Feeding the Infant With Congenital Heart Disease: An Occupational Performance Challenge

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The purpose of this article is to review the complexities of infant feeding from an occupational performance perspective using the Canadian Model of Occupational Performance (CMOP) (Canadian Association of Occupational Therapists [CAOT], 1997) as the theoretical framework. The CMOP is a dynamic model that defines the interactions between the person and environment through occupation. The role of infant feeding in supporting infant development within various components of this theoretical model provides a background against which to view the experiences of infants with congenital heart disease (CHD). Many infants with CHD experience feeding difficulties that affect their growth and development (Combs & Marino, 1993; Lobo & Michel, 1995; Schwarz et al., 1990). Feeding the infant with CHD has also been shown to provide special challenges for caregivers (Goldberg, Simmons, Newman, Campbell, & Fowler, 1991; Svavarsdottir & McCubbin, 1996). The literature reviewed here highlights the need for further research, using the CMOP as a method of clarifying the impact of difficult feeding on the infant and family. “Infant feeding is not simply a biological process in response to the metabolic demands of a baby. It is also a complex web of behaviours involving actions and reactions of other people” (Popkin, Lasky, Litvin, Spicer, & Yamamoto, 1986, p. 2).

Theoretical Framework

The CMOP provides a way of looking at human occupation across the life span. It embodies a client-centered approach to understanding the complexity of what people...
need to do to participate in “life activities” (Baum & Law, 1997, p. 279), using their personal strengths and the resources of their respective environments. The model also provides a way for occupational therapists to consider the impact of disability or illness on specific occupational performance tasks, such as feeding; of approaching the challenges of adaptation for the person; and of the environment. In infants, viewing the occupation of feeding from a client-centered perspective ensures that occupational therapy interventions go beyond facilitating infant development of oral-motor skills to addressing a myriad of complexities that contribute to successful feeding. A client-centered approach to infant feeding ensures active engagement of infants and family members in a therapeutic process that respects diversity, promotes partnership, and shares and celebrates knowledge and experience from all participants. In a client-centered approach, the therapeutic focus is on those occupations that the infant or family members need to, want to, or are expected to perform. As a multilayered framework, the CMOP assists in teasing out the complex interactions and behaviors that characterize infant feeding.

The CMOP and Infant Feeding

Occupational performance, or ability of a person to perform an activity in a satisfactory way, is influenced by factors in three domains: the person, his or her environment, and the occupation itself. The inner spiritual person is the core of the individual and of the model. The three-dimensional figure (see Figure 1) represents the dynamic interaction among all levels of the CMOP. Optimal occupational performance occurs when there is congruence between and across all levels of the model. With regard to feeding, the model allows exploration of the impact that the occupation of feeding can have at each level as well as the impact that the environment, the person, and other occupations can have on infant feeding.

The Person

At the person level, consideration is given to the physical, affective, and cognitive components of the person. These three performance components describe the skills and attributes the person uses to engage in occupational performance tasks. At this level, the performance components of infant feeding can be examined. Both the infant and caregiver bring cognitive, physical, and affective skills and abilities to the feeding process. Physical skills include those required to sense and satisfy hunger and to initiate and participate in the reciprocal interaction that is necessary in infant feeding. Not only do the infant and caregiver bring physical skills to the occupation of feeding, but also development of the physical skills of the infant are affected when feeding difficulties exist. The negative effect of inadequate nutritional intake on growth and physical development has been studied extensively and is known to affect a child’s physical functioning, particularly neurodevelopmental status, regardless of the disorder’s origin (Bithoney & Dubowitz, 1985).

Cognitive skills include communication of hunger, satiation, pleasure, and displeasure during feeding interactions. These interactive experiences result in the infant learning cause-and-effect processes and lead to an increased understanding that he or she is a participant in the manipulation and control of the environment. Chronic undernutrition and eating irregularities place children at risk for poor social and cognitive functioning (Bremner, Slater, & Butterworth, 1997; Galler, 1984a; Rudolph, 1994) and disrupt normal parent–child interactions such as cuddling, visual attention, and vocalizations during mealtimes (Galler, 1984b).

