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Occupation-Based and Family-Centered Care: A Challenge for Current Practice

Beth Werner DeGrace

Occupational therapy practitioners need to change their “way of thinking” about families to help them meet the demands of providing family-centered care. I suggest this goal can be met while addressing the meaningful occupations of the family unit.

The term family-centered care is not new to occupational therapy practitioners who work with infants and children. We have focused on providing therapeutic services in a family-centered manner for over 20 years. Within the past decade, practitioners who provide services to clients throughout the lifespan have been encouraged to also assume this framework for practice. Although the profession has grown in the understanding of and practice in family-centered care, I argue that we have yet to identify exactly what it means to provide family-centered care. Additionally, as a profession we have yet to clearly articulate how we are (a) addressing the occupations of the family unit, (b) measuring change within the family unit, and (c) helping the family unit to meaningfully participate in everyday life.

Thus, despite occupational therapy practitioners basing their services on the tenets of family-centered care, the true nature of family-centered care has yet to be captured and practiced. This article will introduce a “way of thinking” about the family unit and describe a way to provide services aligned with the tenets of family-centered care. This way of thinking will focus predominately on the meaningful aspects of “being” and creating a family, rather than the “doing” of family tasks.

Family-Centered Services

Dunst, Trivette, and Deal (1994) identified the basic tenets of family-centered care to encompass eight distinct but related areas. These areas include: (a) adopting a social systems perspective, (b) placing the family as a unit of intervention, (c) empowering families, (d) promoting growth-producing behavior rather than treatment of problems, (e) focusing on family-identified needs, (f) building upon family capabilities, (g) strengthening the family’s social network, and (h) expanding professional roles and the way the roles are performed. I believe that many practitioners have made sincere attempts to adhere to the tenets of family-centered care and have been unsuccessful at meeting this challenge.

How can practitioners be more proficient at providing family-centered services? I believe for family-centered care to be actualized, an understanding of what constitutes the meaningful occupations of being a family needs to be developed. When occupational therapy practitioners capture and measure the meaningful occupations of the family unit and ensure this as the focus for practice, the provision of authentic family-centered and occupation-based services can transpire. To support occupational therapy practitioners to assume this framework this article will describe the importance of being a family, examine the indicators of family health and well-being, and discuss the difference between “doing” family occupations and “being” a family engaged in meaningful occupations.

Importance of the Family

The family unit is important not only to developing children but also to the growth of our society. Families are comprised of people who have a shared history and a shared future (Carter & McGoldrick, 1999). A person experiences life with and through his or her family. A person’s life cycle takes shape as it moves and evolves within the matrix of the family life cycle, which is embedded within the larger sociopolitical culture. Therefore, understanding and being able to impact the occupations of the family unit has the potential to influence not only the children we work with, but also their families and society at large.

Occupational therapy practitioners are being held accountable for demonstrating how our services influence the health and well-being of those we serve. This leads me to the questions: What is a healthy family? What are the general indicators of health in a family unit? There are no simple answers to these questions. However, systems and ecological theorists suggest family units are dynamic systems that continuously evolve and change. Thus, family health is a dynamic and relative state of well-being. Yet, there does appear to be consensus that one measure of family health is whether or not the family unit can meet its daily challenges (Wright & Leahy, 1987). Whether or not a family meets its daily challenges is based upon a variety of resources that include a combination of biological, cultural, psychological, and sociological dimensions. These dimensions directly relate to the components of human performance and are familiar to occupational therapy practitioners.

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Family Identity and Family Health

Research has suggested that the identity of the family unit has a direct relationship to its health. A family’s identity forms through negotiating and engaging in daily living experiences (Boyce, Jensen, James, & Peacock, 1983). Thus, how a family participates in daily routines defines who that family is and plays a key role in determining its health. Family routines relate to family health because they provide: (a) a stabilizing force in the family, (b) a means for family identity development, (c) a protective force that promotes the health of family members, and (d) a measure for ensuring the well-being of family members during stressful times (Newby, 1996; Schuck & Bucy, 1997). When these repetitive acts occur within a family the message conveyed to the family members is that a supportive family exists.

