



The Giving Parents Support Study: A randomized clinical trial of a parent navigator intervention to improve outcomes after neonatal intensive care unit discharge

Cara L. Carty^a, Lamia M. Soghier^{b,c}, Katherine I. Kritikos^c, Lisa K. Tuchman^{c,d}, Michelle Jiggetts^e, Penny Glass^f, Randi Streisand^{c,f}, Karen R. Fratanoti^{c,e,*}

^a Division of Biostatistics and Study Methodology, Children's Research Institute, Children's National Health System, 111 Michigan Ave NW, Washington, DC 20010, USA

^b Department of Neonatology, Children's National Health System, 111 Michigan Ave NW, Washington, DC 20010, USA

^c Center for Translational Science, Children's Research Institute, Children's National Health System, 111 Michigan Ave NW, Washington, DC 20010, USA

^d Department of Adolescent and Young Adult Medicine, Children's National Health System, 111 Michigan Ave NW, Washington, DC 20010, USA

^e Goldberg Center for Community Pediatric Health, Children's National Health System, 111 Michigan Ave NW, Washington, DC 20010, USA

^f Psychology and Behavioral Health, Children's National Health System, 111 Michigan Ave NW, Washington, DC 20010, USA

ARTICLE INFO

Keywords:

Neonatal intensive care
Hospital discharge
Peer support
Parent navigator
Parent depression
Parent stress

ABSTRACT

Parents of infants hospitalized in a neonatal intensive care unit (NICU) experience increased anxiety and stress, which may persist after discharge. The rationale and design of a randomized clinical trial assessing the impact of a 1-year, post-discharge, peer support intervention (parent navigation) on parental mental health and infant health care utilization is described. Qualitative methods guided the adaptation of an existing parent support program to target emotional and resource-related needs of NICU families. Approximately 300 parent-infant dyads were enrolled at discharge and randomized to either receive a care notebook (control group) or a parent navigator and a care notebook (intervention group). We aim to determine if the parent navigator intervention: 1) increases self-efficacy and decreases stress in parents, 2) decreases overall levels of anxiety and depression in parents, 3) decreases infant hospitalizations and emergency department visits, and 4) increases adherence to infant vaccination recommendations during 1 year of follow-up. Standardized, self-reported psychological scales to assess parent depression, anxiety, self-efficacy and social support were administered at baseline (NICU discharge) and at 1-week, 1-, 3-, 6- and 12-month intervals. Infant immunization status and health care utilization during the study period were also assessed. This paper reviews challenges and successes during implementation. If this intervention improves outcomes, NICUs may choose to provide similar parent navigation services for infants and families transitioning from the NICU to home. This study was registered with [ClinicalTrials.gov](https://clinicaltrials.gov) (NCT02643472) on December 31, 2015.

1. Introduction

Of the nearly 4 million infants born in the United States each year, > 300,000 require hospitalization in a neonatal intensive care unit (NICU) for prematurity or for specialized medical care [1]. The abrupt separation between NICU infants and their parents, coupled

with parental concern for the child's medical condition, can cause significant parental distress [2,3]. Parents of NICU infants are at higher risk of depression, anxiety, and post-traumatic stress [4–6], which may impact infant bonding [5,7,8], reduce the duration of breastfeeding [9], lower future school competency in their children [10], and contribute to long term neurodevelopmental impairment [11].

Abbreviations: NICU, neonatal intensive care unit; PN, parent navigation; PNs, parent navigators; ED, emergency department; GPS, Giving Parents Support; DTaP, diphtheria-tetanus-acellular pertussis; Hib, Haemophilus influenzae b; PCV13, pneumococcal conjugate; Bayley III®, Bayley Scales of Infant and Toddler Development™, Third Edition; CNHS, Children's National Health System; REDCap, Research Electronic Data Capture; CSHCN, children with special health care needs; SD, standard deviation; PMPS-E, Perceived Maternal Parenting Self-Efficacy Questionnaire; PSS-10, Perceived Stress Scale; PSS, Parental Stress Scale; PSS:NICU, Parental Stressor Scale:Neonatal Intensive Care Unit; STAI Y-1, State-Trait Anxiety Inventory (state portion); CES-D 10, Center for Epidemiologic Studies Depression Scale (10-item); STAI Y-2, State-Trait Anxiety Inventory (trait portion); CES-D 20, Center for Epidemiologic Studies Depression Scale (20-item); FSS, Functional Status Scale; MSPSS, Multidimensional Scale of Perceived Social Support

* Corresponding author at: 111 Michigan Avenue NW, 1.5 WW, Suite 600, Washington, DC 20010, USA.

E-mail addresses: calyca@uw.edu (C.L. Carty), lsoghier@childrensnational.org (L.M. Soghier), kkritikos2@childrensnational.org (K.I. Kritikos), ltuchman@childrensnational.org (L.K. Tuchman), mjiggett@childrensnational.org (M. Jiggetts), pglass@childrensnational.org (P. Glass), rstreis@childrensnational.org (R. Streisand), kfratanoti@childrensnational.org (K.R. Fratanoti).

<https://doi.org/10.1016/j.cct.2018.05.004>

Received 26 January 2018; Received in revised form 2 May 2018; Accepted 3 May 2018

Available online 05 May 2018

1551-7144/ © 2018 Elsevier Inc. All rights reserved.

Psychosocial support in the NICU is often provided by the staff [12] and augmented by variable programs unique to each NICU [13]. However, an infant's continuing medical needs and parent's distress may persist long after NICU discharge, once these support systems have ended. Parents of infants with complex needs may also question their ability to independently care for their child after going home. Parental self-efficacy could be enhanced by targeted support programs after discharge [14]. In 2012, the American Academy of Pediatrics made key, NICU-specific recommendations to promote patient and family centered care, including peer support among families with similar cultural needs, backgrounds, and medical conditions [15]. To optimize care after NICU discharge, careful connection with community resources, as well as family and patient support, is needed [16].

