

## Prospective Evaluation of Physical Contact with Critically Ill Child on Caregiver Spiritual Wellbeing

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**Objectives** To evaluate whether a pediatric intensive care unit initiative promoting physical contact between caregiver and patient improves caregiver spiritual wellbeing. The secondary objectives were to evaluate caregiver perceptions of care before and after the initiative and to follow unplanned extubation rate as a marker of safety of the initiative. We hypothesized that caregiver spiritual wellbeing and caregiver perceptions of care would improve with implementation of our physical contact initiative known as Project ROSE (Reach Out, Soothe, and Embrace).

**Study design** Project ROSE was a practice change initiative promoting physical contact between caregiver and hospitalized child in an academic quaternary care pediatric intensive care unit. Caregivers' spiritual wellbeing and perceptions of care were surveyed at days 1 and 4, then compared pre- and postimplementation of the unit-wide initiative. Wilcoxon rank sum tests compared groups (pre- and post-Project ROSE). A total of 331 caregivers returned surveys.

**Results** We analyzed 331 surveys (pre, n = 174/post, n = 157). Caregiver spiritual wellbeing at enrollment (day 1) was no different between groups ( $P = .47$ ). Caregiver spiritual wellbeing on day 4 was greater in the postintervention group (pre 40.0 [32.0, 44.0] vs post 42.0 [37.5, 45.0]  $P = .03$ ). Caregiver perceptions of care improved postintervention. There was no change in the unplanned extubation rate between groups.

**Conclusion** Project ROSE improved caregiver spiritual wellbeing and perceptions of care, was implemented safely, addresses a need in family-centered care of critically ill pediatric patients, and merits consideration for integration into practice. (*J Pediatr* 2017;■■■:■■■-■■■).

The hospitalization of a child in a pediatric intensive care unit (PICU) is overwhelming and frightening, both for the patient and family. The literature identifies spirituality and faith as integral for coping and processing information during such situations.<sup>1-5</sup> Many spiritual practices revolve around physical contact. Baptism, anointing, the laying of hands, Hakomi (Native American massage therapy with hot stones to enhance spirituality), and Reiki (channeling energy through touch) are examples of spirituality-based acts that demonstrate this principle.<sup>6,7</sup> Physical touch has been described as a means of sharing spirituality.<sup>8</sup> This deserves greater attention, as a large survey of pastoral care providers identified that hospitalized children and families receive only 60% of ideal spiritual care.<sup>9</sup>

Furthermore, there have been many demonstrated medical benefits of physical contact. Physical touch in infants and neonates reduced symptoms of regurgitation, improved weight gain, and decreased length of hospitalization.<sup>10,11</sup> A model known as "Kangaroo Care," which encourages skin-to-skin contact between newborn and parent, has been shown to decrease rates of neonatal sepsis and strengthen the mother-baby bond, enhancing self-worth for mothers.<sup>12,13</sup> Welch and Myers<sup>14</sup> described decreased maternal anxiety and depression symptoms in association with a neonatal intensive care unit, "Family Nurture Intervention," which emphasized mother-infant sensory stimulation. Unfortunately, dedicated literature discussing the effect of physical contact between patient and family on spiritual wellbeing, defined as "A sense of peace and contentment stemming from an individual's relationship with the spiritual aspect of life," is largely absent.<sup>15</sup> Meert et al<sup>2</sup> previously published literature identifying parents' wishes to maintain a physical connection with their child at the time of the child's death, specifically the ability to touch and/or hold, thus supporting the need for further exploration of this interaction. This is pertinent in the PICU, where high patient acuity, hemodynamic instability, respiratory failure requiring mechanical ventilation, and various forms of indwelling catheters lead to both functional and perceived barriers to physical contact with the hospitalized child.

|             |   |
|-------------|---|
| FACIT-Sp-12 | Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being; The 12-item Spiritual Well-Being Scale |
| PICU        | Pediatric intensive care unit   |
| ROSE        | Reach Out, Soothe, and Embrace  |

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| Please answer the following questions based on how you feel since your child has been admitted to the Intensive Care Unit. (1-5 scale, 1= Not at all, 5= Very much) |                       |                       |                       |                       |                       |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
|   | 1 (Not at all)        | 2 (A little bit)      | 3 (Somewhat)          | 4 (Quite a bit)       | 5 (Very much)         |
| I feel peaceful   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have a reason for living  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| My life has been productive   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have trouble feeling peace of mind  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I feel a sense of purpose in my life  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to reach down deep into myself for comfort  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I feel a sense of harmony within myself   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| My life lacks meaning and purpose   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I find comfort in my faith or spiritual beliefs   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I find strength in my faith or spiritual beliefs  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| My child's illness has strengthened my faith or spiritual beliefs. -----  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| -----   |                       |                       |                       |                       |                       |
| I know that whatever happens with my child's illness, things will be okay.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Figure 1.** Representation of the FACIT-Sp-12 distributed to caregivers during the Project ROSE study period. It is a 12-question survey designed specifically to evaluate spiritual wellbeing at a given point in time.

We hypothesized that caregiver spiritual wellbeing scores on day 4, measured by the validated Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being; The 12-item Spiritual Well-Being Scale (FACIT-Sp-12) (Figure 1), and caregiver perceptions of care would improve postimplementation of our PICU physical contact initiative, Project Reach Out, Soothe, and Embrace (ROSE), without compromising patient safety, measured by unplanned extubation rate.

## Methods

This study was a 14-month, prospective, pre/postinterventional study designed to measure spiritual wellbeing in caregivers (primarily parents) of children hospitalized in the PICU before and after implementation of Project ROSE. For the purposes of this study, we defined caregiver as mother, father, or primary caregiver in the child's home environment. No other specific family-centered care initiatives were introduced or ongoing during the Project ROSE study period. Institutional review board approval was obtained before the start of the study. The a priori primary outcome for this study was comparison of FACIT-Sp-12 scores on day 4 between the pre- and post-ROSE implementation groups. Secondary outcomes included caregivers' perceptions of care, unplanned extubation rates, and subanalysis of day 1 vs day 4 FACIT-Sp-12 scores in the post-ROSE caregiver group.

Caregivers of children hospitalized in the PICU for greater than 24 hours were eligible for enrollment, with the enrollment period limited to 36 hours thereafter. Day 1 was defined as the day of enrollment. In an attempt to focus the evaluation to caregivers of patients with high acuity, we excluded caregivers of children admitted to the PICU for less than 24 hours, babies transferred from the neonatal intensive care unit for home ventilator training, and children readmitted to PICU during the same hospital stay. Caregivers of children admitted to PICU with active Child Protective Services involvement were excluded because of concerns that potential visitation restrictions would limit opportunities to experience and benefit from the ROSE intervention. Non-English-speaking caregivers were excluded because of the lack of language-support resources available for this study.

During the first 6 months before the implementation of the ROSE initiative, we assessed baseline caregiver spiritual wellbeing and perceptions of care. Eligible caregivers were identified consecutively, and those who enrolled completed a Caregiver Initial Survey on study day 1 consisting of demographic information, a series of novel questions created by the multidisciplinary research team focused on assessing caregiver perceptions of physical contact and components of family centered care (Figure 2; available at [www.jpeds.com](http://www.jpeds.com)), and the validated FACIT-Sp-12 spiritual wellbeing assessment tool (Figure 1). With permission from the FACIT-Sp-12 organization, questions 11 and 12 were modified to reflect appro-

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