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PARENTAL PERCEPTIONS ABOUT PAIN AND PAIN MANAGEMENT PRACTICES IN NEONATAL UNITS: A REVIEW
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PARENTAL PERCEPTIONS ABOUT PAIN AND PAIN MANAGEMENT PRACTICES IN NEONATAL UNITS: A REVIEW

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ABSTRACT

Background: Pain management in neonates remains sub-optimal in sub-Saharan countries like Kenya 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 neonates in Kenya. Successful use of these interventions is depended on parents' perception about neonatal pain and how well pain in neonates is managed during hospitalisation.

Objective: To determine parents' perception about pain and pain management practices in neonatal units.

Data sources: MEDLINE, CINAHL, Embase and PsycINFO databases were searched using the following key words: parent(s), perception(s), view(s), neonate, newborn, pain, procedural pain, management, and practices.

Study selection: Studies published in peer-reviewed English journals that focused on acute procedural pain or acute persistent pain on neonates were included in the review.

Data extraction: Two independent authors critically reviewed retrieved articles and extracted data on study sample, setting, design as well as key findings on parental perceptions about pain and pain management practices.

Data synthesis: A meta-synthesis approach involving a critical evaluation of convergences and divergences of participants' views about pain and pain management practices.

Results: Of the 101 articles generated through the databases search, four met the inclusion criteria. Parents believe that neonates experienced a lot of pain during hospitalisation that is often not adequately treated and desire to be involved in the pain care of their neonates.

Conclusion: The high frequency of pain experienced by neonates in the course of hospitalisation should serve as an impetus to involve parents in procedural pain management in neonatal units.

INTRODUCTION

Babies admitted in neonatal units undergo many diagnostic and care-related procedures in the course of hospitalisation (1,2) causing pain at a time when the neonate is physiologically immature and developmentally vulnerable (3). Epidemiological studies in high income countries in Europe (1,4) North America (5) and Australia (6) show that neonates undergo 12-14 painful procedures per day, a majority that are performed during the first three days of life. Neonates in low- and middle-income countries

(LMICs) undergo equally high number of painful procedures (2,7,8). In China (7), neonates are reported to undergo 3-30 (median 6.0) painful procedures per day which is comparable to the 7.5 painful procedures per day reported in other Asian settings (8) but slightly higher than the four procedures per day reported in neonatal units in sub-Saharan Africa (SSA) (2).

Despite the exponential increase in knowledge on neonatal pain and pain management strategies over the last two decades (9-12), procedural pain management remains suboptimal in neonatal units

globally (1,2,5,7). In Europe, Carbajal *et al.* (1) reported that less than 10% of the 42, 413 painful procedures experienced by 430 neonates over a two week period were performed with some form of analgesia. Slightly better pain management practices have been reported in North America (5) where more than half of the tissue-damaging procedures are accompanied with some form of pain relief. Procedural pain is, however, severely undertreated in LMICs in Asia (7) and SSA countries like Kenya (2) where all procedures, a majority that are associated with moderate-to-severe pain intensity, are performed without any form of analgesia.

The sub-optimal procedural pain management continues despite the empirical evidence that repeated and unmanaged pain in neonates has serious immediate and long-term consequences (13-14) including, sleep disturbance, poor weight gain, delayed healing, increased intracranial pressure (15-16) exaggerated response to subsequent painful experience, poor brain development, as well as behavioural and emotional disorders in childhood and early adolescent period (17-18).

The severe under-treatment of pain in neonates in SSA, like other LMICs, has been associated with lack of resources to procure pharmacological analgesics such as morphine and commercially prepared oral sucrose (19). However, there exist effective, low-cost, mother-driven pain management strategies such as breastfeeding and kangaroo care that can be used for pain relief in neonates (10-12). The successful utilisation of these mother-driven interventions for pain relief is, largely, depended on parental perception about pain and how pain in neonates is managed during hospitalisation (20). However, the empirical evidence on parental perceptions on neonatal pain and pain management practices in neonatal units has not been comprehensively synthesised. Therefore, the aim of this systematic review were to describe parents' perceptions about (a) neonatal pain, and (b) pain management practices in neonatal units.

MATERIAL AND METHODS

Search strategy: A systematic search of four major electronic databases (Medline, CINAHL, Embase and PsycINFO) was conducted by the first author (O.K) from 1990 to September 2014. The search terms

included parent(s), perception(s), view(s), neonate, newborn, infant, pain, procedural pain, management, and practices. Reference list of retrieved articles was also manually searched for any relevant article.

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

Data extraction: Two authors (O. K. and D. K.) independently extracted data from retrieved articles that met the inclusion. 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 on parental perceptions about pain and pain management practices.

Data synthesis: Data were critically synthesised to arrive at convergences and differences in parents' perceptions about pain and pain management practices between and 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 four met the inclusion criteria (21-24). Ninety seven studies were excluded because they were (a) not on parental perceptions or views about pain (n = 44), (b) not on neonatal or infant pain (n = 35), (c) published in a language other than English (n = 12), and (d) published as conference abstracts (n = 6). Of the four studies that met the inclusion criteria, only one was specifically on parental perceptions about neonatal pain (22) while the rest covered both parental perceptions about neonatal pain and pain management practices in neonatal units (21,23-24) Table 1.

