Parental Perception on Neonatal Pain and Pain Management Practices In Special Care Nurseries

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Abstract

Although pain in neonates remains sub-optimal globally, the situation is very dire in sub-Saharan countries like Kenya where all procedures are performed without any form of analgesia due to lack of resources to procure pharmacological analgesics. There, however, exist low-cost, mother-driven pain management strategies such as breastfeeding and kangaroo care that can be used for pain relief in babies in neonatal units in Kenya. The successful use of these interventions is, however, depended on parents' perception about pain and how pain in their babies is managed during hospitalization. The aim of this systematic review was to describe parental perception about pain; and to describe parents' perceptions about procedural pain management practices in neonatal units. Electronic searches were conducted on MEDLINE, CINAHL, Embase and PsycINFO using the following search words: parent(s), perception(s), view(s), neonate, newborn, infant, pain, procedural pain, management, and practices. The search generated 101 articles four of which met the inclusion criteria. Parents believed their infants experienced a lot of pain and that the pain was often not adequately treated. Parents believe that infants undergo a lot of pain while in the neonatal unit without sufficient

pain relief and desire to be involved in pain care of their infants.

Keywords: *Parents, Neonate, Procedural Pain, Perceptions*

Introduction

Neonates admitted in special care nurseries (SCNs) undergo multiple and repeated procedures in the course of hospitalization (Carbajal et al., 2008). These procedures occur routinely as part of care causing pain at a time when the neonate is physiologically immature and developmentally vulnerable (Guedj et al., 2014). Epidemiological studies in high income countries in Europe including Netherlands (Simons et al., 2003) and France (Carbajal et al., 2008) show that neonates undergo 12-14 painful procedures per day. Studies in otherhigh income countries in North America (Johnston et al., 2011) and Australia (Foster et al., 2013) have reported similar number of painful procedures with the highest number of procedures being performed during the first three days of life (Johnston et al., 2011).

In low- and middle-income countries (LMICs) neonates equally undergo many painful procedures. In China, neonates are reported to undergo 3-30 (median 6.0) painful procedures per day (Chen et al., 2012) which is comparable to the

7.5 painful procedures per day reported in South Korean NICUs (Jeong et al., 2013). Although there are limited studies on prevalence of pain in neonates in sub-Saharan Africa (SSA) a recent study carried out in Kenya showed that neonates undergo an average of four procedures per day (Kyololo, et. al, 2014). Despite the exponential increase in knowledge on neonatal pain and pain management strategies, procedural pain management remains suboptimal in neonatal units globally (Carbajal et al., 2008; Johnston et al., 2011; Kyololo et al., 2014; Linhares et al., 2012). In Europe, Carbajal et al. (2008) reported that less than 10% of the 42,413 painful procedures experienced by 430 neonates over a 2-week period were performed with any form of pharmacological or non-pharmacological pain relief. In North America, Johnston et.al (2011) reported slightly better pain management practices with 54% of the 3508 tissue-damaging procedures performed on 582 neonates in 14 Canadian NICUs over a one week period being done without some form of pain relief.

Procedural pain remains severely undertreated in neonatal units in LMICs. In China, none of the 10, 633 painful procedures performed on 108 neonates during hospitalization were accompanied by any form of analgesia (Chen et al., 2012). A similar trend of under-management of procedural pain has been reported in neonatal units in SSA. A recent survey in neonatal units in Kenya showed that, similar to the situation in Chinese NICUs, none of

thepainfulprocedures, a majority that were associated with moderate to severe pain intensity, were performed with any form of analgesia (Kyololo et al., 2004).

The poor procedural pain practices in neonates continue despite the empirical evidence that repeated and unmanaged pain in neonates has deleterious immediate and long-term consequences (Abdulkader, Freer, Garry, Fleetwood-Walker, & McIntosh, 2007; Brummelte et al., 2012; Grunau et al., 2006; Zwicker et al., 2013). On the short-term, repeated and unmanaged pain lead to irritability, sleep disturbance, increased heart rate, poor weight gain, increased oxygen consumption, delayed healing, increased intracranial pressure, and impaired emotional bonding (Bellieni et al., 2009; Cignacco et al., 2007). On the long term unmanaged pain may result in exaggerated response to subsequent painfulexperience, poor brain development, as well as behavioral and emotional disorders in childhood and early adolescent period (Abudkalder et al., 2007; Brummelte et al., 2012; Zwicker et al., 2013).

