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A Parent Group Initiative in an Intensive Care Unit in South Africa

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Note: The initial plan was to run a group to meet caregivers' needs and we wanted to deliver the best service possible to reflectively respond to actual needs. Our intention was never to collect data for the purposes of generalisation/research, and the work was conducted only as a practice improvement initiative. Our aim was to improve our own clinical practise. Whilst running the groups we found useful lessons, and came to learn that there is no other literature to date of OT's and social workers running similar groups. This together with the interest from colleagues who felt that what we learnt might be clinically useful to others, we were prompted to write this article

Introduction

While families' experiences in Paediatric Intensive Care Units (PICU) have been well documented in the literature (Flacking et al., 2012; Frazier, A., Frazier, H. and Warren, 2010; Johnson, n.d.; Latour et al., 2011; Latour, van Goudoever, & Hazelzet, 2008; Macdonald, Liben, Carnevale, & Cohen, 2012; Meert, K.L., Clark, J. and Eggly, 2013; Miles & Mathes, 1991; Romer, L. H., Nichols, D., Woods, B. H., Latour, J. M., & Mesman, 2008; Rushton, 1990; Scott, 2002), very few, if any pertain to a unit in an African setting. This contribution aims to bridge this gap and to explore the barriers, as well as the opportunities, that present themselves in the PICU of a tertiary hospital in South Africa.

Red Cross War Memorial Children's Hospital (RCWMCH) is a 300-bed specialist health facility paediatric hospital in Cape Town. It is the only stand-alone paediatric hospital in Sub Saharan Africa offering a

full range of sub-specialties at quaternary and tertiary levels of care (Western Cape Government, 2015). The majority of patients and their families come from impoverished communities (Children's Hospital Trust Annual Report, 2012). RCWMCH has the largest ICU for children in Africa. It has a 22 bed PICU with a high turnover. 1300 children are admitted per annum with an average length of stay of 3 days. The largest age group of children admitted is below one year of age (RCWMCH PICU, 2013).

Despite constant presence, it was observed that parents often had minimal interaction or physical contact with their sick infants. We assumed that this would be very different to how they would have handled their children at home.

However, to appreciate the ordinary environmental context more fully, the culture from whence our children and families originate needed to be understood.

In our diverse setting, the African Xhosa culture predominates. Xhosa speaking patients make up about 60% of PICU patient turnover, the remaining 40% is predominantly Afrikaans speaking with a growing group of families from other parts of Africa who speak French /Portuguese or other languages including English. There is a wide diversity of cultural background in the RCWMCH PICU (for both staff and patients).

As staff we therefore needed to listen to mothers to give us insights into indigenous caregiving practices. It became apparent that parents had a wealth of existing knowledge and skills regarding their infants. For example Thula Thula is a well-known South African lullaby, frequently used to soothe infants and is a phrase that has become synonymous with being loving and soothing. It is in stark contrast to the PICU shrill alarms or beeps. Parents unanimously reported that the alarm bells were not only the first stimulus they noticed, but also the most disturbing.

The Problem

The majority of parents were observed by the PICU Occupational Therapist (OT) and Social Worker (SW), to not talk, touch or interact with their sick infants; they were very rarely seen to be participating in care-giving activities. Thus it was thought that parents' existing knowledge and skills were being inhibited when their child was in the PICU.

The OT and SW working in the PICU were concerned about the long term effects on both the infant and caregiver's wellbeing and mental health from not touching or interacting during this time. This concern is amply supported in the literature. (Bowlby, 1973; Feldman & Eidelman, 2003; Latva, Korja, Salmelin, Lehtonen, & Tamminen, 2008; Robertson, 1958; Scher et al., 2009; Treyvaud et al., 2009)

While the negative effects of the separation of mother and infant have been documented (Bowlby, 1973; Robertson, 1958), the long term negative effects of reduced physical touch have been researched in more recent years. Physical proximity, including touch as well as emotional closeness were found to be crucial to the emotional, social and physical well-being of parents and infants in NICU's and PICU's alike. Not only were these factors important to the long-term infant-parent relationship, but also to the infant's physical development and health. (Feldman & Eidelman, 2003; Latva et al., 2008; Scher et al., 2009; Treyvaud et al., 2009)

Active parental involvement with the hospitalised preterm infant, particularly skin to skin contact, and supported parental involvement in caring for those infants have been demonstrated to result in positive neurobehavioral and neurodevelopmental outcomes, improved cognition and an increase in psychomotor organization (Als et al., 2004; Milgrom et al., 2010; Scher et al., 2009).

