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Mothers' Perceptions about Pain in Hospitalized Newborn Infants in Kenya

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ABSTRACT

Purpose: Explore views of mothers about pain and pain treatment practices in hospitalized newborn infants.
Design and methods: A Qualitative descriptive study using photo-elicitation technique was conducted in a level I and a level II neonatal units in Kenya. Fifteen semi-structured interviews were conducted with mothers of hospitalized infants. The interviews were audio-recorded, transcribed verbatim and analysed using inductive content analysis approach.
Results: Mothers described the experience of witnessing their infants undergo painful procedures as emotionally and psychologically traumatic. Participants felt helpless for not being able to protect their infants from pain a situation which was made worse by health care providers who appeared less concerned about pain relief during procedures. Mothers' views demonstrated a good understanding of pain-relief strategies; they identified strategies that health care providers should routinely use to relief pain in hospitalized infants. Furthermore, participants desired to be involved in comforting their infants during clinical procedures.
Conclusion: Repeated and untreated painful procedures continue to define the hospitalisation experience of newborn infants despite the presence of mothers who desire to be involved in comforting their infants during procedures.
Practice implication: Minimizing the burden of pain and using pain-relieving interventions could reduce parental stress and optimize parental role attainment following hospitalisation.

Introduction

The last few decades have witnessed massive technological and scientific advancements in neonatal care that have resulted in extremely premature and critically ill infants surviving beyond the hospitalisation period (Montirosso, Provenzi, Calciolari, & Borgatti, 2012). Concomitant with the improved survival rate are the many painful procedures that are performed as part of routine medical care. In a recent systematic review, Cruz, Fernandez, and Oliviera (2016) reported that hospitalized infants undergo 7–17 painful procedures per day including heelsticks, venepunctures, lumbar punctures and vaccinations; previous estimates concur with this finding(Carbajal et al., 2008; Chen et al., 2012; Kyololo, Stevens, Gastaldo, & Gisore, 2014).

Although the pain associated with procedures is sub-optimally treated in neonatal units globally (Johnston, Barrington, Taddio, Carbajal, & Filion, 2011; Roofthooft, Simons, Anand, Tibboel, & van Dijk, 2014), the situation is more dire in low- and middle-income countries. For instance, in Brazil very few procedures are accompanied by some form of pain relief (Linhares et al., 2012) while none of the infants in Chinese (Chen et al., 2012) as well as in Kenyan neonatal units (Kyololo et al., 2014) are given any form of pain relief during procedures. These limited infant pain treatment practices in low-income countries, and particularly in sub-Saharan Africa, have been associated with the lack of knowledge and negative attitudes of health care providers (HPCs) towards pain (Rampanjato, Florence, Ndimubanzi, Patrick, & Finucane, 2007; Walters, 2009) and unavailability of analgesics including opioids, local anaesthetic creams and oral sucrose (Cignacco et al., 2010; Clancy, 2014; Kyololo et al., 2014).

Repeated and untreated painful experiences have the potential to alter the physiological and behavioural functioning (Valeri, Holsti, & Linhares, 2015) as well as impair the neuro-anatomical, cognitive and behavioural development of the infant (Abdulkader, Freer, Garry, Fleetwood-Walker, & McIntosh, 2008; Bellieni et al., 2009; Brummelte et al., 2012; Duerden et al., 2018; Grunau et al., 2009; Ranger et al., 2013; Schwaller & Fitzgerald, 2014; Slater et al., 2012; Vinall et al., 2014). Efforts to avert these effects of untreated pain have catalysed the development of numerous clinical practice guidelines (CPGs) and consensus statements recommending the prevention and prompt and

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adequate treatment of pain in hospitalized infants (American Academy of Pediatrics [AAP], 2016; Lee, Yamada, Kyololo, Shorkey, & Stevens, 2014).

