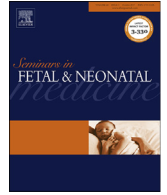
ARTICLE IN PRESS

Seminars in Fetal & Neonatal Medicine xxx (2017) 1–8

Contents lists available at ScienceDirect

Seminars in Fetal & Neonatal Medicine

journal homepage: www.elsevier.com/locate/siny



Improving neonatal care with the help of veteran resource parents: An overview of current practices

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Keywords:
Neonatal intensive care unit
Neonatology
Family-centered care
Peer-to-peer support
Resource parents
Patient-centered research

A B S T R A C T

Over the past decade, veteran parents who have lived a neonatal intensive care unit (NICU) experience have become increasingly involved as 'resource parents' to provide peer-to-peer support to "new" NICU parents. These parents can provide a unique form of support to new parents. They can also assume other roles in clinical care, research, administration and/or teaching, but those roles are rarely described in the literature. This article reviews many of the activities performed by resource parents in neonatology. These activities were identified/examined and classified according to the location of involvement (hospital or not), the presence/absence of direct interaction with families and providers, and the topic of involvement. We have also identified gaps in knowledge relative to recruitment and training, development and evaluation of programs, structuring of responsibilities, and remuneration of resource parents. Future research is needed to measure the impact of resource parents on neonatal care.

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1. Cases

1.1. Robin

Robin had a perfect family and job. She thought her third pregnancy would be as easy as the first two, until she delivered Alex at 26 weeks. Alex was very sick and had a prolonged neonatal intensive care unit (NICU) stay. During one of Alex's most unstable nights, Robin prayed and decided that if he survived, she would give back to the cause and to other NICU parents. Alex has survived, surrounded by his parents and large family. He has started school this year and has learning difficulties. Robin decides that it is time to honor the promise she made years ago, during that dark night. Her husband also wants to help and do something meaningful to help new parents. On the other hand, he states clearly that he never wants to set foot in a NICU again, hear the alarms and potentially relive any of the stress they went through. He also tells Robin he does not have the strength to hear "NICU stories" and potentially meet new parents.

1.2. John and Catherine

John and Catherine were married for five years when they finally became pregnant with the help of assisted reproductive technology. They were overjoyed when she heard they would have twins, but one of the twins had a serious heart anomaly. Catherine then delivered Brianna and Beth at 28 weeks. Brianna died at five days of life but Beth had a relatively easy NICU course. The first year after NICU discharge was hard as the couple grieved. At Beth's three-year neonatal follow-up visit, the pediatrician tells them they all look healthy. They reminisce together about the long road it has been. John asks if there is anything they can do to help other parents. Their neonatal follow-up pediatrician is the chair of the NICU's family-centered care committee. He asks whether they would like to be involved in the committee. John is enthusiastic and promptly

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https://doi.org/10.1016/j.siny.2017.10.005
1744-165X/© 2017 Published by Elsevier Ltd.

Please cite this article in press as: Bourque CJ, et al., Improving neonatal care with the help of veteran resource parents: An overview of current practices, Seminars in Fetal & Neonatal Medicine (2017), https://doi.org/10.1016/j.siny.2017.10.005

accepts. Catherine is also willing to help, but it would be easier if she could help from home; she is now pregnant and does not want a long-term commitment she will not be able to honor.

2. Introduction

Neonatology is a recent specialty. Indeed, several decades ago, most premature children died. Because of advances in neonatal care, the majority of children admitted in the neonatal intensive care unit (NICU) now survive and have a good quality of life. The philosophy of care has also changed. For many years, parents had minimal contact with their sick children and were excluded from decision-making processes. Many parents of neonates who died at birth were often not allowed to see their child, as providers thought this would accentuate the grief. Thankfully, care has changed and parents are now often welcomed as part of the care team. Today, parents can be caring partners in their baby's journey and family-integrated care practices are increasingly widespread among NICUs. Yet, for parents, the experience of having a baby in the NICU is difficult. No parent can be fully prepared for the stress and range of emotions experienced when caring for a sick newborn. Parents are often still trying to understand what it feels like to be a parent and to process the responsibility of that role, as they establish an intimate relationship with their newborn. Furthermore, most of the neonates in the NICU depend on life-sustaining interventions, making bonding more complex [1]. Many interventions have been attempted to improve the well-being of children and their parents; one such intervention is introducing “resource parents” (parents who had previously spent time in the NICU) to provide peer-to-peer support to parents of sick neonates in the NICU [2,3]. In some units, resource parents meet with families and optimize their integration while also providing support. These parents also assume many other roles in neonatology, whether in clinical care, research, teaching and/or administration, but those roles are scarcely described in the literature.