In addition, parental stress and mental health have been shown to have long term impacts on the child's emotional development and behaviour (Huhtala et al., 2012). Helping parents to interact with their infants may reduce their level of stress and give them a sense of competence and mastery. This will therefore have a positive effect on the child's behavioural and emotional development (Butler & Als, 2008; Davidge, 2009; Feldman & Eidelman, 2003; Latva et al., 2008; Scher et al., 2009; Treyvaud et al., 2009).

It needs to be emphasized that the medical excellence that has been achieved in critical care will not on its own determine

the eventual outcome for the child and the family. The interactions and relationships within healthcare teams, families and patients which in turn impact on parental levels of stress, as well as on their physical and emotional relationship, with their sick infant are of equal importance (Flacking et al., 2012).

The concern of the RCWMCH PICU OT and SW was thus well-founded as the PICU setting in the RCWMCH clearly revealed some barriers that made it more difficult for parents to interact with their children as they were accustomed to doing at home.

The PICU OT and SW therefore conducted individual interviews, pre and post group questionnaires, observations as well as open discussions in the group. This was a clinically informed intervention from which valuable information to improve clinical practice was gained. Prior to initiating an intervention available literature was studied in order to help inform their practice.

The Family Centred Approach

The RCWMCH PICU OT and SW's response to the problem was to examine and put into practice the "Family-Centred Approach". The Family-Centred approach is recognised as the "best practice" in paediatric health care settings including the PICU (Frazier, A., Frazier, H. and Warren, 2010; Meert, K.L., Clark, J. and Eggly, 2013).

The core principles of family care practice acknowledge that the family is the child's primary support and strength; and that the family's information and perspective is important in care plans, clinical decision making and service delivery (American Academy of Pediatrics, 2003; Macdonald et al., 2012).

Macdonald et al (2012) found that although international PICU's may adopt the family-centred care model, the parents lived experience demonstrated that much work still needs to be done with regards to including the family. Parents reported that the most hurtful experience was being treated as visitors. They were distressed that the bedside was more of an office than a bedroom, that it offered little privacy, it favoured staff above parents and had many loud noises (Macdonald et al., 2012).

It was therefore important to understand the particular challenges in the RCWMCH PICU affecting the families in order to develop a service that could best address their needs. Current literature was therefore first explored to best guide clinical practice.

From the literature there were 3 areas in which the notion of a Family Centred Approach was challenged. Namely challenges to the physical relationship, the emotional relationship and the loss of caregiver role.

1. Challenges to the Physical Relationship

For the caregiver who accompanies the child, the impact of the clinical technologically rich environment of the PICU and its serious lifesaving interventions are immediately felt. Frazier and Warren (2010, p. 83) describe PICUs as "busy, crowded and over stimulating, short staffed, procedure orientated and hectic". The technological equipment is experienced as an intrusive bombardment of unfamiliar machinery, technology and sounds which are unanimously stressful and consistent with Dutch studies that the first things parents commented on were the alarms (Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002; Latour et al., 2011).

Other stressors were the changes in their child's appearance and behaviour and restraining technical equipment (Meyer, Snelling, & Myren-Manbeck, 1998).

