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Making a case for investing in small and sick newborn care analysing the patient journey to identify areas for investment

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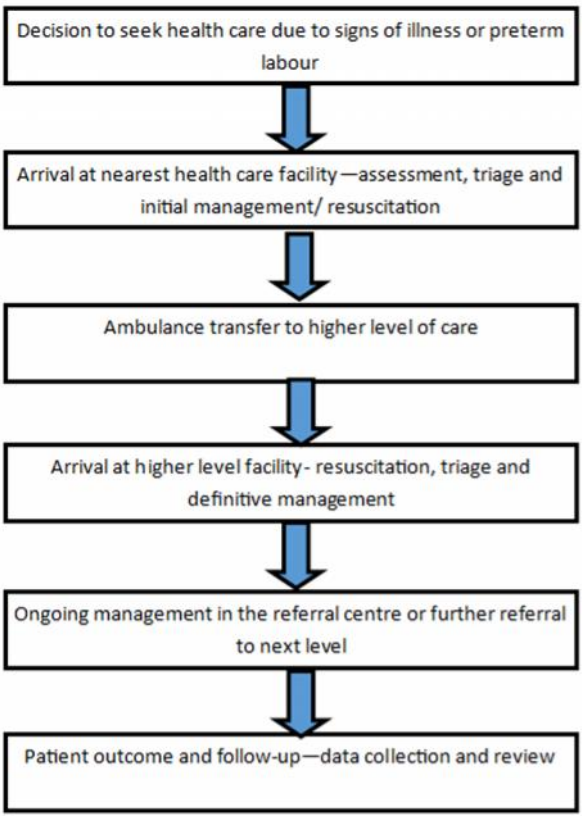
Introduction

It is well recognised that the most vulnerable time of a child's life is from the moment of birth to the end of the first 28 days of life[1]. Overall, globally, the Neonatal Mortality Rate is 18 per 1000 live births[1]however in Zambia it stands at 27 per 1000. Authors frequently highlight insufficient investment in neonatal care as one of the contributors[2], however, any investment made needs to be targeted at interventions which have proven benefit, ideally low cost, high impact, easily reproducible and easily able to be disseminated. Under the presumption that the global focus, under the sustainable development goal 3.2 to end preventable deaths of newborns[3] already highlights the need for investment, if we consider the patient journey particularly around the time of birth, we can identify some of these possible interventions as areas for investment and therefore improve outcomes.

Annually, for the past 15 years, we have celebrated the International World Prematurity Day with themes such as 'zero separation' and 'immediate skin to skin from birth'. In 2019 we marched under the banner campaigning for 'providing the right care, at the right time, in the right place'[4]. Neonatal mortality rates remain high and we continue to experience challenges in meeting this goal. There is ongoing investment in evidence based interventions such as the development of staff training, equipment and resources in neonatal units including recent steps to establish iKMC (immediate Kangaroo Mother Care) units which is encouraging. Yet many barriers remain, especially within our rural communities, to accessing that care. Stigma and myths surrounding preterm birth and preterm babies prevail[6] as seen in one study in Kenya and South Africa, with poor pregnancy knowledge also identified in their interviewees, especially in the first pregnancy.

In the following scenario, a woman experiencing symptoms consistent with preterm labour waits at home, maybe uncertain of what she is experiencing, hoping that things won't progress or even believing that care for small babies isn't available. Then as labour progresses the baby is delivered without antenatal steroid exposure or antibiotic cover, at home/ on the road/ or immediately on reaching the rural health centre where few staff and minimal equipment is available. An ambulance is then called, whilst the health centre staff do their best to resuscitate and stabilise in KMC (kangaroo mother care), but usually without essentials such as oxygen or CPAP source, and even sometimes lacking correct sized IV cannulas, appropriate drugs or IV fluids for neonates. The ambulance then arrives, also without any level of respiratory support and proceeds to transfer the mother and baby on a long journey across poor roads which can span hours. On arrival at the centre the baby is in extreme respiratory distress, hypothermic from exposure due to need to remove from KMC for resuscitations that were necessary whilst in the ambulance, hypoglycaemic from lack of IV fluids or feeds en-route and with established sepsis making stabilisation difficult. Clearly there are many gaps along this patient journey. How can we make strides to ensure that small and sick newborns are receiving the right care, at the right time, in the right place? This essay chooses to focus on the patient journey from antenatal /peri-partum to admission to the nearest neonatal unit at the main referral hospital to identify areas for investment (fig 1), with references to the information and recommendations in the Newborn toolkit[6] (hereafter referred to as 'the toolkit') and how these can be applied locally.

