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COVID-19: Neonatal Nursing in a Global Pandemic

In this October 2020 edition of the Journal of Neonatal Nursing, we continue to welcome the contributions of neonatal nurses around the world, who have reflected on the impact of the COVID-19 pandemic on neonatal care, babies, families and staff. This writing project is being coordinated by Dr. Katie Gallagher (University College, London (UCL)), Breidge Boyle (Co-Editor; Journal of Neonatal Nursing), Alex Mancini (Chelsea and Westminster NHS Trust, London) and Julia Petty (COINN and UK Neonatal Nurses Association Board member).

Here, in the second of the reflective series, we present contributions from Brazil, Northern Ireland, New Zealand and England. The world regions represented in this issue are highlighted in Fig. 1. Nuances in language have been retained to emphasise the authenticity of our contributors.

Reflections on the impact of COVID-19 on neonatal care in Brazil

Andréia Cascaes Cruz: Professor at the Escola Paulista de Enfermagem, Universidade Federal de São Paulo, Brazil
Myriam Aparecida Mandetta: Professor at the Escola Paulista de Enfermagem, Universidade Federal de São Paulo, Brazil

At the time of writing, over 1.3 million COVID-19 cases, with approximately 57000 deaths have been confirmed in Brazil, according to WHO data. Nonetheless, COVID-19 has not had a major impact on babies’ health in the country, as few neonates have been affected and nearly all those testing positive have recovered. Brazil comprises a huge territory, with stark differences in neonatal care. Meanwhile, the COVID-19 pandemic has adversely affected parents and whole families likewise. The birth of a new family member has now acquired an unprecedented feature; parents are now alone—a dramatically changed family event.

Having a child admitted to a NICU (Neonatal Intensive Care Unit) is hard on families, which in times of COVID-19 has been made more difficult to bear. Families are now affected by mandatory separation, not only between parents and baby, but also between the two parents. In some NICUs, either the mother or the father (but never both) can stay with the child. Visiting time, moreover, is limited to three hours a day in some NICUs. Before the pandemic, parents were free to remain with their children for unlimited time in Brazilian NICUs, while siblings and grand-

Fig. 1. World map.
SOURCE: https://upload.wikimedia.org/wikipedia/commons/c/c3/BlankMap-World.png

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1355-1841/
attitudes of some mothers can present challenges—nurses have reported incidences of mothers hiding their COVID-19 symptoms, while others, despite evident symptoms, have refused to be tested for fear that a positive result will isolate them from their babies for at least 15 days. Nurses are feeling lost amid this “unknown landscape.”

The COVID-19 pandemic has forced families and nurses to face an as-yet unmapped challenge, and there is an urgent need to devise ways of mitigating their distress.

When PPE stands for Preventing Portrayal of Emotions

Colm Darby, Advanced Neonatal Nurse Practitioner, Northern Ireland

Due to the necessity of wearing personal protective equipment as routine uniform during the COVID-19 pandemic, the only visual aspect of our identity that parents see is our name badge. Although our eyes are visible, the physical barrier of visors, goggles and masks (Fig. 2) create an obstruction for parents to see our emotions, empathy and feelings. It is our ability to interpret, display and respond to emotions that cements our nursing practice. Our caring hands can no longer extend for greetings or be placed on shoulders to deliver a gentle touch to inform those that we are here, and we understand. Our non-verbal communication has been diminished when we obstruct our mouths, faces and reduce touch to convey emotion or connection. The connection and touch are what parents remember from the point of admission and throughout the roller-coaster journey in the neonatal world. The hustle and bustle of the gowns and aprons are drowning out the monitors and natural neonatal sounds that we have learnt to live with and use as our daily backing track. As the ambient environment maintains its neonatal tune, new personal protective equipment (PPE) measures are impacting on our verbal communication with reduced audible clatters as voices are muffled and hushed by the masks or restricted by the sealed ventilation device on the enhanced airway protection.

We are discovering our reliance on lip reading is evident more now than we assumed we had previously. When the most common phrase in the units was “does anyone have the keys”, this has been replaced with frustrated tones of “can you repeat that please”. As we draw in air to think of to try to reduce contact and therefore reduce risk.