2. Challenges to the Emotional Relationship

The circumstances, which precede a PICU admission for children and their families often involve crises of such severity that they cause fear and feelings of helplessness in parents (Meyer et al., 1998; Romer, L. H., Nichols, D., Woods, B. H., Latour, J. M., & Mesman, 2008). Similarly, Dyer (1995) goes as far as describing "the experience of the intensive care unit patient as comparable to that of a torture victim". PICU admissions have a higher possibility of the child dying compared to other areas of paediatrics (Ramnarayan, Craig, Petros, & Pierce, 2007).

Lee and Lau (2003) state that when a family experiences stress from a situation such as an ICU admission, the members of that family often feel disorganized and helpless; they may have difficulty in accessing resources that would assist with coping. Families can be overwhelmed with feelings of despair, anger at what has happened, guilt, denial and a real fear that they could lose their loved one (Verhaeghe, van Zuuren, Defloor, Duijnste, & Grypdonck, 2007).

The psychological effects of injury and illness are not only applicable to the

child but extend to the family system within which the child functions (Scott, 2002). For this reason all family members were considered and included in the intervention at RCWMCH as much as possible.

3. Loss of Caregiver Role

The disruption to the parenting or caregiving-infant role has been named as one of the most distressing factors of the PICU admission (Latour et al., 2011; Meyer et al., 1998). The PICU environment and process strips caregivers of their familiar parental and protective roles (Meyer et al., 1998).

Parents are the most important resource in reducing children's anxiety (Miles & Mathes, 1991). Therefore attempting to eliminate or reduce parental stress when in the PICU is even more important.

The above 3 challenges in the domains of physical and emotional relationships and the loss of caregiver role, were starkly illustrated in the RCWMCH PICU.

In view of this the RCWMCH PICU OT and SW identified the need for a parent group. This was an innovative intervention which has not previously been described.

The Intervention

A unique intervention to involve as many family members as possible to address stressors was developed. This consisted of a weekly caregiver support group in which the families' needs were addressed. All caregivers and extended family in the PICU were invited and it was co-facilitated by the RCWMCH PICU OT and SW. It was an open group that covered three main areas: appropriate neuro-developmental information, orientation to the PICU and psycho-emotional support.

The therapeutic value of a group is well documented by Yalom (1995) as a powerful learning environment, which can facilitate a sense of hope through meeting others in similar situations who have overcome difficulties, observing and imitating behaviours of others.

The group ran weekly since its initiation in 2012. It had a flexible format that allowed reflection and adaptation to emerging needs. A description and analysis of the group over a year (from 2013 – 2014) will illustrate aspects of this intervention in this particular set of parents whose children were patients in the PICU during that time.

Group Participants

All caregivers, friends and family present in the PICU or waiting room on the day of the group were invited to attend. In the South African context the involvement of extended family and friends in raising children is common (Amateng, A.Y., Heaton, T.B. & Kalule-Sabiti, 2007). Hence in this PICU group there was a huge diversity in participants, ranging from biological parents and grandparents to neighbours and aunts. On average, 17 caregivers attended the weekly open group which took place in a quiet room away from the busy and noisy PICU. The caregivers were mostly female with only 2 men, on average, attending per week. Medical, nursing and cleaning staff, allied health professionals, hospital chaplains and students were invited to attend. On average, one staff member/student attended per week.

The majority of participants were isiXhosa speaking, although English and Afrikaans were also spoken by some, so that all 3 languages had to be accommodated. The offering of beverages and snacks proved to increase group attendance, a fact that was anecdotally supported by NICU groups in the UK who termed their meetings 'pudding club' (personal communication from Great Ormond Street).

Occupational Therapist and Social Worker Co-facilitation

The unique collaboration between the social worker and occupational therapist collaboration has had multiple successes: there was harmonious co-facilitation that was reflective and responded to emerging parent needs and it combined a psychosocial and neuroscience developmental focus on an appropriate level

The dual approach means that parents were afforded psychological and emotional support so that they were more contained to be able to have the capacity to understand medical, neuroscience and neurodevelopmental information.

