyer belt at the end, baby is born….You hope somebody picks them up, because the teams that look after them during pregnancy, the cardiac teams for example, don't always look after them post-pregnancy. So, some of them will, but not all of them, because the gastro consultants, the cardiology consultants that manage them in the pregnancy have their own cohort of patients, they don't always manage that condition outside of pregnancy.” - (S11, Consultant in Obstetrics & Gynaecology)

Currently, postnatal care often focuses narrowly on the baby’s health with minimal focus and support around the mother’s wider needs, which does not adequately support women in the postnatal period. Women are tasked with managing their own care navigation, linking up their different teams and coordinating their care themselves, whilst also trying to manage the health of their baby who may also have complications as a result of being born prematurely; as is often the case with multimorbid pregnancies.

I can’t imagine how women dealing with postpartum depression, or any other mental health issues, or those with lack of family support, are able to get through this when I myself, armed with knowledge and family support, still struggled incredibly. In fact, I know that sadly some women DON’T make it through the postnatal period, with the MBRRACE-UK report highlighting that 40% of maternal deaths in the post-natal period were due to mental-health related problems.[2]

Having now gone through medical training myself, I have seen the difference simple strategies like ‘Hospital Passports’ and SBAR (Situation, Background, Assessment, Recommendation) handovers to community care can make. A similar ‘Perinatal Passport’, providing real-time access to the mother, with information about her medical condition and strategies for times of ill health or symptom exacerbation, along with the baby’s information, is essential for effective and safe interprofessional communication. This allows for more cohesive management and supports the implementation of a personalised, MDT-led care plan, even in areas where services are often dispersed. This information not only equips health visitors and community professionals to ask the right questions, reducing the risk of complications being missed, but empowers the mother to discuss her needs, ask for help and feel supported so that both she and her newborn can thrive. Currently, Badger Notes are used by many trusts in this way. These should be adopted across the UK.

Postnatal care needs to value the mother’s health alongside the baby, particularly in the well recognised ‘Fourth Trimester’. We need to draw from current working models of MDT antenatal care and apply and extend those principles into the community where postnatal care is largely housed.

Policy makers and clinicians must recognise that **birth is not the end of care - it’s the beginning of the next phase of the perinatal period**.

Author Bio: Etomby Namme is a Clinical Research and Sickle Cell Advocate. Dr Etomby Namme, shares her personal experience of perinatal care, with a call to action for better postnatal care for all women.

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[1] Hanley, S.J., McCann, S., Lee, S.I., Vowles, Z., Plachcinski, R., Nirantharakumar, K., Black, M., Locock, L. and Taylor, B. (2024), Lost in the System: Responsibilisation and Burden for Women With Multiple Long-Term Health Conditions During Pregnancy. Health Expectations, 27: e14104. https://doi.org/10.1111/hex.14104

[2] Allison Felker, Roshni Patel, Rohit Kotnis, Sara Kenyon, Marian Knight (Eds.) on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care Compiled Report - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2020-22. Oxford: National Perinatal Epidemiology Unit, University of Oxford 2024. ISBN: 978-1-0687913-0-7