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Fig. 2. Face mask.
Source: Royalty free https://www.pxfuel.com/en/free-photo-ovtgf

COVID-19 has meant a complete shift in how I work. As a neonatal nurse usually at the bedside (or incubator side!) I’ve found myself wandering through adult and paediatric wards, answering calls from nurses, doctors, cleaners, security and administration staff. From tiny babies one week, to helping security men double my size safely don and doff their PPE the next, it has truly been a lesson in flexibility.

Our neonatal unit created a “COVID Team”, swiftly followed by a To-Do list that seemed to grow each day. One of our first priorities was screening parents. We took a multi-layered approach, screening at least 3 times from outside the unit to the bedside. In addition, we created a station at the entrance which gave parents the opportunity to clean their phones and wash their hands and set up a register for parents to facilitate potential future contact tracing. We designed guidelines for admissions and deliveries with associated care plans, and edited them, and edited them, and edited them again with each new piece of Ministry of Health guidance. We cleared out rooms for isolation, printed educational posters and laminated everything. We put out weekly FAQs, to provide constant and consistent feedback to staff and to ensure concerns were responded to promptly.

In conjunction with the New Zealand government’s alert levels, the neonatal unit altered to reflect the same. Visitation was reduced to exclusively parents with only one parent at the bedside per visit. We reduced the number of people who could be in shared spaces such as the mother’s room, work room and staff tea room at any given time to facilitate social distancing. We increased our use of teleconferencing apps which facilitated reducing the number of staff on ward rounds, meetings and education sessions. We took every opportunity we could think of to try to reduce contact and therefore reduce risk.

This was a collective “we”; however, I found myself inadvertently becoming a person staff felt comfortable raising their concerns and anxieties to as COVID evolved, both in formal and informal conversations. My nursing colleagues began to contact me increasingly over social media, sharing concerns and questions that they perhaps did not want to raise directly at work. I was moved that people felt comfortable to give their honest feedback and ask me their questions, even if I didn’t have all the answers myself.

The world suddenly feels uncertain; healthcare workers are only human and have a life and worries both inside and outside the hospital walls. Managing staff anxieties, ensuring their concerns were heard, and hopefully helping them feel protected and valued has been, in my opinion, the greatest achievement of our “COVID Team”.

Working as part of the team of the greater hospital has underscored how this is new territory for us all and we need to venture into it together with kindness, compassion and a degree of flexibility. I feel hopeful that by retaining our humanity through a collective effort and empathy with one another and our colleagues across the globe we can protect our tiny precious patients, their families and each other.

Lisa Leppard, Family Liaison Sister, Princess Anne Neonatal Unit, Southampton, UK

Reflect. I needed to step off the Merry go round. I needed to breathe. I felt like I’d been holding my breath for 12 weeks. Locking down my ability to breathe and think freely. I walked into intensive care to see another little baby moving towards end of life. I just couldn’t do it. I couldn’t face the parents. I had nothing left to give. I turned and walked away. Was I brave or broken? COVID......None of us know how we will truly emerge from this as people. Nurses. Mothers. Friends. Family. I know it has changed me. I’m not entirely sure how I will emerge, but I’m determined that this negative monster will not tame me. I will process, reflect and incorporate it into me, not let “it” define who I am. In this time of lack of control and enforced change I will take back the reins and find my way through “this”. My ways of working with and supporting families through their neonatal journey can only be stronger, more informed and the value of hugs will be priceless.
Bereavement response on the Neonatal Intensive Care Unit during COVID-19: a case study

Daniella Davies, Staff nurse, Neonatal Unit, Liverpool Women’s Hospital

Abstract

Providing the best possible bereavement care is always challenging. This article reflects on the care of twins who died separately on the neonatal unit during a time that was complicated not only by working in a half-completed new build, but also the pandemic of COVID-19. Whilst the national social distancing measures and policies we have had to put in place due to COVID-19 are essential, this has caused a massive strain on family support with restricted visiting leading to sadness to both families and staff. Amidst all this, the death of a baby remains a critical time for families which will affect them forever; working around all the new procedures and adapting our normal care is paramount to provide a positive experience in the current circumstances.