The severe under-treatment of pain in neonates in Sub Saharan Africa has been associated with lack of resources to procure pharmacological analgesics such as morphine and commercially prepared oral sucrose (Molyneux, 2012). However, there exist effective, low-cost, mother-driven pain management strategies such as breastfeeding and kangaroo care (Pillai Ridell et al., 2011; Shah et al., 2012) that can be used for pain relief of babies in neonatal units. The successful utilization of these mother-driven interventions for pain relief is, depended on parental perception on pain and how pain is managed on their neonates during hospitalization (Franck & Bruce, 2012). However, the empirical evidence on maternal perceptions on neonatal pain and pain management practices in neonatal units has not been comprehensively synthesized. Therefore, the purpose of this study was to conduct a systematic review to comprehensively understand parents' perceptions about pain and pain management practices in neonatal units.

Objectives

The aims of this systematic review were to:

1. Describe parental perception about pain in neonates
2. Describe parents' perceptions about procedural pain management practices in neonatal units.

Methods

Search strategy

A systemic search of four electronic database (Medline, CINAL, Embase and PsycINFO) was conducted by the second author (O.K) from 1990 to July 2014
.The search terms included parent(s), perception(s), view(s), neonate, newborn, infant, pain, procedural pain, management, and practices.

Study selection

Titles and abstracts were independently screened by two authors for relevance. Studies irrespective of their design, were included if (a) full articles could be accessed, (b) focused on neonates and/or infant pain, and (c) were on acute pain, procedural pain or acute persistent pain (e.g. repeated heel lance). Articles on other language than English and those focusing on chronic pain in neonates of infants were excluded.

Data extraction

Data from retrieved articles were extracted independently by the first two authors (D.K. and O.K.). Each article was critically reviewed and data extracted on (a) study setting, (b) sample size, (c) aim of the study, (d) design, and (e) key findings and recommendations

Data synthesis

Data were synthesized to arrive at convergences and differences in parents' perceptions about pain and pain care across settings and the factors that influence such perceptions.

Results

Description of studies included in the reviews

The five databases searched returned 101 results out of which five met the inclusion criteria (Franck et al., 2001; Franck et al., 2004; Franck et al., 2011; Gale et al., 2004). Figure 1 illustrates the studies that were excluded and the rationale for their exclusion. One study (Franck et al., 2004) was specifically on parental perceptions on neonatal pain while the rest covered parental perceptions on neonatal pain as well as parental perception on pain management practices (See Table 1 for summary of studies)

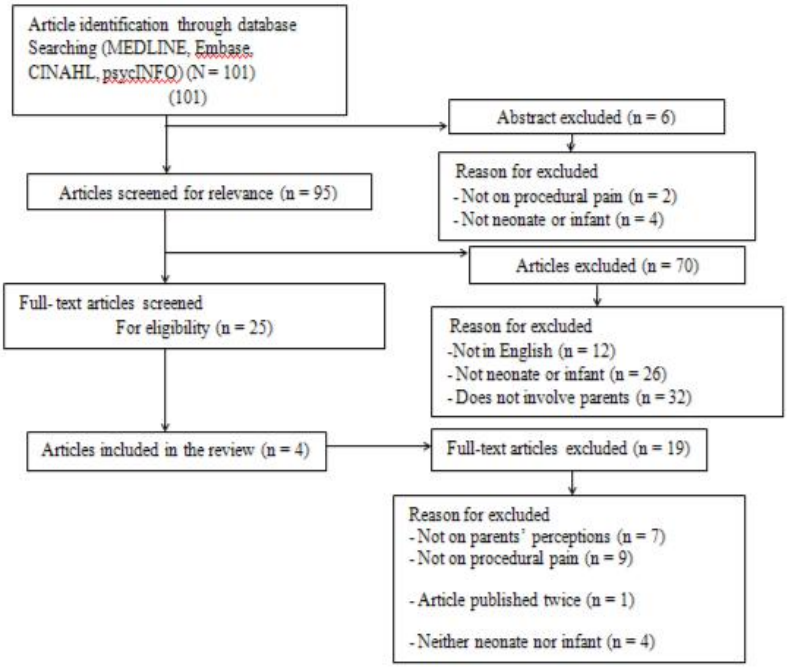

Figure 1: Study selection flow diagram

Parental perceptions about neonatal pain

Of the four studies included in the review three were on parental perception about pain in neonates (Franck et al., 2001; Franck et al., 2003; Gale et al., 2004). Franck et al. (2004) surveyed 257 parents in neonatal units in the United States of America (USA) and United Kingdom (UK) to determine their concerns about infant pain. Parents reported that their infants had experienced more pain than they had expected. The parents were, however, generally satisfied with the pain management their infants received. Moreover, parents preferred to be present during painful procedures; and their presence during painful procedures was associated with less parental stress and anxiety.