This article reviews the activities performed by resource parents in neonatology. We do not analyze how parents of neonates in the NICU can partner with the clinical team to optimize the care of their children, but rather how parents who have experienced the NICU with their family can be integrated in neonatology after their NICU stay. We describe and examine recent experiences regarding the involvement of resource parents in neonatology, based on our experience in CHU Sainte-Justine (Montréal) and in Sunnybrook Hospital (Toronto) and on the current literature [4,5]. Two authors of this article are full-time resource parents (G.M. and K.R.) co-developing their roles in neonatology with clinicians, teachers, administrators and researchers. The goals of this article are to define what a resource parent is, what activities they currently do in neonatology and how these activities can be classified. Gaps in knowledge are also identified relative to recruitment and training, responsibility, development, evaluation and remuneration of resource parents within programs. These areas represent important research avenues to explore.

3. The resource parent role in neonatology

With the development of family-centered and family-integrated care, parents of children hospitalized in the NICU are often described as collaborators, team members, partners, carers and co-carers. “Patient partner” (or “parent partner”) is an expression often used to define patients/parents as primary actors in their own healthcare trajectory [6]. Partnership, teaming with patients and/or parents, sharing goals, co-defining treatment paths, whole person care, holistic care, expert patient/parent, or accompaniment medicine are expressions used in practice that should be an integral part of the medical culture and healthcare education. Whereas we fully embrace working with patients and families as partners, we want to distinguish another kind of partnership that also exists but is based on different roles, activities, settings and goals.

In the medical world, many different terms related to different notions/topics are widely used to describe resource parents. Resource parents in neonatology are parents who use their “NICU experience” and contribute to clinical, teaching, research or administrative initiatives. In these roles, they represent the parent voice. In neonatology, we have found that many resource parents – and providers who work with them – preferred the term “resource parent” to “veteran parent” [7]. For some parents this is because of the association with war/battles, for others because they are unsure if several weeks or months in the NICU made them veterans. In some neonatal units, resource parents are referred to as the active role they provide in the unit. For example, resource parents providing peer-to-peer support may be called “peer-to-peer parents”, “buddy parent/mother,” “support parent,” “parent coordinator,” “parent hosts,” or “parent spokesperson.” This is also true in teaching, research or administration where resource parents can be identified in a number of ways: “parent co-presenter,” “parent representative,” “stakeholder,” “parent co-researcher,” “co-evaluator,” “member of parent advisory group,” “data safety and monitoring group parent,” “family faculty member,” etc. [8,9].

4. Inventory of activities

As seen from the cases presented at the beginning of the article, different parents may have various desires or motivations to get involved and/or “give back.” We have separated the activities in which resource parents can become involved into categories that are usually separated in medicine: clinical care and administration (Boxes 1 and 2), education (Table 1), and research (Table 2). We have further separated the activities according to parental preferences [10].

5. Resource parent preferences

Parents can be involved in many different activities in neonatology. The terms “veteran parents” or “resource parents” are often associated with peer-to-peer support and contact between a veteran parent and a new parent. But this is not always the case. As seen in the vignettes, some resource parents may want to get involved in some specific types of activities and settings whereas others would rather not. As illustrated in the vignettes, when parents consider being involved, three main factors influence the role they may wish to assume: (i) contact with other parents; (ii) contact with the NICU and/or the hospital; (iii) time and distance constraints. Indeed, some parents want to get involved in activities where they meet other families and/or providers and have direct human interactions, whereas others do not. Some parents – not all – are willing to share their personal story. Some families do not want to come back to the NICU and/or hospital, due to lack of time, issues related to distance, or lack of desire.

At the present time in neonatology, when parents become involved as a resource parents, they are often either integrated in a project or a committee in a non-official way. Some parents, like Robin, directly seek a way to help or “give back,” either through parental associations or by communicating their desire to providers they are still in contact with. Other parents, like Catherine, will be approached by a clinician who works with resource parents, because they seem to have the capacity to get involved in ongoing projects. Because involving veteran parents in neonatology is a rather new phenomenon, parents are generally not all systematically approached for their potential involvement. There is a great

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