Interactions between the infant and caregiver during feeding and the emotional bonding that can occur in successful feeding experiences provide rich opportunity for early development of the infant’s affective abilities (Brazelton & Cramer, 1990; Stern, 1985, 1995) and promote the development of a relationship between the caregiver and infant. All aspects of the person level of the CMOP can and must be engaged for satisfactory occupational performance of infant feeding to occur.

**The Environment**

The outer sphere of the CMOP portrays the elements of the environment, including cultural, institutional, and physical and social resources that can be used to develop strategies to resolve occupational performance issues or that may contribute to occupational performance difficulties. The social context within which an infant and caregiver experience the occupation of feeding has been shown to influence infant development at the person level of the model (Hammer, 1992; Popkin et al., 1986). For example, sources and supplies of infant foods, which are related to household resources (Popkin et al., 1986), may influence feeding, which in turn may affect physical and cognitive development. In addition, the social context in which feeding occurs is important to the development of attachment, an “enduring relationship between a young child and his [or her] mother” (Ainsworth, Blehar, & Waters, 1978), and for learning social and culturally based skills (Brazelton & Cramer, 1990; Hammer, 1992; Stern, 1985, 1995). Affective development at the person level of the model is influenced by early attachment patterns that develop as the person interacts with his or her environment (Brazelton & Cramer, 1990; Stern, 1985, 1995).

Attachment patterns are not present at birth but are mediated in the first year of life through attachment behaviors (Ainsworth et al., 1978; Zeanah, Boris, & Larrieu, 1997) and are linked with the development of a reciprocal caregiving system in the caregiver (George & Solomon, 1996). As the caregiver and infant interact, social and affective exchanges occur. In early infancy, many of these interactions occur during routine tasks of feeding and sleep–wake regulation (Stern, 1995). Indeed, various authors (Lobo, 1992; Ulrey & Rogers, 1982) have used feeding as a “clinical window” (Stern, 1995, p. 70) for viewing attachment and infant–caregiver relationships, thus highlighting infant feeding as a critical occupation. The formation of secure attachment depends on the infant eliciting behavior from the caregiver and receiving reciprocal responses from the environment (George & Solomon, 1996; Zeanah et al., 1997). Research has shown that children who do not establish secure attachment are more prone to psychological or psychiatric ill health (Zeanah et al., 1997), exhibit emotional and behavioral problems in school (Lyons-Ruth, Easterbrooks, & Cibelli, 1997), and have more difficulty in their own relationships as adults (Adams & Cotgrove, 1995).

The social and cultural contexts of the feeding experience gradually give meaning to the routines and behaviors specific to the infant and the caregiver (Frank, Huecker, Segal, Forwell, & Bagatell, 1991; Hammer, 1992; Stern, 1995) and provide a key place for learning social and cultural mores (Waxler-Morrison, Anderson, & Richardson, 1990). The physical environment influences feeding methods and equipment (Popkin et al., 1986), and when infants experience ill health or developmental difficulties, they and their caregivers may encounter feeding within an institutional health care environment. Infants in the hospital may receive food by tube on schedule rather than by mouth on demand, and they and their caregivers may not experience close human contact while feeding.

In addition to the effect that the environment may have on the infant’s feeding experience, infant feeding will also affect components of the environment in which it occurs. This effect may be as simple as the introduction of infant feeding equipment in the home or as complex as changing and developing the social, cultural, and, perhaps, institutional experiences and roles of the caregivers.

**The Occupation**

The CMOP also facilitates an understanding of the complexities of occupation itself, of the intricacies of the activities of self-care or looking after personal needs, of productivity whether as a child or an adult, and of leisure or those activities that restore and refresh the person. The model defines occupation as a basic human need that is culturally defined and age related. In infancy, feeding and behavioral regulation are the key occupations (Brazelton & Cramer, 1990). Although feeding is typically classified as a self-care task throughout the rest of the life span, in infancy it can have meaning within each occupational classification. As a daily occupation, feeding is a self-care task that maintains health and well-being. Feeding is also a component of the infant’s productive role. Feeding is complex and effortful, and the infant must actively engage in its dynamic process. Feeding is work and provides routine opportunity for behavioral organization. Because feeding influences...
the social and interactive development of the infant (Brazelton & Cramer, 1990; Popkin et al., 1986; Ulrey & Rogers, 1982), it is also implicated in the leisure component of the model.