Introduction

I work as a senior band 5 neonatal nurse in a tertiary Neonatal Unit in the North West England that cares for around 1,000 sick and preterm newborns from across Cheshire and Merseyside, Isle of Man and Wales. We have a team of leading neonatologists and aim to be a centre of excellence. Bereavement care is undertaken by the nurse caring for the family following the ‘North West Perinatal/Neonatal Palliative Care Guideline’, 2020 and supported by the consultant, room leader and resources on the unit. Parents are encouraged to make all decisions about their baby’s bereavement care and to have siblings and extended family involved from as early on in the journey as possible. We had a dedicated bereavement room where parents and families could have time alone with their baby, and a parent room to stay overnight with their family. Parents can take their baby home either before or after death, with the support of our local hospice and hospital bereavement team.

Our local hospice has a link nurse to the hospital who attends the foetal medicine centre for parental support and parallel planning. She attends a weekly ward round on the neonatal unit to identify families that can benefit from support or future hospice respite. They provide memory making sessions which includes hand and footprints on canvas and make charms with the baby’s prints. This helps them to gain a good rapport with families which has increased the number of parents wanting to go to the hospice for their end babies’ of life or bereavement care.

All parents are offered pastoral support with baptisms or religious ceremonies provided by on-call clergy or chosen religious leaders. Families are encouraged to spend time alone with their baby; to bath and dress their baby in new clothes and whichever family or friends they choose can be there for support. Memory making resources that we offer include hand and footprints, 3D casts of hand and feet, clay hand and footprints, and charms. Families can keep all resources available to them, including changing mats, baby soap, hooded towel, a baby brush and a lock of hair, USB locket for photographs and baby books. Parents are offered professional photographs, but these are only offered after death when transferred to the hospital bereavement team.

We aim to provide happy memories from day 1 of admission for all Intensive Care babies by giving them a diary, journey box, admission hand and footprints, event cards, regular photo updates and encouraging early registration of birth to make it a positive experience.

Support for expressing breast milk is also given with the use of Cabergoline to stop milk production if mums choose this. There is the option to donate any breast milk alongside a leaflet on how to manage lactation after loss. This service has been streamlined as mum is asked early on in the process if she wants to donate her milk; if she approves, the nurse looking after the family will ask mum questions from the ‘Milk donation guidelines for referring health professionals’ (Human milk bank, 2019), and phone the milk bank. If she is a suitable donor mum can speak to the milk bank to confirm donation. A doctor on the unit will take mums, bloods and the milk bank will collect the expressed breast milk from the unit. If Mum is undecided this can be done with the hospital bereavement team to prevent mum having to organise this herself with the GP.

Once babies have been discharged from the NICU they are transferred to the hospital bereavement team who provide outstanding bereavement care. They help families plan funerals, gain consent for post-mortems, have a dedicated registration of birth and death, provide support and signpost to services such as CBUK and SAND’s. They work alongside many charities such as Aching Arms, 4Louis and the Rainbow Trust and provide their own support groups. They also have a beautiful bereavement room (Figs. 3 and 4), which is used mainly for babies when parents are coming back to visit.

Bereavement care on the NICU always has challenges in normal circumstances; this has been added to with the current COVID-19
pandemic. Hospital visiting has been restricted to only one parent visiting the NICU per day, consequentially siblings, grandparents and friends may tragically never meet babies. This will ultimately affect parent’s grief as their loved ones have never met their baby. Due to the unfinished new build temporarily, we only have an option of a clinical isolation room, the cot side, or a parent’s bedroom next to the low dependency unit for end of life care.

One of our regular priests who visits the NICU is over 70 and self-isolating at home leaving limited options for baptism and less pastoral support for families. He often walks around the unit speaking to parents offering a familiar face and a person to talk to who is not medical. Birth registrations have been suspended; death certificates are being conducted over the phone without the birth being registered meaning that once the lockdown is lifted parents will then have to register their baby’s birth.

There are now barriers to families taking their baby home for bereavement care. Parents who wish to take their baby home or even to a hospice before death are being refused due to limited transport staff, national ambulance shortages and limited support at home. The increased deaths and workload of funeral directors has caused them to refuse to support families taking their baby home after death. The exception to this is the local hospice being able to support parents to care for their baby. However, this is a case by case event as each hospice is funded differently and local hospices themselves are limited with rooms and staffing.

Due to COVID-19 many things we normally provide have been stopped including 3D casts and professional photography; this is due to restrictions on people entering the hospital and unknown infection control risks. Bereavement supplies such as clothes are low as shops are shut and deliveries are not reliable. Our hospital charity supplying knitted blankets and clothes is closed.