Understanding that routines support the health of the family unit is important for occupational therapy practitioners. However, generalizations about what types of routines support family health cannot be assumed for each family unit is unique. Each family unit is influenced by its ethnic background and cultural beliefs. Occupational therapy practitioners should be aware of their biases, and sensitive to the ethnic and cultural ways of living of those we serve.

Customs and beliefs of the family serve as the foundation for routines and how the family engages in them on a daily basis. Furthermore, what a family unit values, the norms it has for specific situations, and sanctions for rewards and punishments, influence the family institution on a daily basis. This foundation provides structure for the family and helps determine the relationships among family members and the roles they fulfill. The family defines expectations for behavior that guide how the family operates (Berry & Hardman, 1998). Thus generalizations about who families are, how they operate, and how to work with these families are often inaccurate. Practitioners need to learn how each family unit has collectively constructed its meaning of family. This meaning comes from how family members interact with each other, share time, space, and life experiences and as they communicate about these experiences. Learning and appreciating the cultural and ethnic contributions of the family unit are ways practitioners can begin to provide family-centered services.

Family Doing

Typically, and unfortunately, families are often defined by their roles or by what they “do.” For example, the basic tasks a family engages in and who fulfill the roles are often defined by practitioners as a basis for therapeutic outcomes. Practitioners may question families about “What does your family do for leisure?” or “Who bathes the child?” These types of questions encourage one-answer responses and may not capture the meaningful and occupational nature of the family unit. Additionally, these questions encourage practitioners to write goals such as “Joey will play ball for 5 minutes,” “Eileen will tolerate a wash cloth during bath time for 2 minutes,” or “John will remove his shirt with minimal assistance.” Although the flavor of the goals is occupational, I question whether these accurately portray family-centered care. These examples suggest the focus of the goal is helping the child to meet his or her developmental needs rather than capturing how these goals affect the growth of the family as a unit.

I believe these goals that emphasize the doing aspects of occupation miss the meaningful aspects of being a family. By focusing on things families “do” or how a child performs a task we miss who the families are and who they want to become. Therefore, not to address the meaning of the family’s occupations, I believe, limits the effectiveness of occupational therapy interventions and makes creating family-centered interventions difficult. The difference resides in the family’s “doing” occupations and “being” meaningfully occupied as a family unit. Wilcock (1998) suggests to “be” requires time for people to “discover themselves, to think, to reflect, and to simply exist” (p. 250). Therefore, to “be” a family requires the unit to establish a sense of connection and to acquire a sense of inner satisfaction in their daily patterns of doing. Thus, “being” a family implies being able to derive a sense of meaning from engagement in daily living experiences.

Family Being

Family systems theory suggests that family members collectively construct family meanings as they interact with each other. This is accomplished as the family shares time, space, and life experiences and dialogue about these experiences with each other (Patterson & Garwick, 1998). An illustration of the differences between being and doing is seen in the interview with Christopher Reeve (1998) on the Oprah Winfrey Show. In response to a question about his family Christopher stated:

Well you know what I found is the key to the whole thing? The difference between being and doing. Like with my kids we used to do a lot of things. I taught them to ski and sail and play tennis, I played the piano while my daughter played the bassoon and we...I did all these activities together. But actually sometimes just sitting down for a couple hours and really just being together is even more rewarding for both of us. So even if I’ve lost the physical activities, sometimes the content of what’s going on between us is even better and even closer.

This represents to me a phenomenon of family occupation, that families believe the unit must “do” in order to “be” a family. Yet, as illustrated in Christopher Reeve’s story, taking time to just be together is a critical and meaningful aspect of family occupation. Therefore, a family unit is more than a unit engaged in doing. As practitioners we need to understand who the families want to be and how they can engage in meaningful experiences together. I believe this is the core of family-centered care and meaningful occupation-based practice.

Family systems theory suggests that family rituals represent the nature of family “being” and thus meaningful occupation. Like routines, rituals contribute to a common identity among family members. Rituals preserve a sense of family meaningfulness (Schvaneveldt & Lee, 1983), create and maintain family cohesion (Wolin & Bennett, 1984), and provide means for maintaining family contact (Meredith, 1985). Family meaning is created by rituals.
because they make special time out of ordinary time and create acts that link people through shared meaning (Imber-Black & Roberts, 1998). Rituals provide a place for people to explore the meaning in their lives and to build family relationships.