Parents play a critical role in the care of hospitalized infants and more so during procedures (Franck, Oulton, & Bruce, 2012; Palomaa, Korhonen, & Pölkki, 2016) whereby their views inform HCPs' decisions about pain practices (Finlayson, Dixon, Smith, Dykes, & Flacking, 2014; Franck, Allen, Cox, & Winter, 2005; Vazquez, Cong, & DeJong, 2017). They are not only key participants in physical and behavioural pain-relieving interventions (e.g., breastfeeding, kangaroo care) (Johnston et al., 2014; Pillai Riddell et al., 2015; Shah, Herbozo, Alowalas, & Shah, 2012) but also advocate for (a) minimisation of pain exposures and (b) use of pain treatment interventions (Johnston, Barrington, et al., 2011; Johnston, Campbell-Yeo, & Filion, 2011; Lester et al., 2014).

Emerging evidence from high-income countries shows that parents acknowledge the efforts made to treat pain (Franck, Cox, Allen, & Winter, 2004; Vazquez et al., 2017) but still desire greater utilisation of pain treatments during procedures (Gale, Franck, Kools, & Lynch, 2004). Failure to meet this expectation, coupled with memories of infants' suffering and inability to protect them from pain, contribute to increased parental stress (Franck et al., 2004; Montirosso et al., 2012; Power & Franck, 2008) and may, in the longterm, impair parental role attainment (Franck et al., 2011). Surveys in developed countries show that parents of hospitalized infants worry about pain even when they know their infants have received pain medication (Franck, Scurr, & Couture, 2001; Vazquez et al., 2017). Parents are also distressed by the multiple painful procedures and the unresponsiveness of HCPs to attend to the comfort needs of hospitalized infants (Power & Franck, 2008). Efforts to improve infant pain treatment practices globally would benefit from a comprehensive understanding of the views of all critical stakeholders in neonatal care, and particularly parents, about pain and pain treatment practices in diverse settings. However, minimal qualitative studies investigating the views of parents about pain and pain treatment practices in low-income settings, where procedure-related pain is untreated (Kyololo et al., 2014), exist. The aim of this study was to explore mothers' perceptions about pain and pain treatment practices in neonatal units in a low-income country.

Methods and procedures

Methods

This qualitative descriptive study was part of a large mixed-methods project (Kyololo, Stevens, Gastaldo, & Songok, 2016). Semi-structured interviews using photo-elicitation techniques (Harper, 2002; Hurworth, 2003) were conducted with mothers to understand their perceptions of procedural pain and pain treatment practices of hospitalized infants. Photo-elicitation technique entails incorporation of photographs into research interviews to (a) facilitate communication between participants and the researcher, and (b) give participants visual cues to reflect on during interviews (Clark-Ibáñez, 2004; Hurworth, 2003). The study was approved by research ethics board (REB) in a university in Canada as well as in the study hospitals in Kenya.

Settings and sample

The study was conducted in two neonatal units in Kenya; a community hospital Level I unit and a federal government Level II unit, between November 2014 and February 2015.The Level I unit is a 45 bed capacity, special care nursery that admits less critically ill infants born more than 32 weeks gestational age (GA). The Level II unit is a 70-bed capacity high-dependency unit (admits infants who do not require intensive care but who still require complex care) that serves as a training centre for two universities and two mid-level colleges. In Kenya, generally, mothers of hospitalized infants are accommodated in the hospital for the entire hospitalisation period of their infant. They are allowed 24-hour access to the neonatal unit although, in reality, they are encouraged to visit only every 3 h for feeding due to the large number of babies and space constraints. Similarly, due to the large number of infants in the units, and to reduce the risk for infections, fathers are only allowed brief access to the unit daily (1–2 p.m. and 5–6 p.m.). Even then, very few of the fathers spend a substantial amount of that time with the infant. Since we intended to gather views of parents who have lived through the full spectrum of painful events with their infant over the hospitalisation period, only mothers were targeted for interviews.