Parents did have the option to stay in a bedroom upstairs next to the low dependency unit if their baby is sick or dying, however this has been stopped as the rooms have been allocated to maternity services in the event of high admissions. This means parents cannot stay overnight with their baby and are being separated from them to stay in a hotel nearby. We are allowing both parents to visit if their baby is dying but the decision to allow extended family and friends onto the unit is extremely difficult and there is just not a satisfactory answer.

Case presentation

I am one of the bereavement links on the NICU who provide training and support for members of staff. I supported a member of staff caring for Twin 1 who was very premature and deteriorating clinically. Mum was called in and spoken to by the team about her baby and the decision was made to redirect care as he was deteriorating on maximum respiratory and cardiovascular support. Mum wanted both the twins to be baptised together, the on-call priest was on their way. However, he started deteriorating and the shift leader quickly performed a baptism on Twin 1.

Mum was out of area for our local hospice and didn’t want to leave Twin 2 who was also unstable; therefore, her only options were for her baby to die at the cot side or for her to be moved into an isolation room. The isolation room is also used for the eye clinic so has clinical equipment and a couch in the room. This made me feel uncomformable as this was not an appropriate end of life setting for both the mum and baby and I was trying to think of an alternative room. We use the hospital bereavement room for when parents return to see their baby after death as most deaths happen either on the NICU or in the hospice. However, I rang the Bereavement team to enquire if we could use their room while the baby was still on the ventilator and provide end of life care there. As this was not normal practice it was escalated to the bereavement matron who agreed a plan with the consultant caring for the family.

We removed all monitoring and the feeding tube and attached the baby to the portable ventilator; mum carried him downstairs to the bereavement room with morphine running on the maximum rate for comfort. Due to COVID-19, the baby’s Dad could not visit as he was sole carer for his son at home. Therefore, the maternal grandad was supporting mum through this. As nurses we routinely lead the care at this point, and we removed the endotracheal tube (ETT) when mum was ready. The consultant confirmed time of death and we removed lines, bathed and dressed the baby and help her to create memories. Unfortunately, we could not offer 3D casts but managed to offer every other service. Mum wanted to stay overnight with her son and be close to Twin 2 but there were no rooms available for her to stay in. Instead of separating mum and babies, the only option was for mum to sleep in the isolation room with a camp bed borrowed from maternity services.

Two weeks later I was looking after Twin 2, he was also now on maximum respiratory and cardiovascular support and was slowly deteriorating. Mum was called in and I asked if she wanted to speak to the consultant. Our normal practice is for the consultant to have these difficult conversations with a nurse present so we can carry on appropriate conversations for the rest of the day. Mum refused to speak to the consultant, so I updated her on her baby’s condition. This was difficult as it was the first time that I had solely informed a parent that their child was dying and the clinical reasons why. I had supported parents while medical staff had this conversation with them and advocated for both the baby and parents in the meetings, but this was different. I suddenly felt the pressure of delivering this news as I knew she would remember it forever. I was conscious of the words and how I could tell her in an easy to understand way which was factually correct and professional. I have had no formal training on how to deliver bad news, but I felt able to do this as I had supported mum with her previous bereavement and built up a relationship with her and I realised that bad news should be delivered by someone who the person trusts. I told the consultant what I had said and he agreed that everything was correct.

I quickly returned to mum who wanted to hold her baby. I informed her that there was a possibility that he may die when we got him out for a cuddle and if she was waiting for anybody to arrive then we could wait. However, mum wanted to hold her baby close to her chest and I didn’t want him to die in the incubator alone. His feeding tube was removed and with the help of another nurse, we got him out for a cuddle. As soon as he was moved his heart rate and saturations dropped. The consultant spoke to mum and explained that, as his lungs and kidneys were not working anymore, the potassium levels were rise to a dangerously high level which will stop his heart. Mum was crying and the consultant left her to spend time with her baby.

All medications were stopped apart from pain relief. I bent down and placed my hand on mum’s knee. She looked at me and I told her “he is dying now”. Mum sobbed and said she wanted to go downstairs to the bereavement room she had used with his brother and she wanted her in an easy to understand way which was factually correct and professional. I have had no formal training on how to deliver bad news, but I felt able to do this as I had supported mum with her previous bereavement and built up a relationship with her and I realised that bad news should be delivered by someone who the person trusts. I told the consultant what I had said and he agreed that everything was correct.

