OBJECTIVE. The purpose of this study was to describe the occupational concerns and goals of mothers who care for children with disabilities.

METHOD. Retrospective data collected from 38 mothers of children with disabilities using the Canadian Occupational Performance Measure (COPM) were analyzed qualitatively.

RESULTS. Six themes emerged: (I) doing and being alone: taking care of my own health and well-being; (II) doing and being with others: expanding my social life; (III) improving my child's quality of life; (IV) household management: organizing time and resources; (V) balancing work, home, and community responsibilities; and (VI) sharing the workload.

CONCLUSION. Overarching patterns in the data suggested that the occupational performance of mothers of children with disabilities is constrained by time, overlaid by difficult emotions, and involves a desire for increased social contact. Qualitative analysis of data from the COPM may provide insight into contextual factors that affect occupational performance as well as signaling point of entry for therapists to facilitate client-centered occupational goals.


Mothering is an integral human occupation that personally resonates for each of us as the wellspring of our sustenance and connection to the Earth; it is also the thread that sews human evolution forward into an imaginable future. Mothering may be considered from innumerable perspectives. Pierce and Frank (1992) explored how mothering represents a feminist quandary while Dyck (1992), using a sociopolitical lens, illustrated how mothers' work is frequently undervalued and invisible. Larson (2000) took a historical view and metaphorically compared the work of mothering to “cultural bedrock,” a deep and sturdy foundation that provides reliable care in addition to transmitting social values.

Mothering is a particularly important social role and a time- and energy-intensive occupation. A mother's work becomes even more demanding when caring for a child with a disability whose need for care may extend indefinitely into the future (Eisner, 1993). As a result of constraints imposed by the demands of long-term caregiving, mothers of children with disabilities are often prevented from participating in discretionary occupations (Breslau, Salketer, & Starch, 1982; Crowe, VanLeit, Berghmans, & Mann, 1997). Occupational imbalance may potentially lead to diminished well-being and life satisfaction. In order to support the health of mothers of children with disabilities, this study seeks to describe their occupational concerns and goals and to qualitatively analyze the personal characteristics associated with these goals.

J. Mark Donovan, MOT, OTR/L, is Occupational Therapist, Veteran's Administration Health Care System, PO Box 10123, Albuquerque, New Mexico 87184; mark.donovan@med.va.gov

Betsy J. VanLeit, PhD, OTR/L, FAOTA, is Assistant Professor, Occupational Therapy Program, Department of Pediatrics, University of New Mexico, Albuquerque, New Mexico.

Terry K. Crowe, PhD, OTR/L, FAOTA, is Director and Professor, Occupational Therapy Program, Department of Pediatrics, University of New Mexico, Albuquerque, New Mexico.

Elizabeth B. Keefe, PhD, is Assistant Professor, Special Education Program, College of Education, Department of Educational Specialties, University of New Mexico, Albuquerque, New Mexico.
Background

Women's lives often lose their sense of balance, if only temporarily, when a child is born. An infant's needs are exigent (Kreiger, 1996). Kreiger described motherhood as "the existential truth of the present, a matter of concreteness and immediacy" (p. 245). A similar theme, Doing "What I Got To Do," emerged in a study by Olson and Esdaile (2000) based on the occupational experiences of urban mothers caring for young children with disabilities. Ruddick, a feminist philosopher, defined mothering as meeting a child's demands for preservation, growth, and social acceptance through "preservative love, nurturance and training" (1989, p. 17). Mothering has also been described as providing both instrumental and emotional support for a child (Francis-Connolly, 2000). The literature is full of examples of how mothers, whether or not they work outside the home, assume far more responsibility for childcare than do fathers (Aldous, Mulligan, & Bjarnason, 1998; Crowe, VanLeit, & Berghmans, 2000; Dyck, 1992; Hochschild, 1989; Traustadottir, 1991; Young & Roopnarine, 1994).

Caring for a child with a disability introduces even more demands on a mother than caring for a typically developing child. Mothers of children with disabilities often take on additional roles including those of developmental interventionist, liaison between the family, health care, and school systems, and advocate for the child (Allen & Hudd, 1987; Lawlor & Mattingly, 1998; Odom & Chandler, 1990). Housework and caregiving may be increased when caring for a child with a disability. In a study of women's time use, Breslau (1983) reported that married women spent an additional 3 hours per week on housework when a child with disabilities was present in the home. Johnson and Deitz (1985) found that mothers of children with physical disabilities spent significantly more time in physical child care (feeding, personal care, and transportation) than did mothers of typically developing children. Crowe's (1993) study of the time use of mothers with young children both with and without disabilities found similar results. However, some studies show caretaking burden (time spent and difficulty) varies in relation to the type of the child's disability, the child's age, and the absence or presence of behavioral concerns (Erickson & Upshur, 1989).