Study participants were recruited by a social worker, not directly involved in the care of infants or mothers in the units, and one of the lead author (OMK) through one-on-one, face-to-face interactions. The purpose of the study and study procedures were explained, in detail, to participants; questions and concerns related to the study were addressed before participants were requested to sign consent forms. To ensure multiple views of mothers were captured, a purposive sampling with maximum variation approach was employed (Polkinghorne, 2005; Teddlie & Yu, 2007). Mothers with diverse demographic characteristics (i.e., age, educational level, parity, duration of hospitalisation, previous neonatal unit experience) who (a) were older than 18 years (legal age to give consent in Kenya), (b) had completed at least three postnatal days, (c) had an infant eligible for discharge in the next 24 h (to capture views about pain practices over the entire hospitalisation period), and (d) could speak either English or *Swahili* (a national language in the country) were interviewed. Mothers of terminally ill infants and those whose babies were being discharged as a referral to another facility were ineligible to participate. Mothers were recruited and interviewed consecutively until data saturation was attained. Only two mothers declined to participate; one felt the study would not benefit the infant and the other stated that she needed time to prepare for the discharge.

Procedures

Developing the interview kit

An interview kit consisting of photographs of local mother-baby pairs was incorporated into the interviews to (a) stimulate participants' recollections of the hospitalisation experience, (b) serve as visual cues for participants to reflect on during interviews and (c) ease any tension during interviews by allowing participants to focus on the photographs rather than the researcher (Clark-Ibáñez, 2004; Harper, 2002; Hurworth, 2003). A professional photographer affiliated with the hospital took the photographs, with parental consent, under the direction of the lead author. Short- and long-range photographs, from different angles, of neonates undergoing painful procedures using different physical pain relieving strategies (e.g., breastfeeding, kangaroo care, positioning, and pacifier) were taken. The legal and public relations (PR) departments of the hospital were involved during the generation of the photographs to ensure privacy and confidentiality of patient information and that images were protected. The PR department was the custodian of all the photographs; the research team was given digital copies of the photographs that they had selected for the interview kit. The selected photographs (20 in total) were processed, laminated and assembled in a hole-punch photo-binder that was used to conduct interviews.

Interviews

Interviews were conducted by a neonatal nurse (lead author) experienced in infant pain and neonatal care in the local context. The interviews were conducted shortly before discharge such that mothers could reflect on their experiences of parenting a neonate undergoing procedures over the entire hospitalisation period. A two-part interview guide consisting of six open-ended questions (each with 2–3 probes) was used for the interviews. The interview guide was developed by a team of investigators comprised of two neonatal nurses with extensive expertise in neonatal pain, a neonatologist, and a qualitative researcher. The first section of the interview guide elicited mothers' perceptions

about the hospitalisation experience broadly and, in particular, their thoughts about the painful events experienced by infants. Subsequently, mothers were asked specifically about their role with their infants' pain during procedures.

The photographs were integrated at the beginning of the second part of the interview; participants were handed the photo-binder and informed that the photographs will be the focus of the section of the interview. Participants took time to remove and explore each set of photographs and to reflect on their experiences in relation to what was captured in the pictures. The first interview question was framed to draw the attention of participants to the images (i.e., "*what is happening in the photograph*?"). As the participants studied the photographs, questions were posed to provoke higher level of reflection (e.g., "*to what extent does what is captured here relate to what you experienced or witnessed while in the hospital*?").

The interview guide and interview kit were piloted with three mothers who met the study inclusion criteria. Since no modifications to the interview guides were necessary, the pilot interviews constituted part of the main study results. The interviews were conducted at the mothers' convenience during daytime in a private room within the unit and lasted 35–65 min. During the interviews, the participant and interviewer sat on same side of the table with the participant holding the interview kit. Participants were allowed to remove the photographs from the binder, hold, point to, and share their views and reflections regarding the images.

Following each interview, the researcher documented any peculiar response to interview questions (e.g., staring into space for long) or any inaudible reaction to viewing certain set of photos (e.g., fidgeting or teary eyes on viewing photos of a baby being injected). All interviews were audio-recorded. Each participant completed a brief demographic survey (age, number of other children, length of hospital stay) after the interview.