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This was the second time she had walked to the bereavement room carrying her dying baby. Once we were in the bereavement room everyone left apart from the shift leader. We asked mum if she wanted Twin 1 to spend time with them both which she did. Mum video called the twin’s Dad to see Twin 2 on the ventilator before he died.

Mum sat on the couch with both of her twins, waiting for her dad to arrive. I took photos of them all together as a family using mums’ phone and the tips that the photograph charity had sent the trust to ensure we capture moments with good quality photographs. I made mum a hot drink and asked if she wanted me to leave them alone but stay close if she needed me.

Mum wanted me to stay with them all; we sat together and spoke about ‘normal’ things - family, jobs, and relationships.

Twin 2 had started to deteriorate on the ventilator while waiting for Grandad to visit; I turned all the infusions to maximum as he was...
showing gasping reflexes. I reassured mum that he was not in pain and called the consultant to check if there was anything else I could give. Grandad arrived and mum was starting to get upset again about the gasping. She said she wanted to stop his suffering, but she wasn’t ready to let him go. I reassured mum that he wasn’t in pain and I could make the decision for her if she wanted, I told her that it wasn’t her choice or her fault. Previously when I have cared for a surviving twin some parents had confided in me that they thought it was their fault, that somehow, they could have done more to stop it. From hearing parents bargain with their grief and blame themselves I always make an effort to reassure parents that it was not their fault and they did everything for their baby. Mum agreed and then quietly said “take the tube out”. I stopped the ventilator and removed the ETT and gave mum wet gauze to wipe his mouth. Mum held Twin 2 in her arms as he died with Twin 1 and Grandad surrounding them.

The unit has a mobile phone dedicated for bereavement which stays with the nurse caring for the family. I left my number and gave the family time together. I told mum to phone me when she wanted to bath him. Mum phoned about 30 minutes after and I went with the doctor to confirm time of death. I took the portable bath and supplies down to the bereavement room. Sadly, mum didn’t need any guidance on how to bath him as she had recently bathed Twin 1. I removed his long line and Mum bathed Twin 2 while Twin 1 was wrapped in his blanket in the Moses basket next to Grandad. She dried and dressed him, and we wrapped him in the same blanket as his brother but an opposite colour. We had a ‘photo shoot’ of the family and twins together and mum really appreciated these unique photos.

This end of life care was seamless and uninterrupted by different professionals. Mum got all her care from me and I got my support from the team on the unit. A nurse contacted delivery suite for Cabergoline for milk suppression and brought it down for mum; we talked about milk donation. Mum stayed in the bereavement room all day with the twins and her Dad where they all spent time together. I managed to arrange a bedroom off the unit for mum to stay and set up the cuddle cot; once mum was settled into the room, I left her for the night with a different member of staff and returned the next day to care for them both again.

Discussion

Despite the difficulties, I felt this bereavement care was seamless and high quality due to the teamwork of not only the neonatal unit but the whole hospital, including the bereavement team, maternity services and pharmacy. The use of bereavement links meant that up to date knowledge was shared and support was available for staff. The nurse and consultants worked together to ensure that the parents had support from appropriate professions at the right time.

Alongside teamwork, effective communication and quick thinking meant mum had similar uninterrupted bereavement care on both occasions. The photography tips that the professional charity had sent us improved my skills and advised me on what to include in photographs, leading into mum being able to keep these precious beautiful photos forever.

Using mums’ phone to take the photos has both a positive and a negative outcome. Mum phone has a better camera, but this is the only place the photos are stored so if she loses her phone these are lost forever. Mum’s phone was also running out of battery, so we had to stop taking photographs for a short moment. However, if we had a better quality unit camera then I may have been able to take some more natural photos of the family and store them in the baby’s notes.

Conclusion

These are unprecedented times that none of us could have imagined; daily there are questions raised that, despite the constant update of information and polices, we know that currently no-one knows the answers. However, the barriers to high quality bereavement care that COVID-19 has caused can be overcome with effective communication, teamwork and challenging current practice by different ways of working.

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Supporting resources

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