Table 1
Summary of studies included in the systematic review

Author	Sample	Objective	Design	Key Findings and Recommendations
Franck <i>et al.</i> , 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	<ul style="list-style-type: none"> - 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 <i>et al.</i> , 2004 (UK).	Parents (N = 12)	Explore parents' perception of their infants' pain and pain management in the NICU	Qualitative descriptive study	<ul style="list-style-type: none"> - 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 <i>et al.</i> , 2001 (USA).	Parents (N = 95)	To elicit parents' views on infant pain assessment and management practices in the NICU	Descriptive survey	<ul style="list-style-type: none"> - 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 <i>et al.</i> , 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	<ul style="list-style-type: none"> - Parents believed infants experienced more pain following the intervention. - Parents were less satisfied with infant pain care and 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 improved through educational interventions.

Parental perceptions about neonatal pain: Of the four studies included in the review three were on parental perception about pain in neonates (21-22,24). Franck *et al.* (21) 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, during hospitalisation, than they had anticipated. Parents were, however, generally satisfied with the quality of pain management their infants had received; and preferred to be present when painful procedures were performed. Parental presence during painful procedures was associated with less parental stress and anxiety.

Gale and colleagues (24) interviewed 12 parents in the UK, six who had neonates admitted in the neonatal unit and six whose neonates had been discharged from the hospital, to explore their perceptions about their neonates' pain experience in the NICU. Although parents did not expect their neonates to experience pain while admitted in neonatal units, they felt that neonates were undergoing unnecessary painful procedures often causing psychological stress to the parents. Additionally, parents were of the view that neonates should undergo painful procedures in their presence.

In an earlier study, Franck and associates (21) 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 infants 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.* (22) investigated parental attitudes towards neonatal pain as a secondary aim in a randomised 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 parents from four neonatal units in UK were included in the study. Similar to previous studies, parents believed infants experienced a lot of pain in the course of their hospitalisation.

Parental perceptions about pain management practices: Out of the four studies included in the systematic review three (20, 22-23) explored parental perception about pain management practices in the neonatal unit. Gale and colleagues (23) 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 neonates' pain. Similarly, respondents felt that neonates should undergo painful procedures in presence of their parents. Similar findings were reported by Franck and colleagues (22) in a study in the UK. In this European study, parents were less satisfied

with neonatal pain care and had less confidence in staff's ability to manage neonatal pain. Franck *et al.* (22) reported that parents were generally satisfied with pain management practices in the neonatal unit with 82% of the parents believing that their neonates received adequate analgesia during procedures. On the other hand, only 53% of the parents in this study wished to stay with their neonates 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 that neonates 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 (24,25), a factor that has consistently been associated with poor procedural pain management practices in neonatal units globally (1,2).

The review has demonstrated that parents are often dissatisfied with quality of procedural pain care in neonatal units. Similarly, parents' desire to be present during painful procedures was consistently reported across studies. Considering that unmanaged pain in neonates has deleterious immediate and long-term consequences (10,13) there is need for HCPs to position pain care as a critical component of neonatal care. Additionally, considering the empirical evidence on efficacy and safety of mother-driven neonatal pain management interventions (16-18) and parents' wish to be involved in the pain care of their neonates (24), there is need to explore the feasibility of using these interventions for procedural pain relief particularly in LMICs.

The critical role that parents can play in the management of pain in neonates including, communicating with health care providers about pain, comforting the neonates, and making decisions on behalf of the neonate regarding pain (21) cannot be overemphasised. And since parents generally desire to be present and to be involved during painful procedures (20, 23), clinicians should consistently advocate for and support parental participation in pain care of neonates. Allowing parents to participate in relieving pain in neonate reduces anxiety, stress, and the sense of helplessness associated with noninvolvement (22, 24). Additionally, parental involvement in neonatal care, including pain care, has the potential to reduce the high workload in neonatal units which has been associated with sub-

optimal procedural management in many clinical settings (2,27). The involvement of parents should, however, be based on individual parent's preferences and experiences and should be commensurate with their level of competency.

Although the review has generated useful information that could be used to improve procedural pain management practices in resource-limited settings, 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 generalised to LMICs remains unclear. Similarly, majority of the studies included in the review adapted a quantitative design. However, considering that perception is an abstract concept, it is hard to discern whether the study instruments, despite their psychometric properties, could be used to quantify such an abstract concept like perception.

In conclusion, overall, parents strongly believe that neonates experience a lot of pain, often unnecessarily, in the course of their hospitalisation. The parents' expectations about their neonates' pain management is, however, rarely met. Future studies should focus on investigating parents' perceptions about neonatal pain and pain management practices in LMICs. Additionally, barriers to parental involvement in neonatal pain care in neonatal units should be explored.

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