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Pain management for infants – Myths, misconceptions, barriers; knowledge and knowledge gaps.

Twelve years ago, the paper ‘Oral sucrose for pain management in infants: Myths and misconceptions’ was published in the *Journal of Neonatal Nursing* (Harrison, 2008). At this time, eight myths or misconceptions were addressed as follows: (1) Not “baby friendly”; (2) Grows bacteria; (3) Risk of dental caries; (4) Increased risk of poor neurological outcomes in infants <32 weeks; (5) Increases risk of necrotising enterocolitis; (6) Results in hyperglycaemia; (7) Not effective in older babies; (8) Repeated doses lead to development of tolerance to sucrose. Since this time there has been more than 100 further studies published reporting on analgesic effects of sweet solutions in newborns, which have been synthesised and included in systematic reviews (Harrison et al., 2017a; Huang et al., 2019; Stevens et al., 2016) including a systematic review of repeated doses of sweet solutions (Gao et al., 2016). Despite addressing myths and misconceptions of sweet solutions over 12 years ago, and despite the over-abundance of evidence of analgesic efficacy, ongoing studies of pain management practices continue to report inconsistent use of this effective, simple, safe, cost-effective evidence-based pain management strategy (Cruz et al., 2016; Harrison et al., 2018, 2015; Orovec et al., 2019). Since 2008, there has also been a growth of literature to support the parent-led pain management strategies of breastfeeding term medically stable newborns (Benoit et al., 2017), and skin-to-skin care in premature newborns (Johnston et al., 2017). These evidence-based strategies are recommended in national and international clinical practice guidelines (Balice-Bourgois et al., 2020). However multiple barriers have been reported relating to parents being involved and using these known effective strategies in sick and healthy newborns (Harrison et al., 2016b, 2015; Hassankhani et al., 2020; Lavin Venegas et al., 2019b; McNair et al., 2020; Palomaa et al., 2016). The abundant and ever growing body of literature supporting efficacy and safety of sweet solutions,

breastfeeding and skin-to-skin for pain reduction, yet the ongoing reports of inconsistent use of these strategies is occurring in the context of an increasing and concerning body of literature about adverse long term effects of repeated pain exposure (Valeri et al., 2015). We are therefore at a cross-roads of evidence – we have the knowledge of effective treatments, we have knowledge of harm of untreated pain, yet sick, premature as well as healthy infants are continuing to be exposed to painful procedures with no effective treatment. Not using best evidence is not simply a scientific knowledge to action gap – it is a breach of ethics in our nursing and medical care. There are however ongoing myths, misconceptions, and practical barriers to using the evidence as well as ongoing knowledge gaps. This paper will therefore highlight existing myths, misconceptions, barriers and current knowledge gaps in regards to using the three key evidence-based pain management strategies of breastfeeding, skin-to-skin care and sweet solutions, in the hope that this will bring to light practices that can be improved for our smallest citizens.

Myths and misconceptions

1. Breastfeeding during painful procedures results in choking
2. Parents do not wish to be present during painful procedures
3. Repeated doses of sucrose/glucose are harmful to the developing brain

Practical or cultural barriers

1. Routine blood sampling is done when parents are not in the Neonatal Intensive Care Unit (NICU)
2. Clinicians prefer to do bloodwork, other painful procedures without parents
3. Knowledge gap regarding best ergonomics of doing bloodwork

Myth and misconception 1. Breastfeeding during painful procedures results in choking.

The risk of choking while breastfeeding during painful procedures in newborn infants and older infants during vaccination, has been cited as a barrier to facilitating this pain management strategy (Harrison et al., 2016a). However, none of the 25 studies included in two systematic reviews of breastfeeding newborns during painful procedures (Benoit et al., 2017; Shah et al., 2012), which includes six trials including preterm infants (Benoit et al., 2017), nor the systematic review of breastfeeding during vaccination (Harrison et al., 2016a), reports any choking or coughing, or any other adverse effects. This myth can therefore be busted, based on current evidence. However it is important to ensure that breastfeeding is well established before encouraging mothers of sick or preterm infants to breastfeed during a painful procedure. If there are any doubts of the infant's ability to safely orally feed, it is recommended that breastfeeding is not used until breastfeeding is established. It is also recommended that any further studies of breastfeeding during painful procedures include collection of data about fidelity of the intervention during the whole procedure, such as the baby coming off the breast, and being unable to re-latch, as well as difficulties with feeding during the procedure. Ensuring accurate records of all potential adverse outcomes will allow further objective building of the evidence base.

Myth and misconception 2. Parents do not wish to be present during painful procedures.