Good nutrition and successful feeding interactions play a significant role in the development of the occupational roles of infancy and childhood, such as infant play and social interactions. In addition, infant feeding is a contributor to the development of the caregiver’s parenting role (Fosson & Wilson, 1987) and may be affected by or affect other occupations, such as participation in paid employment or leisure pursuits. Recognition of the multiple occupational purposes of infant feeding highlights its importance both to infant development and to the practice of occupational therapy.

**Spirituality**

Spirituality, as the core of the CMOP, is seen as “the experience of meaning in everyday life” (Urbanowski & Vargo, 1994, p. 89). The model portrays spirituality as including concepts of will, drive, motivation, and self-determination. Spirituality encompasses the “innate essence of self” (CAOT, 1997, p. 43) and leads to an appreciation of the uniqueness of every person within the therapeutic context. The person’s spirit is expressed through engagement in occupation (Egan & DeLaat, 1994). It is beyond the scope of this article to explore the developmental stages of expressed spirituality. However, Stern’s (1985, 1995) portrayal of the interpersonal world of the infant lends some insight into the development of “self” in infancy and suggests a schema that represents “acts of meaning” (Stern, 1995, p. 89). Theoretically, spirituality can be influenced by the infant’s early experiences as he or she negotiates daily routines. Meanings attributed to feeding experiences may be an early step in the development and expression of self for the infant and part of an ongoing search for meaning in life for the infant’s caregiver.

Traditionally, occupational therapists have evaluated the physical components of feeding, including the motor control of the oral phase, physiology and safety of the swallow, and the behavioral components of the meal experience (Evans-Morris & Klein, 1987; Wolf & Glass, 1992). The CMOP demands a holistic approach to occupational performance, encompassing broader environmental and occupational components. The model focuses attention on what the mother (or primary caregiver) provides for the infant and on the impact the infant has on his or her environment, including immediate family members. The model clearly acknowledges the dynamic and reciprocal nature of human interaction in this critical occupation.

With the use of the CMOP, feeding can be conceptualized as the interactive process between a caregiver and infant that ensures nutritional intake and provides social and emotional experiences to support development of the infant’s physical, cognitive, and affective performance components. In turn, this interactive process may enable successful engagement in a variety of infant and childhood occupations. The process also affects the caregiver’s occupational choices and performance. Optimal occupational performance in infant feeding will occur when all levels of the model interact with harmony.

**Infants With CHD**

It is common for infants to change their feeding behavior and take smaller feeds over a longer period when they become acutely ill (Conway, 1989). This change in feeding behavior may not affect the long-term development of the typical infant when the illness is short term. For infants with CHD and cardiorespiratory compromise, however, the severity and longevity of the feeding difficulty may have a significant long-term effect on both the infant and the family. The literature describing the role of feeding in supporting infant development at the person and occupation levels of the CMOP and the impact of the environment emphasizes the importance of identifying the needs of infants with CHD and their caregivers when feeding difficulties are present.

CHD is a “structural or functional heart disease that is present at birth” (Hoffman, 1990). The incidence of CHD is between .7% and 1% of live births; 85% of children born with CHD are now surviving into adulthood (Sparacino, 1994). Congenital heart defects range from minor anomalies, such as small atrial or ventricular septal defects, to complex conditions, such as transposition of the great arteries, tetralogy of Fallot, or univentricular heart (Le Blanc & Williams, 1993). The infant’s growth may influence the timing of the surgical management of a heart defect. That is, as infants grow, complications of surgery are likely to be reduced and chances of survival increased (Le Blanc & Williams, 1993). Infants who have complex heart defects may require multiple surgical interventions spanning several years and may experience incomplete repair and cardiovascular compromise either in the interim or as a long-term outcome (Driscoll et al., 1991).