Parent navigation (PN) is a patient-centered service in which parents receive peer to peer support and mentoring from another parent who has experienced a similar situation [17]. Parent navigators (PNs) employ their knowledge and personal experience to: 1) help other families solve problems around access to care, 2) encourage parents to participate in shared, family-provider decision making, and 3) increase parental awareness of available community resources [18]. PNs also provide emotional support, assist with enhancing home care, and ensure adequate primary care follow-up, thereby reducing unnecessary hospital and emergency department (ED) admissions and improving the quality of life for the patient and family [19].

Navigation programs have improved patient access to care, as well as satisfaction with, and adherence to, treatment recommendations in both adult (e.g. lung and breast cancer screenings [20–22]) and pediatric (e.g. choosing a pediatrician [23] and adhering to hearing screen recommendations [24]) populations. Due to the potential value of peer support for parents during and after the NICU stay [19,25], the Giving Parents Support (GPS) Study tailored PN to meet the needs of NICU families at discharge. Using a randomized clinical trial, the impact of PN on parental self-efficacy, stress, anxiety, and depressive symptoms, as well as infant health care utilization, will be evaluated.

2. Study design and methods

2.1. Study aims

The **Primary Aims** of the GPS study were to:

Aim 1: Determine if PN increases overall self-efficacy and decreases stress in parents during the 12 months after NICU discharge.

Hypothesis 1. a: PN will increase parental self-efficacy, when compared with parents receiving a care notebook.

b: PN will decrease parenting stress, when compared with parents receiving a care notebook.

Aim 2: Determine if PN improves overall levels of anxiety and depression in parents during the 12 months after NICU discharge.

Hypothesis 2. a: PN will decrease levels of parent anxiety, compared with parents receiving a care notebook.

b: PN will decrease parent depression, compared with parents receiving a care notebook.

Aim 3: Determine if PN positively impacts infant health outcomes during the 12 months after NICU discharge.

Hypothesis 3. a: PN will decrease the number of infant hospitalizations, compared with parents receiving a care notebook.

b: PN will decrease the number of infant ED visits, compared with parents receiving a care notebook.

c: PN will increase infant immunization rates, specifically rates of the diphtheria-tetanus-acellular pertussis (DTaP), Haemophilus influenzae b (Hib), and pneumococcal conjugate (PCV13) vaccines, compared with parents receiving a care notebook.

Secondary Aim: In this exploratory aim, the composite score for the

Bayley Scales of Infant and Toddler Development™, Third Edition (Bayley III®) [26] will be compared between the two groups. We hypothesize that by supporting parents' emotional function, infant developmental progress will be enhanced.

2.2. Study design and population

This study was designed as a randomized trial at the Level IV referral NICU of Children's National Health System (CNHS) in Washington, DC. The CNHS NICU cares for preterm infants with complications of prematurity and term infants requiring intensive postnatal care in the Washington metropolitan area (Maryland, Virginia, and DC). In 2016, 948 neonates were admitted; of those, 42% were premature and 58% were term infants.

A total of 300 parent-infant dyads were recruited for the GPS Study between January 2016 and February 2017. Parent-infant dyads were randomized 1:1 to either the control or intervention groups at discharge. Parents in the control group were given a care notebook to organize health information and resources. Those in the intervention group were given the same care notebook, and they were also assigned to a parent navigator, who provided peer support during the 12 months after NICU discharge. Baseline characteristics of enrolled dyads are shown in Table 1. Gestational age categories and common medical diagnoses of enrolled infants are shown in Table 1B. Approximately 56% of GPS infants were diagnosed with at least one respiratory condition, and 79% of those affected had respiratory distress syndrome. Additionally, 26% of GPS infants were diagnosed with at least one gastrointestinal condition during their stay.

2.3. Recruitment

2.3.1. Participant identification and selection

Potential enrollees were first identified through an electronic health record system. The entire NICU census was reviewed daily, and chart review was completed for each newly admitted patient. A database of all screened participants was created to monitor and identify potential enrollees. NICU case managers met with research staff twice per week to further determine eligible participants, and social workers and other members of the medical team were consulted regarding the optimal timing for approaching parents. A study recruitment flyer (Appendix A) containing the initial goals of the study was used to introduce GPS to potential enrollees and invite them to participate. Research staff followed up with interested families, either in person or by phone.

2.3.2. Inclusion criteria

A verbal screening survey was used to determine study eligibility. All participants were required to be: 1) the custodial parent of a NICU infant with planned discharge to home within the next 2 weeks, 2) English-speaking, 3) at least 18 years of age, and 4) living within the Washington metropolitan area. Due to the nature of follow-up and the need to consistently communicate with one parent participant, custodial parents were solely enrolled. Because most of the study questionnaires had not been validated in other languages, and there is a shortage of PNs facile in other languages, participants were required to speak and read English. Residency in the Washington metropolitan area was also mandated, as assignment to the intervention would require parents to live where PN resources were available. Parents who did not meet the aforementioned criteria were excluded from the study, and only one parent per infant was eligible to enroll.

2.3.3. Consent and enrollment

Once eligibility was determined, study details were described, and the parent was asked to provide written, informed consent to participate. If more than one parent was interested, the parent who self-identified as the primary caregiver of the infant was enrolled. After consent, baseline measures (Table 2) were administered by research

Download English Version:

<https://daneshyari.com/en/article/8757506>

Download Persian Version:

<https://daneshyari.com/article/8757506>

[Daneshyari.com](https://daneshyari.com)