Fig 1: The patient journey



The Community

If we walk through the above scenario and look at each step in the patient journey, it becomes apparent that the first major step in tackling these challenges starts in the community. There is need to identify prevalent beliefs surrounding preterm birth[5] barriers to accessing timely health care, and also to explain to communities how they themselves play a role in improving the chances of neonatal survival. Stories are powerful[7]and experience suggests that our Neonatal Unit graduates and their mothers, from within these very same communities, would be the ideal people to advocate for small and sick babies to reach the highest level of care possible before delivery.

In our local neonatal unit, consent is sought from discharged mothers to display a photo of their baby during admission to the neonatal unit, with the first name and birth weight on our 'wall of fame' – the majority of mothers agree and there is a sense of pride at having their baby's picture displayed in this way. The photos then serve to encourage the mothers that follow them that survival is possible at a time when they often feel hopeless and exhausted, and normalises medical devices such as feeding tubes and nasal prongs which are a significant source of concern and fear for many mothers and their wider families, as well as providing colour and interest on the walls as mothers sit for extended periods with their babies in KMC. Many of these mothers who have stayed in the neonatal unit with their small or sick baby gain a form of expertise owing to the family centred care, as detailed in the toolkit (6, parent power), where they carry out all of the main care giving for their baby with nursing/ medical support and guidance, and it is not unusual to find them 'teaching' and encouraging the new admissions. The current community based volunteer programs could be extended to include such women in order to extend this 'story telling' to the antenatal period in the community, thereby encouraging early health seeking behaviour in their own communities. During the routine IEC (Information, Education and Communication) sessions in the antenatal clinic, working alongside the SMAGs (Safe Motherhood Action Group community workers), some willing mothers could be identified to come and tell their own neonatal journey story and to encourage the expectant mothers to seek care early if any signs of preterm labour or sickness become apparent during the pregnancy. Seeing a baby who is now thriving despite being born small or sick may begin to change perceptions, and having the chance to ask questions to well-prepared health care staff after hearing the story would open discussion and improve understanding. Early attendance at the first signs of any complications or preterm labour would facilitate exposure to antenatal steroids, antibiotics where required and transfer pre-delivery to a centre more adequately equipped to manage the specific needs of the neonate after delivery. Extension to involve the wider community in these story telling sessions in particular mothers to the expectant mothers (grandmothers) could further increase the efficacy of this intervention, given their pivotal role and influence in care of infant and mother in the peri- and postpartum period[8].

These extended antenatal sessions with 'guest speakers' would give additional opportunity to tackle some of the reasons why we are seeing preterm and small newborns being delivered in such high numbers, such as early identification of syphilis or hypertension/ pre-eclampsia, malaria prophylaxis and discussions about the use of herbal medications including oxytocics. In order to achieve this basic standard of care, all clinics should be equipped with functioning BP machines or sphygmomanometer and the recommended antenatal vitamins, iron, folic acid and antimalarials; and adequate stocks of HIV and syphilis test kits with immediate treatment available[9].