Healthcare professionals (HCPs) report that parents do not wish to be involved with their baby during painful procedures, that parental presence and involvement during painful and stressful procedures results in their distress, and mothers are too stressed to be involved (Axelin et al.,

2015; Harrison et al., 2015; McNair et al., 2020). However when parents are asked their perceptions, most parents report the opposite; that they do wish to be involved and to know more about how they can help to reduce their babies' pain (Franck et al., 2012, 2011; Gale et al., 2004; Gallagher and Franck, 2012; McNair et al., 2020; Palomaa et al., 2016; Skene et al., 2012). In a meta-synthesis of seven qualitative studies on factors affecting parents' participation in pain management during painful procedures in the NICU (McNair et al., 2020), it was highlighted that many parents wished to be involved in reducing their babies' pain and that "...staff cannot presume noninvolvement is their preference" (page 270). This myth and misconception can therefore be busted. However it does highlight the important roles of HCPs in supporting, facilitating and empowering parents' involvement and parents' roles in advocating for themselves and their infants.

Myth and misconception 3. Repeated doses of sucrose/glucose are harmful to the developing brain.

This misconception was addressed in the original publication (Harrison, 2008). Since this time, further evidence has come to light, both concerning potential harms of repeated doses of sweet solutions and harms associated with repeated painful procedures. Results are mixed, making it difficult for HCPs to tease out what is real. Firstly, there is extremely concerning evidence of the risk of painful episodes on the developing brain. The number of painful procedures has been cited as having the strongest association with poor neurobehavioral outcomes independently of other factors for preterm infants (Duerden et al., 2017; Valeri et al., 2015; Walker, 2019). Yet in these studies, including the 13 studies included in the systematic review of neonatal pain and developmental outcomes (Valeri et al., 2015), procedural pain was not treated consistently.

Therefore these results pertain to untreated pain. Whether such adverse outcomes can be reduced if effective pain management strategies are consistently used for all painful procedures is the key question to address. However studies of long term outcomes where either skin-to-skin care or sucrose, or the combination are used for all painful procedures are limited. One study examining use of glucose for painful procedures concluded that use of oral glucose for procedural pain was not protective of adverse neurobehavioral outcomes (Schneider et al., 2018). However, the large majority of painful procedures were performed with no documented pain management, including glucose, which was only used for around 10% of all painful procedures. Such reported practices make it problematic to separate effects of untreated pain, and exposure to sweet solutions. Only one published study to date has reported on neurobehavioural outcomes in preterm infants where either sucrose, skin-to-skin care or the combination of both these strategies was used for all painful procedures throughout the infants' entire hospitalisation (Campbell-Yeo et al., 2019). Findings showed that neurobehavioural outcomes at 32 and 36 weeks gestational age were similar for babies receiving sucrose compared to skin-to-skin and the combination of the two strategies. This finding highlights that repeated doses of sucrose during frequently occurring painful procedures, over a hospitalisation did not increase the risk of poor outcomes. The important point of this study compared to other studies examining long term effects of pain exposure, is that pain management strategies were used for all painful procedures. Therefore, there is no evidence that consistently using sucrose for painful procedures is harmful. However, HCPs need to be cognisant of using sweet solutions appropriately. As the analgesic effects are short term, using sucrose or glucose for calming irritable agitated infants could result in large numbers of doses being given outside of known skin-breaking painful episodes. In addition, using sweet solutions for non-skin breaking, yet known stressful procedures such as airway

suction and adhesive tape removals may also result in large numbers of doses of sweet solutions. The question of exactly when sweet solutions for analgesia are appropriate has not been well addressed in the literature. In addition, it is evident from both published reports (Harrison et al., 2015, 2014) and hundreds of personal conversations over the years with nurses and midwives, that sweet solutions are rarely documented when used. This lack of documentation of care means that audits of practices, and subsequent analyses of risk associations of long term outcomes of preterm and sick infants is inaccurate. In summary, for this myth and misconception 3, there is currently no sound evidence to show that multiple doses of sweet solutions for pain management over a prolonged period result in harm. However, further ethically responsible research in this area is needed and accurate documentation of painful procedures and associated care is essential.

In addition to myths and misconceptions, multiple barriers have been reported to using the evidence-based strategies of parent-led interventions and sweet solutions for infants during painful procedures (Benoit et al., 2016; Harrison et al., 2015; Hassankhani et al., 2020; Lavin Venegas et al., 2019b; McNair et al., 2020). A frequently reported barrier is: 1. Routine blood sampling is done when parents are not in the NICU. This barrier speaks to embedded cultural practices and organisational routines. For healthy newborns, the postnatal stay is very short in most settings. Yet during this brief 24-hour period, HCPs need to support women in their recovery from labour and delivery, monitor and ensure the health of the newborn, provide education about feeding and all aspects of baby care and conduct bloodwork for newborn screening (Lavin Venegas et al., 2019b). For preterm infants, coordinating painful procedures for when parents are in the NICU is perceived as problematic (Benoit et al., 2016; Harrison et al., 2015), even in a NICU where knowledge about effectiveness of skin-to-skin for analgesia is well

known (Benoit et al., 2016). Routines often dictate that non-urgent blood sampling is collected very early in the morning to ensure results are available for decision-making on morning ward rounds. Such early hours are rarely conducive to parents being present in the NICU.