Gale and colleagues (2004) conducted a qualitative descriptive study with 12 parents in London, six who had neonates admitted in the neonatal unit and six that had their infants discharged and being followed up at the outpatient clinic, to explore their perceptions about their infants' pain experience in the NICU. Participants

reported that although they did not expect their infants toexperience pain while admitted in neonatal units, they felt that the infants were undergoing unnecessary pain often causing psychological stress. Similarly, parents were of the view that infants should undergo painful procedures in their presence.

In an earlier study Franck and associates (2001) surveyed 95 parents to determine their views on infant pain and pain management practices in the neonatal care unit. Eighty five percent of the parents believed that their infant experienced pain while in the NICU. Parents also felt that health care providers should assist them and their infants cope during painful procedures.

More recently Franck et al. (2011) investigated parental attitudes towards neonatal pain as a secondary aim in a randomized controlled trial whose aim was to determine the effect of an educational intervention to improve parental involvement in infant pain care. One hundred sixty nine from four neonatal units in UK were included in the study. Similar to previous studies, parents believed infants experienced during hospitalisation in the neonatal unit and their (parents') view that infants experience pain was markedly improved following the intervention.

Parental perceptions about pain management practices

Out of the four studies included in the systematic review three (Franck et al., 2001; Franck et al., 2011; Gale et al., 2004) explored parental perception about pain management practices in the neonatal unit. Gale et al. (2004) reported that parents were not satisfied with health care providers' (HCPs) pain management practices. More specifically, parents felt that HCPs did not respond to and consistently manage their infants' pain; and that infants should undergo painful procedures in presence of their parents. Similar findings were reported by Franck et. al (2011) whereby parents were less satisfied with infant pain care and had less confidence in staff ability to manage infant pain. Unlike these studies (Franck et al., 2011; Gale et al., 2004), Franck et al. (2001) reported that parents were generally satisfied with pain management practices in the neonatal unit

with 82% of the parents believing that their infants received analgesia during procedures and that the medication relieved the pain. On the other hand, only 53% of the parents wished to stay with their infants during painful procedures.

Discussions

To the best of our knowledge this is the first systematic review to comprehensively examine parents' perceptions about neonatal pain and pain management practices in neonatal units. All the studies included in the review were conducted in high-income countries, particularly in North America and Europe; and only a single study adapted a qualitative design. Nonetheless, the results indicate that parents believe their infants do experience pain and that the pain is often poorly managed. The finding that parents believe that neonates experience pain is contrary to the perception among many HCPs that neonates do not experience pain (Akuma & Jordan, 2012; Twycross, 2006) a factor that has consistently be associated with poor procedural pain management practices in high income as well as LMICs (Carbajal et al., 2008; Kyololo et al., 2014).

The review has demonstrated that parents are often dissatisfied with quality of procedural pain care in neonatal units. Similarly, parents desire to be allowed to be present during painful procedures was consistently reported across studies. Considering that unmanaged pain in neonates has deleterious immediate and long-term consequences (Bellieni et al., 2009; Brummelte et al., 2012) there is need to HCPs to position pain care as a critical component of neonatal care. Additionally, considering the empirical evidence on safety and efficacy of mother-driven neonatal pain management interventions (Pillai et al., 2011; Shah et al., 2012), and parents' wish to be involved in the pain care of their infants, there is need to explore the feasibility of using these mother-driven interventions for pain control particularly in resource limited setting such Kenya.

Although this review has generated useful information that could be used in clinical practice, the findings should be interpreted with caution. Firstly, all the studies included in the review were conducted in high income countries. The extent to which the results can be generalized to LMICs remains unclear. Similarly, most of the studies included in the review adapted a quantitative

design. However, considering that perception is a very abstract concept, it is hard to discern whether the instruments, despite their psychometric properties, could be used to quantify such an abstract concept like perception.