Data analysis

Interviews were transcribed verbatim by a professional transcriptionist who spoke both English and *Swahili*. A forward-backward translation process (Al-Amer, Ramjan, Glew, Darwish, & Salamonson, 2015) was conducted for transcripts in *Swahili*. To ensure semantic congruence was maintained during the translation (Karwalajtys et al., 2010), sentences and phrases originally in *Swahili* were translated to English and back to *Swahili*. The retranslated *Swahili* version was then compared with the original transcripts for accuracy of terminology and phrases.

Ritchie, Spencer, and O'Connor's (2003) and Graneheim and Lundman's (2004) inductive content analysis approach was employed in analysing interview data. The analysis process entailed reading the transcripts multiple times to get a sense of the data to identify codes and sub-codes, categories and sub-categories and to develop a coding structure. Initially one of the investigators (OMK – designated primary coder) and another experienced analyst independently reviewed and coded the same transcripts (three in number) that were rich in data in terms of quality and quantity. These two coders met regularly to compare emerging codes, sub-codes, categories, sub-categories and the evolving coding structure. Whenever discrepancies in coding and coding structure could not be resolved through negotiation and consensus, a third coder (BS) was involved. To ensure credibility of the coding structure, additional analysts (BS and DG) independently coded two more interviews. They (BS and DG) met the primary coder multiple times to review and revise the coding structure. Repeated codes were grouped together while redundant categories and sub-categories were collapsed to arrive at the final coding structure. To maintain consistency in data analysis, the codes and categories were explicitly defined using a coding book and examples for each provided.

Subsequently, the primary coder and the analyst independently applied the coding structure to two transcripts that had not been used in the development of the coding structure. Codes, categories and sub-categories for each transcript were compared consecutively for at least 85% coding agreement (Burla et al., 2008). Then the primary coder proceeded to code the remaining (eight) transcripts. Once the coding was complete the primary coder and the second author (BS) met regularly to review the coding and data analysis process. Additional categories and sub-categories were continually generated and refined until no new categories emerged from the data. The generated categories were iteratively compared to arrive at overarching themes and subthemes (Bradley, Curry, & Devers, 2007; Ritchie et al., 2003). The data analytic process was aided by the use of NVivo 10 software for windows (QSR International, 2014).

Rigour

Several strategies were employed to assure rigour. Reflexivity has guided all phases of the study (Finlay, 2002; Morrow, 2005). Contextual factors and ethics in practice were carefully considered during study design and implementation by the local authors (OMK and JS). In addition, the potential impact of the positionality of the researcher during data collection was analysed. Trustworthiness was also achieved through a detailed audit trail and a team approach to data analysis (described above).

Results

A total of 15 mothers (seven from Level I and eight from Level II units) were interviewed. The mean age was 25.8 years ($SD = 6.19$); five were first time mothers and only two had previous neonatal unit experience. The infants had been in the hospital for an average of 15 days (range 3–28 days) at the time of the interviews.

Analysis of interview data resulted in three broad thematic categories that captured mothers' perceptions about pain and pain practices: (a) pain defining the hospitalisation experience, (b) pain-relieving interventions, and (c) improving pain practices (Table 1).

Pain defining the hospitalisation experience

Participants described the hospitalisation experience as extremely stressful; characterized by many painful events. Their views were related to the burden of pain borne by their infants and nontreatment of pain during procedures.

Burden of pain

Mothers described the types and frequency of procedures that were performed on sick infants daily. The many procedures resulted in a magnitude of pain intensity that was described as "a lot" and for some cases, "the worst imaginable". The highest burden of pain resulted from two broad categories of procedures; those that were performed multiple times each day (e.g., inserting gastric tube for feeding) and those that were repeated numerous times to complete. The latter category consisted of procedures that were described as either "pricks" or "injections" and included intravenous cannulation and venepunctures for blood draws. The painful procedures were not anticipated by mothers

Table 1
Mothers' perceptions about pain and pain practices: Themes and Subthemes.