The clinical signs and symptoms of an infant with severe CHD may include cyanosis, respiratory distress, or congestive heart failure. Cyanosis results from reduced hemoglobin and arterial oxygen saturation. Respiratory distress may include an increase in respiratory rate or effort. Congestive heart failure may result in an increased heart rate, changes in cardiac rhythm and output, tachypnea, reduced activity or exercise tolerance, and early fatigue (Daberkow & Washington, 1989). Each of these symptoms may affect the infant’s immediate ability to participate in the occupation of feeding (Seer, 1996).

**Feeding the Infant With CHD**

**Indicators of Prevalence of Feeding Difficulties**

Thommessen, Heiberg, and Kase (1991) studied 40 chil-
dren with CHD between .9 years and 13 years of age and found that refusal to eat or poor appetite was a significant problem for almost 50% of the children in their study. Limperopoulos et al. (1999) studied a consecutive series of 56 infants with CHD before surgery and reported that more than 53% were fed parenterally and that 5 of the 26 who were fed orally required nasogastric supplementation. Of those infants who received only oral feeds, 34% demonstrated decreased feeding efficiency characterized by longer feeding time and more frequent feeds. Varan, Tokel, and Yılmaz (1999) studied malnutrition and growth failure in 89 children with CHD and found that 65% were below the 5th percentile for weight and 41% below the 5th percentile for height. These studies provide some evidence that feeding difficulties occur for a considerable number of children with heart disease.

**Indicators of the Range of Feeding Difficulties**

Infants with complex CHD may experience feeding difficulties while awaiting surgical repair of their heart defect, after surgery due to complications, or in association with a congenital syndrome or anomaly, such as cleft palate (Clare, 1985; Daberkow & Washington, 1989; Park & Neches, 1993). Feeding difficulties include those related to increased respiratory effort and congestive heart failure, resulting in fatigue and inadequate caloric intake (Schwarz et al., 1990; Thommessen et al., 1991; Varan et al., 1999). Postsurgically, some infants sustain damage to the left recurrent laryngeal nerve (Park & Neches, 1993), resulting in inadequate airway protection during swallow and a high risk of aspiration. Infants with complex CHD may spend a considerable amount of time with poor oxygenation because of their heart defect and may require slow, frequent feeds. This prolonged reduction in oxygenation has been postulated to affect weight gain in these infants (Combs & Marino, 1993). In addition, some infants with CHD present with significant oral aversion. Oral aversion may be triggered by oral intubation or surgery (Rudolph, 1994) and results in feeding refusal behaviors that are distressing for both the infant and the caregiver (Dunbar, Jarvis, & Breyer, 1991). Each of these difficulties affects the infant’s performance at the person level of the CMOP, with a corresponding effect on the environment and other infant or caregiver occupations.

**Feeding Strategies**

Attempts to ensure that the infant receives adequate nutrition can result in an altered feeding environment. These strategies might include frequent and prolonged feeding periods, caloric supplementation by bottle or tube rather than by breast, or nasogastric tube feeds for those infants who are unable to meet their nutritional requirements orally (Thommessen et al., 1991). Because malnutrition and growth failure put infants at increased risk during surgery (Le Blanc & Williams, 1993), many studies have focused on methods of improving nutritional intake with the aim of improving surgical outcome. These studies have focused on the physiology or the physical performance components of the infant (Thommessen et al., 1991; Varan et al., 1999). For example, Schwarz et al. (1990) conducted a prospective, randomized study to compare 19 infants with CHD who were fed either by nasogastric tube continuously for 24 hours per day, by nasogastric tube for 12 hours overnight and by mouth during the day, or by mouth only. This was a well-designed and analyzed study, with data drawn from a small sample. Acting on the recommendation that continuous 24-hour nasogastric feeding is effective and safe for children with CHD would result in a significant alteration of the feeding environment and, thus, occupational performance of both the infant and the caregiver. Schwarz et al. did not address the environmental or occupational impact of their recommendation.