So what are family rituals? They expand upon routine, everyday living, and add meaning to and connectedness among the family unit. Picture in your mind times that were special to you when you were growing up, or are perhaps a meaningful part of your family today. In my personal experience, the goodnight kiss, the family dinner, and new school shoes provide examples of family rituals. In general, family rituals can be as simple as saying goodnight to the moon, everyday greetings, mealtime routines, and weekend leisure activities. Thus, whether it is how meals are shared or how major life events are marked, rituals are central to living. Rituals provide a place for people to explore the meaning in their lives and to build family relationships. These simple activities but multifaceted experiences represent the meaningful nature of family occupations.

Clinical Example

My doctoral research investigated how having a child with severe autism influenced the meaningful occupations of five family units. The results of this research indicated that these family units are over-routinized. Their days are strictly scheduled and frequently revolve around the needs of the child with autism. One question I asked the families was to describe a time where they felt like they were a “family.”

Each of the five families I interviewed had a difficult time identifying when they felt like a family unit or engaged in meaningful occupations. The families described these moments as fleeting and infrequent. In the stories shared by these families, only a minor portion of their daily living experiences was meaningful. The families appeared to mourn for a “family” life that they did not experience or feel that they could create. They frequently engaged in “doing” family activities to keep the child with autism occupied and pacified on a moment to moment basis. The families frequently engaged the child with autism in a range of therapies that left little time to be devoted to the family unit. Physically structuring and restructuring the household to prevent behavioral outbursts also consumed a good portion of the family’s day. These families did not experience a sense of proficiency with their occupations, nor did they associate daily events with the essence of being a family. As a result the meaningful aspects of their family’s occupation were sacrificed. These families have learned that attempts to create rituals were not worth the hassle.

If occupational therapy practitioners could provide services that facilitate a family’s engagement in rituals, we could strengthen the ability of the family to become a unit. We would help the family to “be” a family and to meaningfully occupy their time. Therefore, addressing the family’s meaningful occupation in the naturally occurring contexts of the family unit is consistent with being family-centered. Interventions aimed at facilitating a family’s growth in their ability to partake in and meet the occupational challenge of “being” a family would become the root of therapy. For example, practitioners could focus on helping the family partake in dinner rituals or facilitate bedtime rituals. Goals would be dependent upon the valued and meaningful activities the family engages in on a frequent basis. More appropriate “doing” goals may resemble “Joey will engage in an outdoor family leisure activity at least once per week.” “Being” goals would focus more on the celebrations, family traditions, and daily rituals. An example of a “being” goal for a family that used to go out to eat regularly may be, “The family will be able to eat out once per week.” To undertake this effort, practitioners would need to become well versed in assessing the desires of the family to “do” and to “be.”

Practitioners could interview the families with open-ended questions about their ability to negotiate routines and rituals. “Doing” questions could include describing a typical day and “being” questions would include describing the special things the family does together. Other methods include engaging the family in storytelling or observing the family in their valued contexts while closely examining the significance and the structure of the family’s participation in life contexts. In this manner, we could learn about the meanings they ascribe to their experiences about being a family and understand the demands challenging the family unit’s participation in meaningful life contexts. This type of approach would be unique to occupational therapy.

Conclusion

In summary, occupational therapy practitioners can strive to become family-centered by addressing the meaningful occupations of the family unit. Practitioners can become family-centered by examining the occupational functioning of the family unit and assessing the meaning the family attaches to their engagement in daily routines and meaningful rituals. With a shift to this emphasis, the focus of our interventions will no longer be on a discrete aspect of family life, but rather directed at the heart of how the family meaningfully participates in their day. We will provide interventions that influence how these families live and meaningfully occupy their time as a family unit.

Occupational therapy practitioners can focus on the meaningful aspects of family occupation and the construct of being a family. Intervention can be aimed at facilitating the family’s growth in their ability to partake in and meet this occupational challenge of being a family. This focus may encourage the family to grow as a unit and develop more efficient, effective, and satisfying ways of adapting to their occupational challenge of being a family. In doing such, the general well-being of families may improve. Our interventions could then demonstrate the connection between family occupation, family health, and family well-being. ▲

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References


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