Themes	Subthemes
Pain defining the hospitalisation experience	Burden of pain
	Nontreatment of pain
Pain-relieving interventions	Kangaroo care
	Breastfeeding
	Facilitated tucking
Improving pain practices	Creating awareness among mothers
	Involving mothers

at the time of admission but, in the course of hospitalisation, mothers came to view them as a critical part of treatment that every baby had to undergo:

> *I was not expecting it. …* [*thoughtfully*] *but I came to realize that she had to undergo all that process as part of treatment. There is no way she could have got the treatment without those injections* (28-year-old mother of 1).

Participants described the effects the numerous painful procedures had on infants and themselves. The procedures left physical scars on babies that would act as a permanent reminder of the eventful neonatal experience. Knowing that infants were repeatedly being subjected to painful procedures was emotionally and psychologically traumatic to the mothers; there was a feeling of sorrow and helplessness among mothers for not being able to protect their infants from suffering. The situation was made worse by HCPs who appeared not to appreciate the emotional distress mothers were going through:

> *You cannot have peace when your baby is in pain, when she is in pain you feel it too, you feel like they are performing the procedure on you. Unfortunately clinicians never understand that especially when you get emotional on seeing what your baby has to undergo* (23-year-old Mother of 2).

Nontreatment of pain

Mothers acknowledged that, despite the repeated procedures, infants were rarely treated for pain. They recounted numerous instances when HCPs performed procedures on infants and left them without comforting or offering them something to relieve the pain. Participants felt that on the rare occasions when pain was treated, the pain relief strategies employed were not commensurate with the intensity of pain experienced. Mothers observed a tendency among HCPs to be more sensitive about pain relief when they were present; HCPs would handle the infants more gently, verbally soothe them during procedures, and encourage mothers to comfort their infants after procedures. Overall, mothers felt that HCPs were hardly concerned about pain treatment notwithstanding the burden of pain inflicted on infants:

> *… the doctor seeing the baby today will come and find the baby has no cannula, especially the cannula, so he will remove the tissue cannula without giving the baby any form of pain relief, the baby goes through so much pain! After that he proceeds to fix another cannula without giving the baby any analgesic. So the baby really undergoes a lot of pain* (20-year-old mother of 1).

Pain-relieving interventions

Mothers' view reflected knowledge of strategies that could help infants cope with pain during routine clinical procedures. They discussed the possibility of using strategies such as kangaroo care (skin-to-skin, chest-to-chest contact between mother and infant), breastfeeding, and facilitated tucking (using caregivers' hands to gently position the infant's arms and legs close to the torso) on their infants during painful procedures.

Kangaroo care

Mothers regularly practiced kangaroo care (KC) for warmth and bonding. They discussed the usefulness of KC noting that it helped crying infants calm down and fall asleep faster after feeding. Reflecting on those experiences, mothers felt that they should be allowed to routinely hold their infants in the KC position during painful procedures. Mothers' determination to work with HCPs in comforting infants during procedures, by doing KC, was clearly palpable; they were willing to forego their comfort for the sake of their infants' pain relief.

> *I will be uncomfortable but I will do it to help my baby. I can allow him* [*clinician*] *to do it because in that position the baby won't cry for long, she will cry for a short while. But if he does the procedure away from my chest the baby will cry a lot, and it will take time to calm the baby after the procedure when I place her back on my chest* (22-year-old mother of 1).

Breastfeeding

Mothers described instances when they were asked by HCPs to breastfeed their infants after procedures. They appreciated breastfeeding as a strategy that newborn infants were familiar with and which mothers were instinctively inclined to use to soothe distressed infants. Although mothers felt they should be allowed, whenever feasible, to breastfeed their infants after procedures, they were uncertain about allowing HCPs to perform procedures with infants attached to the breast. Whereas mothers strongly felt that they should be allowed to breastfeed during painful procedures, there existed safety concerns related to the practice:

> *The baby wont cry for long although, she may feel the pain as the needle goes in and maybe at that point you may get her out of the breast for the prick because if she cries she may get choked and that becomes another problem. Maybe give her the breast immediately the procedure is done* (23-year-old mother of 2).