A sizable body of evidence indicates that mothers of children with disabilities are more likely to work part-time, earn less money, and reduce the hours they work or take a paid leave of absence to care for their children (Breslau, Saltzker, et al., 1982; Freedman, Litchfield, & Warfield, 1995; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993; Porterfield, 2002; Powers, 2001). This phenomenon may increase stress particularly for single mothers of children with disabilities.

Overall, mothers who care for children with special needs have profound difficulty with time demands (Beckman, 1991; Erickson & Upshur, 1989; Harris & McHale, 1989; Hinojosa & Anderson, 1991; Kellegrew, 2000; McLinden, 1990). Their time for sleep is frequently more limited (Bailey & Simeonsson, 1988). The long-term effects of this lifestyle may include physical and emotional strain that manifests in high rates of stress and depression in mothers of children with disabilities (Beckman, Breslau, Staruch, & Mortimer, 1982; Crnic, Friedrich, & Greenberg, 1983; Dyson, 1991; Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986; McCubbin et al., 1983; Shapiro & Tittle, 1990).

Purpose

Faced with the struggle of keeping up with their daily routines and the loss of discretionary activities, our interest was to explore the occupations that mothers of children with disabilities need and want to do. Thus, the purpose of this study is to characterize the occupational goals and the personal qualities associated with those goals of mothers of children with disabilities. Our guiding questions were (1) What are the primary themes that describe the occupational concerns and goals of mothers who have children with disabilities? and (2) Are there recurring personal qualities associated with these concerns and goals that help to explain their salience? Insight into the subjective occupational concerns of individual mothers as well as the general themes that emerge will inform occupational therapists and other professionals to support the occupational performance and well-being of all members within the family system.

Method

Research Design

This is a descriptive study that employs qualitative techniques to analyze narrative information collected from the Canadian Occupational Performance Measure (COPM; Law et al., 1998). The study is based on a constructivist paradigm (Denzin & Lincoln, 2000) with triangulation of findings among historical documents, a focus group, and professional practice-based knowledge; the method of this study does not include field-based participant observation. Qualitative analysis methods were used in order to build a
complex, holistic picture of a social or human phenomenon (Creswell, 1994), in this case the occupational concerns and goals of mothers of children with disabilities. Context-bound, emergent categories and patterns arise in qualitative research to express the subjective and multiple realities of the participants (Lincoln & Guba, 1985). The process is predominantly inductive with data and theory explored simultaneously.

**Procedure**

The present study employs retrospective data that were generated by an occupational therapy intervention program at the University of New Mexico entitled Project Bien Estar (Spanish for Well-Being). This project consisted of development, implementation, and evaluation of a psychosocial model of intervention to address the time-use and occupational performance needs of mothers who care for children with disabilities (Helitzer, Sabo-Cunningham, VanLeit, & Crowe, 2002; VanLeit & Crowe, 2000, 2002). The intervention phase of Project Bien Estar took place over approximately a 2-month-long period during a sequence of eight sessions (VanLeit & Crowe, 2000).

Thirty-eight mothers of children with significant functional disabilities participated in Project Bien Estar. Mothers met the inclusion criteria if their child was between 3 and 13 years of age and required assistance in at least three of five functional domains including mobility, eating, toileting, communication, and play. Although diagnosis was not part of the inclusion or exclusion criteria, the children’s conditions included autism, neuromuscular conditions, developmental delay, and multiple disabilities. The participants’ ethnicity included: Native American 2%, Hispanic 29%, Anglo 61%, and Other 8%. Reported income ranged from less than $10,000 to more than $70,000. Fifty-three percent of the group earned less than $30,000. Additional demographic variables include participant’s education (M = 16 years, range = 12 to 22 years), participant’s age (M = 37 years, range = 26 to 47 years), number of children in the household (M = 2, range = 1 to 5), number of adults in the household (M = 1.8, range = 1 to 2), and weekly hours of employment (M = 17, range = 0 to 80).

As part of Project Bien Estar, an occupational therapist or an occupational therapy student (a total of three persons) administered the COPM. Data collectors were trained in the research protocol and, before collecting data, had to obtain at least a 95% agreement on both procedural protocol and interpretation of problem identification using the COPM. Multiple reliability checks were conducted following every 10 assessments to ensure consistency of data collection. The data used in the present study originate from information gathered during only the pretest phase of Project Bien Estar.

**Instrument**

The Canadian Occupational Performance Measure (Law et al., 1998) was administered to every participant. In the decade since its inception, the COPM has been used and evaluated widely in Canada (McColl, Paterson, Davies, Doubt, & Law, 1999) as well as receiving significant international attention (Law et al., 1998; Ripat, Etcheverry, Cooper, & Tate, 2001). It has been employed for multiple purposes in practice, research, and education. In practice it is useful both to generate client-driven occupational performance goals, and thus to direct intervention, as well as to assess outcomes. Numerical scores permit standardized mathematical evaluation of attributes and allow comparison across clients as well as from pre- to post-intervention (Toomey, Nicholson, & Carswell, 1995).