Conclusion

Overall parents strongly believe that infants experience a lot of pain, often unnecessarily, in the course of their hospitalization. The parents' expectations about their infants' pain management is, however, rarely met. Future studies should focus on investigating parents' perceptions about neonatal pain and their willingness to be involved in pain care in neonatal units in LMICs such as Kenya.

References

Abdulkader, H. M., Freer, Y., Garry, E. M., Fleetwood-Walker, S., & McIntosh, N. (2008). Prematurity and neonatal noxious events exert lasting effects on infant pain behaviour. *Early Human Development, 84*(6), 351-355.

Akuma, A. O., & Jordan, S. (2012). Pain management in neonates: A survey of nurses and doctors. *Journal of Advanced Nursing, 68*(6), 1288-1301.

Bellieni, C. V., Iantornao, L., Perrone, S., Rodriguez, A., Longini, M., Capitani, S., & Buonocore, G. (2009). Even routine painful procedures can be harmful for the newborn. *Pain, 147*(1), 128-131.

Brummelte, S., Grunau, R. E., Chau, V. Poskitt, K. J., Brant, R., Vinall, J., ... Miller, S. P. (2012). Procedural pain and brain development in premature newborns. *Annals of Neurology, 71*(3), 385-396.

Carbajal, R., Rousset, A., Danan, C., Coquery, S., Nolent, P., Ducrocq, S., . . . Breart, G. (2008). Epidemiology and treatment of painful procedures in neonates in intensive care units. *JAMA, 300*(1), 60-70.

Cignacco, E., Hamers, J. P. H., Stoffel, L., van Lingen, R. A., Gessler, P., McDougall, J., & Nelle, M. (2007). The efficacy of non-pharmacological interventions in the management of procedural pain in preterm and term neonates. A systematic literature review. *European Journal of Pain, 11*(2), 139-152.

Chen, M., Shi, X., Chen, Y., Cao, Z., Cheng, R., Xu, Y., ... Li, X. (2012). A prospective study of pain experience in a neonatal intensive care unit of China. *Clinical Journal of Pain, 28*(8), 700-704.

Foster, J., Spence, K., Henderson-Smart, D., Harrison, D. Gray, P. H., & Bidewell, J. (2013). Procedural pain in neonates in Australian hospitals: A survey update of practices. *Journal of Paediatrics and Child Health, 49*(1), E35-39.

Franck, L. & Bruce, E. (2012). Parental involvement in neonatal pain

Management: An empirical and conceptual update. *Journal of Nursing Scholarship, 44(1), 45-54.*

Franck, L., Scurr. K., & Couture, S. (2001). Parent views of infant pain and pain management in the neonatal intensive care unit*. Newborn and Infant Nursing Reviews, 1(2), 106–113.*

Franck, L. S., Cox, S., Allen, A., & Winter, I. (2004). Parental concern and distress about infant pain. *Archives of Disease in Childhood: Fetal and Neonatal Edition, 89*(1), F71–F75

Franck, L. S., Oulton, K., Nderitu, S., Lim, M., Fang, S., & Kaiser, A. (2011). Parent involvement in pain management for NICU infants: A randomized controlled trial. *Pediatrics, 128*(3), 510-518.

Gale, G., Franck, S. L., Kools, S. & Lynch, M. (2004). Parents perception of their infants' pain experience in the NICU*; International Journal of Nursing Studies 4(1) 51-58*.

Grunau, R. E., Holsti, L., & Peters, J. W. B. (2006). Long-term consequences of pain in human neonates. *Seminars in Foetal & Neonatal Medicine, 11*(4), 268-275.

Guedj, R., Dancan ,C., Daoud, P., Zupan, V., Renolleau, S. ,Zana, E., Carbajal, R.

(2014). Does neonatal pain management in the intensive care unit differs between day and night. *BM J, 4(2); e004086* doi: 10.1136/bmjopen-2013-004086.

Jeong, I. S., Park, S. M., Lee, J. M., Choi, Y. J., & Lee, J. (2013). The frequency of painful procedures in neonatal intensive care units in South Korea. *International Journal of Nursing Practice* (advance online issue).

Johnston, C. C., Barrington, K. J., Taddio, A., Carbajal, R., & Filion, F. (2011). Pain in Canadian NICUs: Have we improved over the past 12 years? *Clinical Journal of Pain, 27*(3), 225-232.