Facilitated tucking

There was a general consensus among participants that facilitated tucking (FT) should be used on infants undergoing painful procedures. However, their views appeared to be informed by a misinterpretation of the strategy as a form of physical restraint. Mothers felt that positioning would minimize infants' movements allowing HCPs to prick the infants fewer times and to complete the procedure faster. Although mothers indicated that they could be engaged in positioning infants, they were perturbed by HCPs who insisted that they should step out of the room whenever procedures were being performed. Participants also acknowledged that holding an infant during an invasive procedure would be a traumatic experience for most of them. Nonetheless, they were willing to endure the discomfort if that would reduce the burden of pain borne by their infants:

> *… it is painful because you see the baby is crying, and then the doctor is holding that needle now, so you just feel the pain the child is experiencing, you feel like crying. But just because it's my baby … I can do anything! I will have to feel the pain she is experiencing* (20-year-old mother of 1).

Improving pain practices

The last overarching theme encompassed mothers' perception about how pain practices could be improved. Mothers indicated that they felt underutilized by HCPs in comforting their infants during painful procedures. They observed that pain practices could be improved by creating awareness on how to help infants and actively involving mothers during procedures.

Creating awareness among mothers

Mothers' views reflected a great desire for knowledge on how to soothe infants during procedures. They felt that they should be provided with information, before admission and throughout the hospitalisation period, on possible pain reducing strategies and how to use them during procedures. The need for HCPs to create awareness, among mothers, that the routinely practiced nursing activities (e.g., breastfeeding, kangaroo care) are beneficial to infants during painful procedures was emphasized. Mothers felt that they would be very receptive to using the

strategies if HCPs emphasized how use of the interventions would benefit the infant:

> *Maybe talk to mothers and educate them on the benefits of those strategies. But there are some mothers who are not comfortable exposing themselves like when doing kangaroo. So it depends on individual mothers. But if you can talk to them and tell them "if you place the baby in this position the baby will calm down and will sleep". Because it is not easy to get it without being explained to its benefits* (22-year-old mother of 2).

Involving mothers

Active involvement of mothers during procedures was considered a critical first step in improving pain practices. Mothers preferred to be allowed to remain with their infants and desired HCPs to encourage, support and show compassion and understanding to those who wanted to remain by the bedside during procedures. They were candid that their involvement would be helpful to infants in varied ways, including calming, holding and breastfeeding after procedures. They observed that, although it was uncomfortable watching their infant undergo procedures, it was more psychologically traumatizing by not being involved. Overall, maternal involvement was associated with a better chance of the infant having pain relief during procedures:

> *You see. It's better to be involved because after the procedure I would hold my baby and try to calm her down because after the procedure she is left all alone in pain* (23-year-old mother of 1).

Discussion

We used innovative qualitative methods to elicit mothers' perceptions about pain and pain practices in hospitalized infants. The photo-elicitation interview technique allowed participants to discuss their experiences as caregivers of infants undergoing painful procedures, aided by visual cues that they could relate to. Our findings are significant considering that they are the first to provide a detailed account of mothers' views about pain practices in low-income settings where pain in infants is underprioritized and undertreated.

Findings of this study, similar to other studies (Franck et al., 2005; Franck et al., 2012; Gale et al., 2004; Joseph, Mackley, Gavis, Spear, & Locke, 2007; Ward, 2001), indicated that mothers were concerned about procedure-related pain and desired consistent and timely use of pain relief strategies during procedures. Mothers identified the sources of pain that, notably, were strikingly similar to those documented in medical records in the country (Kyololo et al., 2014). Parents in other countries are also able to isolate the procedures that contribute the highest burden of pain in infants (Franck et al., 2005; Gale et al., 2004). Additionally, like others, we found that mothers perceived pain is an inevitable part of treatment regimen (Olaogun, Ayandiran, Olalumade, Obiajunwa, & Adeyemo, 2008). This finding has the potential to slow down efforts to improve pain treatment practices especially when the cultural aspects of the perceptions are considered in the African context (e.g., pain is good for development of acceptable traits) (Olaogun et al., 2008). This misperception should be addressed within the social and cultural context (Clancy, 2014) if mothers' role as caregiver is to be optimized for better pain practices (American Academy of Pediatrics [AAP], 2016; Gale et al., 2004; Vazquez et al., 2017).