The rural health centre

However the reality is, even with excellent advocacy within the rural communities, we will continue to see babies who don't reach the clinic in utero in enough time to be transferred pre-delivery. Some will reach the clinic in good time but there will be issues of transport to the next level. To tackle this and prevent inequality of access, all rural health centres should be able to administer antenatal steroids and have adequate stock. Others will reach and deliver almost immediately. A warm environment with adequate availability of items such as small face masks for the bag valve mask, 24g cannulas and 10% dextrose with first line antibiotics and as a minimum, a source of oxygen. These are all high impact

relatively low cost interventions. In Zambia a home-made version of bubble CPAP known as 'pemani' (a vernacular word for 'to breathe') is being taught in neonatal training courses for use when formal bubble CPAP is not available[10,11]. Clinics with an oxygen cylinder could implement this from birth for babies born premature with respiratory distress syndrome after a short training[10]. This training could be conducted in the referral centre Neonatal Unit on a rotational basis to provide exposure to all aspects of neonatal care and stabilisation. Although it could be argued that delivery at a rural health facility may not be the *ideal* place for a preterm or sick baby, with basic equipment, medications and staff training, it moves closer to becoming 'right'.

The Ambulance

The next step in the patient journey is the ambulance transfer. Ideally babies would be transferred in utero but being realistic to the unique challenges for many of finding transport to the clinic itself, waiting for relatives to return to escort them, or the speed of labour and delivery for some, there will always be the need for an adequately equipped ambulance with staff trained in neonatal resuscitation and stabilisation. In the toolkit, recommendations are made regarding suitable ambulance set-up for neonatal transfer (6, Infrastructure for transfer). Current set-up does not meet this standard regarding respiratory support and thermoregulation available. Whilst the 'pemani' CPAP can be used during transport it can be cumbersome to travel with a large cylinder in the ambulance, and the refilling of small cylinders currently necessitates a journey to the capital city. As a result many ambulances do not have oxygen available as routine. KMC can be used for thermoregulation during transport and is indeed encouraged, however is unsuitable for a baby needing resuscitation during the journey. Internationally there is investment into design and innovation for low cost, robust equipment, albeit with some challenges [12,13,14] that can be used sustainably and effectively in the low resource setting. Some examples of such devices that have been locally trialled and are currently using are a portable CPAP that runs on battery power for six to eight hours[15] and a portable incubator which also function for around six hours once the warm pack is heated[16.]But there are many others. Investment into feasibility and clinical efficacy studies into these and other such devices could guide procurement[13] on a national and international level and allow better equipping of our ambulances for transfer and therefore improving the condition of the small or sick newborn by the time they reach the referral centre. Again staff training in when and how to use, and familiarity with any devices is essential along with biomedical maintenance and support.

The neonatal unit

Finally, as our patient reaches the referral centre at whatever stage albeit in utero, or recently delivered, they should find a consistent level of care available regardless of time of day or day of the week (6, toolkit Human resources, People and Team). We can only ethically encourage the communities to present early if we intend to actually deliver the quality of care we are promising. Our neonatal units in the rural district do not need to be 'high-tech' to provide quality care interventions that save lives. Interventions should include: availability of antenatal steroids and other medications; adequate space for continuous skin to skin from birth/ arrival (iKMC) which is shown to reduce mortality and infections rates [17]; investment in good quality bubble CPAP machines specifically designed for the low resource setting, in adequate numbers for expected admissions (as although 'pemani' can be lifesaving, the use of oxygen alone to generate CPAP is not ideal especially in preterm neonates); adequate attention to infection control and availability of running water for hand washing and bathing ([6], toolkit Preventing and controlling infections); well trained staff in adequate numbers to attend to and provide the level of care and expertise required to ensure the best possible outcome for mother and baby. Rural facilities have historically been a less attractive location for medical doctors[17] especially as most want to pursue higher studies and specialisation, so there is high turnover and low numbers. Locally, focus has been on training of first line nursing staff in the neonatal unit, and more recently have embarked upon addition of clinical officer general (COG) to the staffing of the Neonatal Unit. The aim is that the first person receiving the neonate at admission/ attending the delivery should be competent to assess, resuscitate and begin necessary treatment, sometimes with on the ground or remote support ([6], toolkit Human Resource, Workforce Education). This avoidance of delays has in part contributed to reductions in mortalities in our unit and is complemented by the recent addition of the Neonatal Nursing Diploma to Zambia's available higher education repertoire which adds appeal and possibility of career progression within the speciality. Addition of a similar program for the COG cadre could significantly boost the workforce within neonatal care.