**Breast-Feeding and Bottle-Feeding**

Recently, there has been a growing interest in the breast-feeding experiences of infants with CHD. Traditionally, breast-feeding was thought to be more stressful for the infant than bottle-feeding, and many mothers were encouraged to feed by bottle (Combs & Marino, 1993; Lambert & Watters, 1998). In a comparison of growth patterns in bottle-fed and breast-fed infants with CHD, Combs and Marino (1993) found that both breast-fed and bottle-fed infants lost weight over 5 months. Bottle-fed infants, however, lost more weight than did breast-fed infants. This descriptive, correlational study, which compared 45 mother–infant dyads, also gave insight into the person–environment interactions that occur as mothers choose their infant-feeding method. The institutional environment (i.e., length of hospital stay) was found to be positively and significantly related to the mothers’ decisions to change from breast-feeding to bottle-feeding.

In a later study, Marino, O’Brien, and LoRe (1995) compared seven infants with CHD who were both breast-fed and bottle-fed and found that when the infants were breast-fed, they had greater physiological stability with fewer oxygen desaturations and a more stable postfeed period. A number of limitations existed for this study, including the very small sample size and the disparity in bottle nipple flow rates. However, both of these studies suggest potential improvement of the physiology and physical performance of the infant during breast-feeding compared with bottle-feeding. In addition, the findings suggest a positive impact of breast-feeding on the infant’s social environment through the mother–infant interaction.

The positive impact of breast-feeding on the mother–infant environment is supported by the results of an informal breast-feeding survey of 12 parents of children with CHD (Lambert & Watters, 1998). These authors
found that institutional barriers, fasting protocols, and infant factors, such as respiratory distress or congestive heart failure, were obstacles to breast-feeding. This self-selected group of parents, however, also reported emotional benefits for themselves and health, growth, and emotional benefits for their infants from breast-feeding. Successful breast-feeding may provide many of the social and emotional opportunities that hospitalized infants appear to be at risk for missing (Combs & Marino, 1993; Gaskin, 1987; Lobo, 1992; Lobo & Michel, 1995).

Mother–Infant Interactions During Feeding

Lobo (1992) reported on a study that investigated the dynamic interactions between mothers and infants during feeding. She compared infants with CHD (n = 10) with a healthy control group (n = 10). The Nursing Child Assessment Feeding Scale (Barnard, 1978) was used to assess maternal and infant behavior. The findings suggest that infants with CHD gave fewer clear cues and were less responsive to their mothers during feeds than infants without CHD. Mothers of children with CHD also provided less social and emotional growth opportunities while feeding, such as smiling, making eye-contact, touching or singing, than mothers of infants without CHD. Whether the differences in maternal behavior developed in response to infant cues or to maternal fear and stress related to infant fragility remained unclear at the end of this study. Lobo and Michel (1995) analyzed the same data for behavioral and physiological responses during feeding. They found no relationship between physiological response and behavioral cues. However, infants with CHD gave significantly more subtle disengagement cues, such as finger splaying or head-to-head actions, than did the healthy infants. This finding suggests that the affective cues of infants with CHD are more difficult to interpret. Small sample sizes and multiple statistical analyses limit these studies; however, the findings suggest that there may be difficulties in the interaction dynamic between the person and environment during the occupation of feeding when the infant has CHD.

Caregiver Stress Related to Feeding

The impact of feeding on the infant’s social environment has also been studied in relation to parent stress and time spent in caregiving tasks. Caregivers of children with CHD felt significantly more stress than those of children with other chronic illnesses, and they identified feeding as a key contributor to their stress (Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Svavarsdottir & McCubbin, 1996; Thommessen et al., 1991). Thommessen et al. (1991) found that 65% (n = 40) of the parents they studied described feeding children with CHD as difficult, time consuming, and anxiety producing. While studying the information needs of 30 mothers of infants with CHD, Stinson and McKeever (1995) found that more feeding information was the second most frequent request made, supporting Pinelli’s (1981) earlier findings. Svavarsdottir and McCubbin (1996) investigated parenthood transitions for 70 parents of infants with CHD less than 12 months of age. The mothers reported feeding to be the most time consuming and the third most difficult task of their day. The mothers in Combs and Marino’s study (1993) supported the finding of increased time spent feeding, with anecdotal evidence suggesting that they were spending 1 hour out of every 2 or 3 hours feeding their infants. The impact of time spent feeding on the occupational choices of the caregivers was not reported in these studies.