Kyololo, O. M., Stevens, B., Gastaldo, D., & Gisore P. , (2014). Procedural pain in neonatal units in Kenya. *Archives of Disease in Childhood: Fetal and Neonatal Edition.* doi:10.1136/archdischild-2014-306003.

Linhares, M. B. M., Doca, F. N. P., Martinez, F. E., Carlotti, A. P. P., Cassiano, R. G. M., Pfeifer, L. I., ... Finley, G. A. (2012). Pediatric pain: Prevalence, assessment, and management in a teaching hospital. *Brazilian Journal of Medical and Biological Research, 45*(12), 1287-1294.

Molyneux, E. (2012). Needless pain in African Children: An affront to human dignity. *Archives of Disease in Childhood, 97*(12), 1078-1079.

Pillai Riddell, R. R., Racine, N. M., Turcotte, K., Uman, L. S., Horton, R. E., Din Osmun, L., . . . Gerwitz-Stern, A. (2011). Non-pharmacological management of infant and young child procedural pain. *Cochrane Database of Systematic Reviews,* Issue 10. Art. No.: CD006275. DOI: 10.1002/14651858.CD006275.pub2.

Shah, P. S., Herbozo, C., Alowalas, L. L., & Shah, V. (2012). Breastfeeding or breast milk for procedural pain in neonates. *Cochrane Database of Systematic Reviews*, Issue 12. Art. No.: CD004950. DOI: 10.1002/14651858. CD004950.pub3.

Simons, S. H. P., van Dijk, M., Anand, K. J. S., Roofthooft, D., van Lingen, R. A.,
& Tibboel, D. (2003). Do we still hurt newborn babies?: A prospective study of procedural pain and analgesia in neonates. *Archives of Pediatrics*
& *Adolescent Medicine, 157*(11), 1058-1064.

Smith, E. M. (2011). Procedural pain management in neonates, infants and children. *Reviews of Pain, 5(3).* Doi:10.1177/204946371100500303.

Twycross, A. (2006). Managing pain during the first year of life. *Infant* 2(1), 10-14.

Zwicker, J. G., Grunau, R. E., Adams, E., Chau, V., Brant, R., Poskitt, K. J., ...
Miller, S. P. (2013). Score for neonatal acute physiology-II and neonatal pain predict corticospinal tract development in premature newborns. *Pediatric Neurology, 48*(2), 123-129.

Appendix: Table 1: Summary of studies included in the systematic review

Author (yr)	Sample	Objective	Design	Key Findings and Recommendations
Franck et al., 2004 (UK & USA).	Parents (mothers = 184; fathers = 73)	Describe parent views on infant pain care and to explore relations between parents' experience of their infant pain care and parental stress.	Descriptive cross- sectional	- Parents perceived that their infants perceived more pain than they had expected. - Parents were generally satisfied with pain management practices. - Parents concerns about infant pain may contribute to parental stress
Gale et al., 2004 (UK).	Parents (N = 12)	Explore parents' perception of their infants' pain and pain management in the NICU	Qualitative descriptive study	- Parents do not expect their infants to experience pain as part of their neonatal care. - Parents perceive their infants' experience unnecessary pain which causes them psychological stress. - Parents felt that their infants should undergo painful procedures in their presence. - Parents felt that health care professionals did not promptly respond to and consistently manage their

infants' pain.
- NICU staff should promptly respond to and consistently manage infants' pain and provide emotional support to parents.

Franck et al., 2001 (USA).	Parents (N = 95)	To elicit parents' views on infant pain assessment and management practices in the NICU	Descriptive survey	- 85 % of the parents believed that their infants experienced pain while in the NICU. - 82% of parents believed their infants received analgesia and that the medication relieved the pain. - - 53% of parents wished to stay with their infants during painful procedures. - Parents believed nurses and doctors could detect pain in their infants and were satisfied with pain management practices in the NICU.
Franck et al., 2011 (UK).	Parents (N = 169)	To determine effect of an intervention to improve parental involvement in infant pain care and to assess parents' attitudes towards infant pain	Randomized controlled trial	- Parents believed infants experienced more pain following the intervention. - Parents were less satisfied with infant pain and care had less confidence in staff ability to manage infant pain - Parents' perceptions about pain and their desire to be involved in pain care can be

improve through educational interventions.