Monitoring the outcomes

As we consider the patient journey and try to change the narrative, we should follow the advice of Winston Churchill who was recently quoted in a lancet paper[19] to have said "However beautiful the strategy, you should occasionally look at the results". We need robust data collection systems that analyse the mother/ baby journey to truly identify the gaps in care and whether the proposed interventions are having an impact. The toolkit ([6], Data collection and quality) currently provides the ideal information that should be gathered on each neonatal admission, however with low levels of human resource and high case load it is currently not feasible to undertake in depth review of every case. Locally we have begun to make steps to collate data by ensuring a thorough admission form and discharge letter is compiled for each case including relevant results and notes for follow up which is given to the mother on discharge. In order to collate

data more efficiently a copy of this summary should remain in the patient file, requiring an onsite photocopier or other method of producing multiple copies of the same document. The admissions register is a focal document that all members of staff use at different points throughout the neonate's admission including on discharge which could lead to steady accumulation of data throughout the patient stay. Unfortunately the current register is not designed for purpose and extractable data is limited. Steps are being taken to create a carefully designed admissions register to be used in the neonatal unit which gives easy access to relevant data, such as the prototype below, incorporating many of the data sets found in the toolkit. This would move towards collecting truly relevant data (avoiding the 'data rich information poor syndrome as detailed in the toolkit ([6], Information Systems). This central data has the possibility of fuelling ongoing quality improvement projects, perinatal death reviews and internal audits which need to be part of the culture of every neonatal unit, with mentorship to referring centres. If we can identify which patient groups are most vulnerable to poor outcomes in our individual facilities and where they are being referred from, then we can pay particular attention to identifying and addressing gaps in care, skill set, equipment availability and community based interventions.

Fig 2: Proposed neonatal unit admission and discharge book

File number	Date of admission	Name and address	Date of birth	Birth weight	Admission weight	Day of life	EMTCT	RPR on admit	Gestational age	Date discharge	Length stay	Highest resp support	Admission vitals
													HR Resps Temp Sats RBS
													HR Resps Temp Sats RBS

Condition Jaundice	Condition Resp distress	Condition Sepsis	Condition Conj syphilis	Condition Ophthalmia	Condition HIE	Condition Malform	Condition MAS	Condition HDN	Condition Seizures	Condition Hydrocephalus	Condition Premature	Outcome / Additional notes

In Summary

Recommendations for investment after analysis of the patient journey from antenatal to admission in the neonatal unit are as follows:

1. Investment in community action groups to be extended to include Neonatal Unit graduates with a story to tell in order to encourage early health seeking behaviour and dispel common myths around small and sick newborns in rural communities
2. Investment in local clinic basic equipment and training to allow adequate resuscitation and stabilisation pre-referral. As a minimum an oxygen source should be available in all centres
3. Investment in staff training and targeted, well designed medical devices to support safe ambulance transfer of small and sick newborns
4. Investment in 'low tech' life saving equipment including CPAP and drugs at the referral Neonatal Unit/ Maternity Ward in adequate volumes for anticipated admissions
5. Investment in staff training programs to increase the skill set of first line staff but also the appeal of this high demand speciality
6. Investment in tools such as neonatal specific admission and discharge book to assist with data collection and assimilation for an already stretched workforce to allow adequate analysis and identification of gaps, high case load conditions, localities of high need, quality improvement projects and mentorship

Investment in small and sick newborn care should focus on low cost, high impact interventions that can easily be reproducible throughout centres in a given region, thus simplifying the required training/mentorship and budgeting. Funded interventions should be evidence based and where evidence is not currently available, focus should be given to gathering of data to look at efficacy plus the development of small well designed studies in order to drive change and innovation. Funded interventions should be sustainable and acceptable to local populations, with the power of story not to be underestimated in our fight to tackle the unacceptable loss of life and productivity linked to being born small or sick in the low resource setting.

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