These studies of caregiver time use related to feeding are limited by their lack of comparative control group data. However, in other research, families of healthy infants were found to spend only 2.3 hours per day if they had one child and up to 2.9 hours per day if they had four children on all food preparation tasks (Walker & Woods, 1976). Other studies of the challenges of caregiving in relation to time use have not specifically looked at the impact of difficult feeding on time spent caring for a child, and they do not address children with CHD. However, the studies do indicate that families who have a child with a disability spend more time on caregiving tasks than families who do not have children with disabilities (Breslau, 1983; Brust, Leonard, & Sielaff, 1992; Crowe, 1993; Johnson & Deitz, 1985).

Discussion

The literature suggests that feeding in infancy is a complex, multifaceted, and highly critical occupation that is vital to health and well-being. To date, these highly complex feeding processes have been studied in a piecemeal fashion, thus challenging health professionals and family members to determine what “successful feeding” is and how best to facilitate it. The CMOP provides a framework that enables clarification of the multiple factors involved in infant feeding. The dynamic nature of the CMOP means that disturbances at any level of the model will affect other levels. Success in this critical occupation of feeding can influence and be influenced by factors in the infant, the environment, and other occupational areas.

According to the model, successful occupational performance in feeding in infancy will support appropriate development of physical, affective, and cognitive skills at the person level. Environmental variations in physical, cultural, and social contexts may alter the method, style, and specific activities that each infant experiences around feeding. Consequently, each infant will gradually learn varying behaviors, values, and beliefs on the basis of their social and cultural experiences (Waxler-Morrison et al., 1990). These in turn may contribute to the infant’s experience of meaning in everyday life (Urbanowski & Vargo, 1994), once again illustrating the interaction among the levels of the CMOP.
The negative effect of inadequate nutrition on each component of the person level of the CMOP supports a medical focus on ensuring optimal nutritional input to infants and the emergence of alternative methods of feeding when oral intake is not sufficient. However, few studies address the broader implications of changing how an infant’s nutritional needs are met, as the change relates to the ability of either the infant or caregiver to participate successfully in occupational performance tasks.

A causal relationship between occupational performance difficulties in infant feeding and social–emotional difficulties in early or late childhood has not been established. However, feeding is an important component in the early affective development of the child and may have later consequences in the child’s ability to participate successfully in occupational performance tasks.

For the caregiver, providing an opportunity to confirm and develop the parenting role (Fosson & Wilson, 1987) as well as a reciprocal opportunity to develop a relationship with the infant (Braziel & Cramer, 1990; Stern, 1985, 1995). Caregivers of infants with CHD were found to experience some of the occupational challenges of caregiving, including feeding, as stressful and time consuming (Stinson & McKeever, 1995; Svarsvardottir & McCubbin, 1996; Thommessen et al., 1991). It is not yet clear, however, which components of feeding contribute to this stress or which interventions are effective in promoting the development of the caregiving role as well as infant feeding skills.

Occupational research based on the CMOP could combine ethnographic methodology and quantitative measurement to uncover the complexity of the infant-feeding experience when the infant has CHD. Exploration of caregivers’ needs and hopes might be gathered through caregiver narrative. Information on the impact of feeding on the infant’s occupational opportunities, such as the frequency of shared social and cultural experiences within the family mealtime environment, could be gathered through participant observation or diary recordings. The influence of difficult feeding on caregiver and infant patterns of occupation and time use could also be measured through participant observation or direct measurement of time use.

Identifying the scope and multiple effects of difficult feeding is unlikely to be simple. Use of the CMOP allows for multiple factors to be exposed, thus facilitating the negotiation of interventions with caregivers that support both infants and caregivers in their quest for meaningful and satisfying feeding experiences. ▲

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