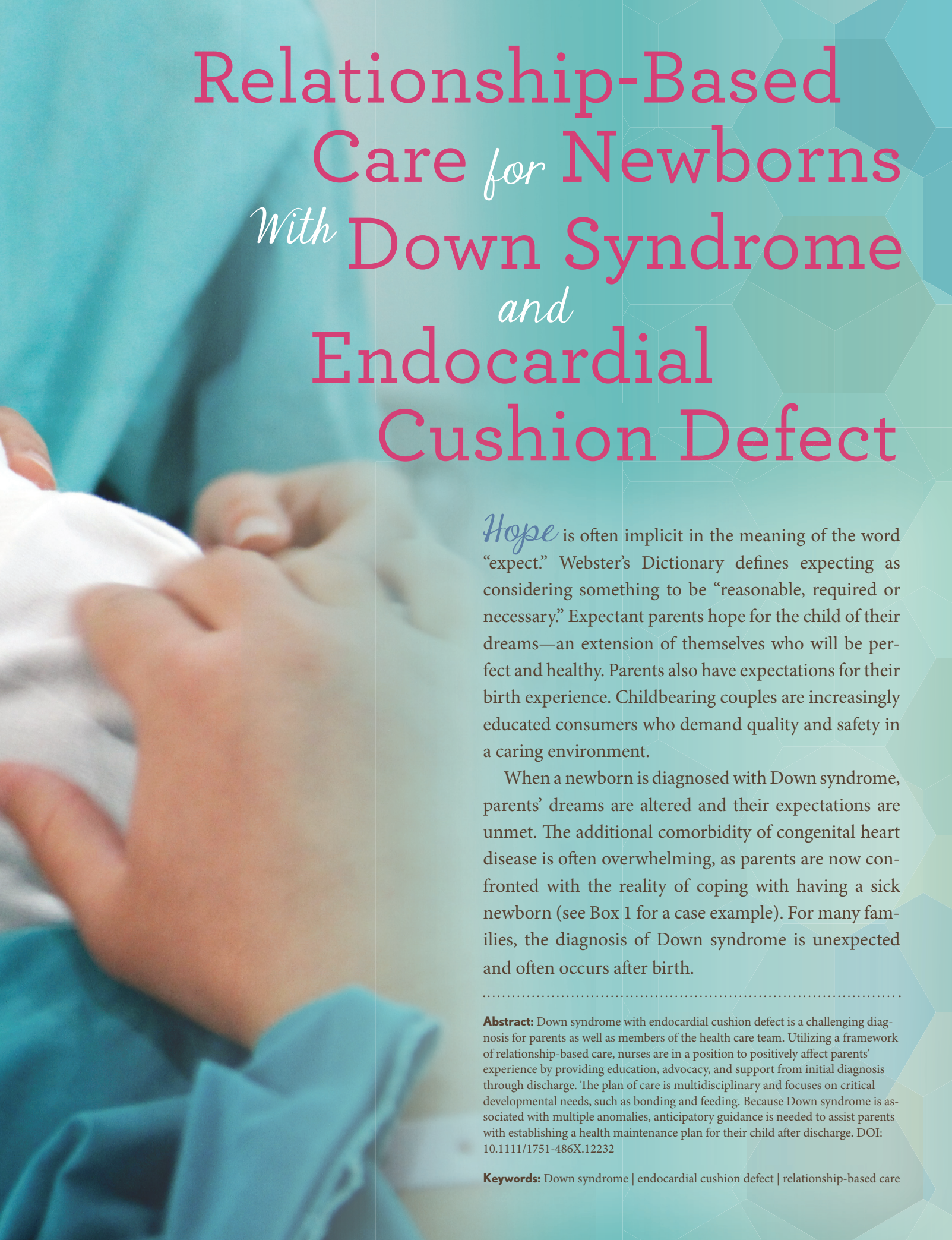


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Relationship-Based Care *for* Newborns *With* Down Syndrome *and* Endocardial Cushion Defect

Hope is often implicit in the meaning of the word “expect.” Webster’s Dictionary defines expecting as considering something to be “reasonable, required or necessary.” Expectant parents hope for the child of their dreams—an extension of themselves who will be perfect and healthy. Parents also have expectations for their birth experience. Childbearing couples are increasingly educated consumers who demand quality and safety in a caring environment.

When a newborn is diagnosed with Down syndrome, parents’ dreams are altered and their expectations are unmet. The additional comorbidity of congenital heart disease is often overwhelming, as parents are now confronted with the reality of coping with having a sick newborn (see Box 1 for a case example). For many families, the diagnosis of Down syndrome is unexpected and often occurs after birth.

Abstract: Down syndrome with endocardial cushion defect is a challenging diagnosis for parents as well as members of the health care team. Utilizing a framework of relationship-based care, nurses are in a position to positively affect parents’ experience by providing education, advocacy, and support from initial diagnosis through discharge. The plan of care is multidisciplinary and focuses on critical developmental needs, such as bonding and feeding. Because Down syndrome is associated with multiple anomalies, anticipatory guidance is needed to assist parents with establishing a health maintenance plan for their child after discharge. DOI: 10.1111/1751-486X.12232

Keywords: Down syndrome | endocardial cushion defect | relationship-based care

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