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Nurses' Perceptions of Rooming-in for Caregivers of Infants with CCHD

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ABSTRACT

Congenital heart disease (CHD) is the most common congenital defect. Infants with critical congenital heart disease (CCHD) require complex medical care, and their caregivers need extensive training before being discharged home to safely care for their child. The rooming-in process provides caregivers with an opportunity to learn, practice, and manage the skills required for discharge to home during hospitalization. Although the literature reflects positive implications for the use of the rooming-in process in other populations (e.g., neonatal abstinence syndrome), literature about the rooming-in process in a pediatric cardiac care setting is limited. There remains a gap in the literature pertaining to the viewpoints of nurses, specifically as it relates to implementing a rooming-in process. Therefore, a qualitative study design was chosen to explore the nurses' perceptions of the rooming-in process using focus groups. The purpose of this study was to gain insight from nurses as to strategies to enhance the rooming-in process for caregivers of infants with CCHD. Additionally, we explored potential education and interventions to improve outcomes for infants with CCHD preparing to be discharged home.

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Congenital heart disease (CHD) is the most common congenital defect affecting approximately eight of every 1000 infants each year in the United States (American Heart Association, 2020). CHD ranges in complexity from simple to complex. Infants with critical congenital heart disease (CCHD) require complex care. To adequately and safely care for their child, caregivers require extensive training before discharge to home.

Transitioning from the hospital to home for infants and children who require complex care can be an overwhelming experience for caregivers (Gaskin, Barron, & Daniels, 2016). In order to be discharged home, caregivers are often expected to demonstrate competence performing complex skills. Acquiring these skills requires an extensive amount of information to be absorbed by the caregiver in a short period of time (Wright, 2018). These skills include wound care, medication administration, respiratory maintenance and monitoring, weight monitoring, feeding regimens, and follow-up care (Wright, 2018). As a result, caregivers of infants with CCHD often identify the transition to home as challenging and stressful (Golfenshtein, Hanlong, Deatrck, & Medoff-

Cooper, 2017). These experiences are influenced by a multitude of factors, including stressors within family members, uncertainty of complex medical regimens, and adherence to a strict nutritional diet for their child (Patton & Gladbach, 2019). To better support families during the transition to home, pediatric in-patient units have begun implementing processes termed rooming-in or nesting (Bennett & Sheridan, 2005; Lee et al., 2010). These types of programs allow for a window period of 24 to 48 h during hospitalization, where caregivers learn, practice, and manage the skills required for caring for their infants following discharge to home (Lee et al., 2010; Wright, 2018).

The World Health Organization (WHO) first began advocating for the process of rooming-in during the post-partum period in order to support mother-baby bonding and increase breastfeeding efficiency (WHO, 1998). Since that time, many organizations have recognized the importance of rooming-in across other populations. The physical health benefits of rooming-in for infants are well documented, including the reduced need for medications (20–60% reduction) and shortened length of hospital stay (Wachman, Schiff, & Silverstein, 2018). As a result, rooming-in has been shown to contribute to tremendous cost savings to hospitals and families. Studies have also found that neonates participating in a rooming-in process are less likely to have moderate to severe neurodevelopmental impairments (Avram, Yieh, Dukhovny, & Caughey, 2020). Lastly, not only has the rooming-in process been shown to improve developmental and physical outcomes, it has also been shown to improve the psychological well-being of parents and

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infants, thus enhancing quality of life (Avram et al., 2020; Saurabh, Prateek, & Jegadeesh, 2013).

As pediatric nurses and interdisciplinary team members caring for infants with CCHD, we recognize the difficulties and struggles encountered by caregivers when assimilating the knowledge and skills necessary to care for an infant or child with CCHD. The recognition of these clinical issues and concerns led to the need for a better understanding of strategies to improve the rooming-in process for caregivers of infants with CCHD. Although the literature reflects positive implications for the use of rooming-in, there is a paucity of literature reporting outcomes following rooming-in process in a pediatric cardiac care setting. Moreover, few studies discuss nursing perceptions of the rooming-in process and how prepared families are for discharge. Therefore, our team set out to hear the viewpoints of nurses currently implementing a rooming-in process in a pediatric in-patient hospital unit for infants with CCHD.

A qualitative study design using a hermeneutical phenomenological approach was chosen to explore the nurses' perceptions of the rooming-in process. This approach is particularly helpful to understand and interpret a phenomena by obtaining the lived experience and attempting to fill in the gaps between theory and practice (Denzin and Lincoln, 2017; Guba, 1996). Focus groups were chosen for data collection given their ability to allow a flexible and stimulating environment that produces rich data among participants (Polit & Beck, 2008). A total of three focus groups were held on a Cardiac Acute Care Unit (CACU) at a pediatric in-patient hospital. Focus groups were led by a trained moderator using a semi-structured interview guide. Participants were recruited using a purposive sample of registered nurses caring for infants with CCHD. Each focus group lasted approximately 60 min and included four nurses. Participants received compensation in the form of food and beverages. Hospital Institutional Review Board approval was obtained, and all participants completed a verbal informed consent. Focus groups were audio recorded and transcribed verbatim to allow for qualitative analysis. A team of four independent coders was led by a PhD-prepared pediatric nurse scientist in an academic school of nursing who has extensive expertise conducting qualitative research. Analysis was conducted using qualitative software (NVivo).

Infants with CCHD have complex needs and thus caregivers must be adequately prepared to care for these infants. Although research has been conducted on the rooming-in process in pediatric units such as the neonatal intensive care unit, very little is known regarding this process for infants with CCHD. Nurses work directly with caregivers during the rooming-in process and thus can provide critical insight as to ways to enhance the process. This study is the first to explore the nurses' perspective of the rooming-in process for infants with CCHD. Findings from this study will provide critical insight into ways to enhance the

rooming-in process for caregivers of infants with CCHD and potential education and interventions to improve outcomes for infants with CCHD preparing to be discharged home.

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Declaration of Competing Interest

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