Barrier 2. Clinicians prefer to do bloodwork procedures without parents.

This barrier to using the strategies of breastfeeding healthy medically stable infants or holding preterm or sick infants or infants who are not breastfeeding, skin-to-skin may be related to a number of factors. As highlighted in the meta-synthesis of qualitative studies relating to barriers to parents' participation in the NICU (McNair et al., 2020), in studies conducted in the postnatal setting (Lavin Venegas et al., 2019b) and NICU and special care nursery settings (Benoit et al., 2016; Harrison et al., 2015), this preference may relate to the perceived extra work and time it takes to coordinate blood sampling around facilitating parents' presence, preparation of the infant, ensuring the infant is well latched and sucking if breastfeeding, or calm and settled if holding skin-to-skin. In addition, nurses and midwives perceived that mothers are too fatigued following labour and delivery. Other factors concern cultural norms, environmental factors, such as insufficient space to accommodate parents, or lighting in parents' rooms, organisational factors and self-confidence of HCPs in performing blood sampling while being observed by parents. Barriers such as self-confidence, can potentially be addressed with education, skills training, and reassurance about parents' focus, plus acknowledging that blood sampling by heel lance may be easier and quicker when infants are being held skin-to-skin, due to them being warm and non-distressed, facilitating more rapid flow of capillary blood. However, factors such as cultural norms, including organisational and environment factors are more difficult to address, especially without the support of the organisational leaders and without a true commitment of the

unit and whole organisation to family centred care and parental participation in all aspects of care. Even in a NICU where skin-to-skin care was one of two intervention conditions in a randomised controlled trial (Benoit et al., 2016), nurses still reported not consistently using skin-to-skin care during painful procedures. A shift in focus such as that embedded in the Family Integrated Care model (O'Brien et al., 2015) may be required to fully support parental involvement in all aspects of care, including pain care.

Barrier 3; The knowledge gap regarding best ergonomics of doing bloodwork, has been reported as one of the key reasons why nurses and midwives do not facilitate breastfeeding or skin-to-skin during painful procedures (Benoit et al., 2016; Harrison et al., 2015; Lavin Venegas et al., 2019b). To address this identified knowledge gap, a clinician-targeted video demonstrating best ergonomics of performing heel lancing while infants were being breastfed and held skin-to-skin was produced and posted onto YouTube for public accessibility in 2019 (<https://www.youtube.com/watch?v=lpZNwP7bnkg&feature=youtu.be>) (Harrison and Children's Hospital of Eastern Ontario, 2019). This video was co-produced with parents of newborns, an occupational health physiotherapist, nurses, midwives, organisational leaders of one large postnatal unit, researchers and an audio-visual team. Whether this brief video is considered a useful and acceptable education tool by clinicians and clinical leaders, and whether viewing the video actually results in increased facilitation of parents to use breastfeeding and skin-to-skin where possible and feasible during their infant's non-urgent blood sampling, has not yet been evaluated. Further research is required to evaluate effectiveness of such interventions targeted at specific barriers to using known effective newborn pain treatment strategies.

In conclusion, the ethical imperative to sufficiently treat pain in infants and children has been well and truly argued. Over 25 years ago, Walco et al (1994) stated “Failure to provide adequate control of pain amounts to substandard and unethical medical practice” (Page 543), (Walco et al., 1994). It can be argued that one quarter of century later, we are still failing to provide adequate control of pain for newborn infants, especially during frequently performed painful procedures in sick and preterm infants. We have the evidence of effective treatments which are included in multiple clinical practice guidelines (Balice-Bourgois et al., 2020). We have the knowledge of the concerning adverse long-term outcomes associated with untreated (Duerden et al., 2017; Valeri et al., 2015). We have the knowledge that parents prefer to participate in reducing their infant’s pain during painful procedures (Lavin Venegas et al., 2019a), and we have knowledge translation materials to aid use of evidence in practice (Campbell-Yeo et al., 2017; Harrison et al., 2017b; Harrison and Children’s Hospital of Eastern Ontario, 2019). Myths and misconceptions to using sweet solutions and parent-led interventions have been busted, and barriers to using available accessible, feasible strategies have been addressed. The time is long overdue to move the extensive knowledge about newborn pain treatment into consistent clinical practice.

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