Mothers were emotionally and psychologically traumatized by the painful procedures, compounded by the attitudes of HCPs. Many other researchers have reported similar stressful states among parents of hospitalized infants (Franck et al., 2001; Franck et al., 2005; Gale et al., 2004) with most of the distress arising from not being able to protect the infant from pain and not knowing how to comfort the infant during procedures. In another study of fathers of infants who underwent surgical procedures, seeing the infant in pain, being unable to offer protection from pain and not being able to comfort the infant were associated with the highest level of parental distress (Joseph et al., 2007). Our findings, taken together with others (Franck et al., 2005; Gale et al., 2004), demonstrate the significant role of infant pain experience in shaping parental roles and hospitalisation experiences. Adapting family-centred care approaches and encouraging dialogue between HCPs and parents on pain and pain relieving strategies has the potential to address the parental stress and improve on parental role attainment in the care of hospitalized infants (Franck et al., 2012; Holditch-Davis & Miles, 2000; Joseph et al., 2007).

Mothers felt that their infants were likely to be treated for pain when they were at the bedside than when not. This finding is not unique to the Kenyan context; empirical evidence from Europe (Carbajal et al., 2008) and North America (Johnston, Barrington, et al., 2011; Johnston, Campbell-Yeo, & Filion, 2011) show that HCPs treat infant pain much better in presence of parents. Although it is unclear why presence of parents would result in better pain treatment practices, it is hypothesized that parents' presence may influence use of pain relief by (a) being used as sources of pain relief strategies (e.g. breastfeeding, KC), (b) advocating for their infant's pain treatment or (c) prompting HCPs to use pain relief strategies during procedures. Nonetheless, the finding highlights the need for parents to be encouraged to be present during procedures if we are to achieve better pain treatment practices, particularly in settings where infant pain is sparingly treated.

Mothers identified strategies that they could use to comfort their infants, including kangaroo care contact, breastfeeding and facilitated tucking. These strategies have been shown to be effective in reducing pain from most commonly performed procedures in neonatal intensive care units (NICUs) (Johnston et al., 2014; Pillai Riddell et al., 2015; Shah et al., 2012). Notably, these strategies are either mother-driven (Benoit, Martin-Misener, Latimer, & Campbell-Yeo, 2017) or parents could be successfully taught how to use them effectively during procedures (Axelin, Lehtonen, Pelander, & Salantera, 2010; Axelin, Salantera, & Lehtonen, 2006). The misinterpretation of facilitated tucking as a method of restraint is not unique to our study; researchers in countries where the intervention is routinely used for pain treatment have reported similar misconceptions (Johnston, Barrington, et al., 2011; Johnston, Campbell-Yeo, & Filion, 2011). Nonetheless, the misperception raises serious practice concerns. Facilitated tucking as a pain relief strategy requires different techniques and skills from physical restraint (Axelin et al., 2006) and could result in injury if not properly done (e.g., applying too much pressure) (McNair, Campbell Yeo, Johnston, & Taddio, 2013). Addressing the misperception and training mothers on how to use the strategy to comfort infants during procedures are warranted.