Pragmatic Techniques

Various techniques were developed to optimise support in these language and educationally diverse parent groups. Techniques used included: sharing information using dolls and visual media; creating tolerance and advocacy for cultural beliefs; facilitating engagement with their infants and empowering by advocating for PICU parent rights.

Caregivers reconnected with their infants' needs, obtained pertinent information about neuroscience for infants including (Berg, 2006; J. Bergman, 2010; N. J. Bergman, Linley, & Fawcus, 2004) Ayres' Sensory Integration (Mailloux et al., 2011) and neurodevelopmental techniques theory (Lubbe, 2008; Moore, Anderson, Bergman, & Dowswell, 2012) were enabled through the doll and pictures. Practical hands on techniques (nesting and safe handling) were demonstrated and practised.

The most fundamental learning however was listening to caregivers' narratives and learning from their dynamic emerging needs what was needed in the group.

As expected the journey to the PICU was frequently experienced as traumatic, as caregivers often had to go to several institutions before being referred to the tertiary PICU at RCWMCH (Hodkinson, Argent, Wallis, Reid, & Perera, 2016). Caregivers often needed to gather their infant and run in the middle of the night to the nearest medical facility without money or additional food or clothing. Asking a neighbour or relative stranger to look after siblings was common in these extreme situations.

As Maslow's hierarchy would dictate (Maslow, 1943), once hunger and thirst were satisfied and crucial information about the critically ill infant accessed then psycho emotional needs could be addressed.

Common beliefs, needs, fears and questions were elicited through observations, group discussions, pre and post group questionnaires and individual interviews. These were then used to improve group facilitation.

Lessons learnt from the RCWMCH Caregivers

Our caregivers expressed fear, anxiety and anticipatory grief, reflecting findings around the world (Latour et al., 2011; Macdonald et al., 2012).

The common perception of an ICU was based on pre-existing knowledge of an ICU depicted on television. This contributed to the belief held by a large majority of caregivers that almost all patients would die once in an ICU. Some caregivers reported that they believed questions and discussions with medical staff would result in families being asked to turn off machines because machines/ventilators were only allocated to those that were terminal. This explained why many

caregivers reported that they were 'too scared to ask questions'. It also highlighted a truth that was difficult for staff to adjust to: not only were caregivers not touching their children due to fears of the pipes and tubes surrounding them, but because they felt that emotionally they needed to let go. Some caregivers felt they needed to detach from their infants as they believed their infant was dying or already dead.

The RCWMH PICU statistics demonstrate that in the last 2 years mortality has decreased from 10% to 3 to 7 % (RCWMH PICU, 2013). This made the caregivers' grim perception even more distressing to staff and highlighted the significance of sharing information to refute misconceptions.

Following the group, individual needs were addressed e.g. counselling, one-on-one intervention or referral to other services. Parental feedback and reflections from the questionnaires have shaped the group and translated into changes in practice in the multidisciplinary team (including parents) in the RCWMH PICU and other wards.

Outcome

Following the implementation of the RCWMH PICU support group numerous other caregiver groups were started in other wards of the hospital. Based on caregiver's feedback, the PICU multidisciplinary team began investigating how best to implement neurodevelopmental supportive care in sustainable and pragmatic ways in this critical care setting.

The RCWMH PICU implemented a daily "Quiet Time" where nonessential procedures stop, lights are dimmed and noise is reduced. This quieter environment benefited infants, caregivers and staff. It reduced sensory bombardment allowing infants to sleep, caregivers to relax and staff to work. The success of the PICU group was noticed greatly over the Christmas period when there was a break in the group. During this time the nursing staff reported a dramatic increase in complaints, and through investigating the complaints truly learnt the value of the group in reducing anxiety, misconceptions and calming and containing caregivers.

Conclusion

Caregiver feedback and reflections from the questionnaires have shaped the group and translated into changes in practice in the multidisciplinary team and throughout the hospital. In the PICU a more contained, informed caregiver is now able to engage

with their infant and re-establish their role. Caregivers are now close enough for their infant to smell, feel and hear them sing Thula Thula.

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