Participants were also concerned about the safety of breastfeeding when used during painful procedures. Researchers have found no safety concerns to warrant discouraging breastfeeding during procedures (McNair et al., 2013; Shah et al., 2015; Taddio et al., 2009; Zhu et al., 2015). Caution should, however, be exercised when encouraging breastfeeding for pain relief in human immunodeficiency virus (HIV) endemic countries such as Kenya (Hoshi et al., 2016) due to the risk for transmission of infection. Mothers who desire but for whom breastfeeding is unfeasible (e.g., premature or critically ill infants, HIV infected mothers) could be encouraged to give expressed breast milk instead (Shah et al., 2012) or other sweet-tasting solutions such as sucrose (Harrison et al., 2016; Stevens et al., 2018).

Mothers' views on strategies for improving infant pain treatment practices, including creating awareness about pain relieving strategies and encouraging active participation during procedures, are shared by parents in mid-high resource settings as well (Franck et al., 2004; Franck et al., 2005; Gale et al., 2004; Vazquez et al., 2017). Franck et al. (2012) found that British parents wanted information about infant pain and specific strategies for comforting their infants and desired the option of attending to their infants during procedures. The benefits of involvement during procedures are well documented. Mothers are

sources of pain relief (Johnston et al., 2014; Shah et al., 2012); they are relieved of the emotional distress related to inability to comfort or protect their infant from pain and develop better relationships with their infants (Franck et al., 2004; Gale et al., 2004; Joseph et al., 2007); and their involvement has potential to mitigate the human resource burden during procedures (Cignacco et al., 2010). The latter point is particularly important in neonatal units in low-income countries where workload is an impediment to optimal pain treatment (Clancy, 2014; Kyololo et al., 2014). With few HCPs to attend many, often critically ill, neonates the priority becomes completing the life-saving procedures rather than pain treatment (Kyololo et al., 2016). Therefore, involvement of mothers has the potential to improve pain practices by relieving pain during procedures through strategies such as FT and breastfeeding (Axelin et al., 2006; Cignacco et al., 2007).

The finding that mothers were willing to forego their comfort for the sake of their infants' pain relief has also been reported elsewhere (Axelin et al., 2006) and is quite encouraging. A judicious evaluation of individual parent's preferences and experiences should, however, be carried out prior to being engaged during procedures (Kyololo, Kereri, & Marete, 2015).

Study limitations

Although the study shed light on the perceptions of mothers about infant pain in a low-income setting, some methodological issues may limit the transferability of our findings. First, the study was conducted in a specific geographical region of the country; mothers in other regions may have had different views from the study participants. Furthermore, although the photographs were meant to provide visual cues for participants to reflect on during interviews, their inclusion may have led participants to give views based on what was depicted in the images rather than unbiased reflection on their hospitalisation experience. Additionally, despite the rigorous language translation process, some meanings inherent in participants' phrases and expressions may have been lost or distorted.

Conclusion

Parents are important stakeholders in the care of hospitalized infants and their views about the quality of care are critical in informing strategies to change practice. Mothers felt that their hospitalized infant experienced unexpected but unavoidable pain without adequate comfort measures. Although the pain experienced by infants was emotionally traumatic to mothers, the stress could be minimized by active involvement during procedures. To maximize parental involvement and to improve pain practices, HCPs should inform parents of hospitalized infants about strategies for relieving pain during procedures and address the inherent misperceptions about pain and pain relieving strategies. Furthermore, HCPs should show sensitivity to parents' needs by encouraging and offering them an opportunity to be present and assist during procedures based on individual preferences and competences. Understanding HCPs' perceptions about infant pain and pain treatment practices should be the focus of future research.

Authors' statement

Dr. Kyololo conceptualized and designed the study, developed the study protocol, collected and analysed the data, drafted the initial manuscript, made revisions and approved the final manuscript as submitted; Dr. Stevens conceptualized the research idea, provided mentorship to Dr. Kyololo in writing the study protocol, during data collection and analysis, and critically reviewed and revised the manuscript and approved the final version submitted; Dr. Songok participated in conceptualization and design of the study protocol, provided mentorship to Dr. Kyololo during data collection in Kenya, reviewed and revised the manuscript, and approved the final manuscript as submitted.

Competing interests

The authors have no competing interests to declare related to this paper.

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