The COPM is administered in a semistructured interview format: a person is asked to describe his or her typical daily routine from getting up in the morning to going to bed at night. The therapist subsequently facilitates identification of occupational performance concerns (i.e., occupations the person needs, wants, or is expected to do but has difficulty doing). The intrinsic flexibility of the COPM allows it to be used with persons across the lifespan who exhibit a broad range of occupational performance difficulties.

The COPM’s psychometrics have been evaluated by a number of investigators. Law and Stewart (1996) determined test–retest reliability to be .79 for Performance and .75 for Satisfaction scores in a sample of young children with disabilities. Bosch (1995) found test–retest reliability to be .80 and .89 for Performance and Satisfaction scores, respectively.

Content, criterion, and construct validity have also been evaluated for the COPM. Content validity, or the degree to which the test domain (occupational performance) is measured as determined by experts, was found to be good (Chan & Lee, 1997) and is supported through the wide use and worldwide distribution of the measure (Law et al., 1998). McColl et al. (1999) demonstrated solid evidence of construct validity by showing significant correlations between the COPM and a variety of other measures representing the constructs of satisfaction with performance, reintegration to normal living, and life satisfaction. Evidence of responsiveness and sensitivity to change has also been reported (Carpenter, Baker, & Tyldesley, 2001; Healy & Rigby, 1999; Law, Polatajko, Pollock, McColl, Carswell, & Baptiste, 1994).
Trustworthiness

Trustworthiness, the extent to which the findings of a naturalistic inquiry can be viewed with confidence, may be assessed using the criteria of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). In the present study, credibility was addressed through the psychometrics of the instrument used, the COPM, as well as through collaborative formation of concepts and constructs between two of the authors (JMD, BVL). The criterion of prolonged engagement as an element of credibility (Lincoln & Guba) was met through the extensive professional experience three of the authors (TKC, EK, BVL) brought to the study in working with this population over many years. Credibility was also strengthened through negative case analysis and the search for disconfirming data throughout the analytic process. Most importantly, our findings were returned to some of the participants and verified in a member check. Mothers who participated in the member check validated the thematic categories as representative of their occupational concerns and goals.

The criterion of transferability was supported through the employment of thick description and use of the mothers’ own words in the results section. Demographic data also aid transferability of findings to other populations (VanLeit & Crowe, 2002). Finally, an audit trail consisting of records containing raw data, electronic documents created in NVivo (version 1.3, QSR International, 2000), and a journal of reflexive notes kept over a period of 2 years throughout the development of the study support the criteria of dependability and confirmability.

Data Analysis

A constant comparative method of analysis (Glaser & Strauss, 1973) also known as grounded theory was used. Over 400 units of data were initially open-coded as the authors began to divide the data into coherent themes. Every sentence cluster was examined to see what it revealed about the experience being described (VanManen, 1990). Subsequent ordering of the data into a delimited framework involved axial coding, or collapsing of categories into one another, and finally, closed coding in which every unit of data was filed into one of six categories that, taken together, were able to contain and give meaning to the data.

Two of the authors (JMD, BVL) conducted separate yet parallel analyses of the data and then synthesized their findings. Outcomes were very nearly identical. All minor differences except for one were resolved through dialogue in which the researchers easily reached consensus. However, one significant difference remained. This issue related to the classification of occupational goals in which the mothers expressed a desire for help, for another person to assume a part of their responsibility. One of the authors saw these goals as strategies used by mothers to balance their occupations; the other author considered them to be freestanding occupations unto themselves.

With time, our analysis was refined as we gained distance and objectivity from the initial results, and an opportunity to continue building conceptual relationships. Returning to the idea of negative case analysis and the need to reconcile inconsistent data, we eventually agreed that the concerns identified on the COPM relative to finding help did indeed represent occupations unto themselves, albeit a cognitive type of strategic “doing,” a process skill, rather than an empirically observable action. In turn, this broadened our understanding of the sensitivity of the COPM and the multiple layers related to occupational performance that it references.

A member check (focus group) was organized following initial data analysis to return the authors’ proposed thematic categories to the participants for feedback, validation, and/or change. Women from both the intervention and control groups of Project Bien Estar were invited to participate in the member check. The group met on a weekday evening on the campus of the University of New Mexico; an occupational therapy student provided childcare. Two of this study’s authors (JMD, EK) facilitated the meeting according to the member-check protocol in Lincoln and Guba (1985). The women present agreed that the proposed results represented their occupational concerns, however, one participant stated that identical themes might apply to mothers of typically developing children; she proposed that the difference between the two groups lies in the quality of the everyday lived experience. The mothers’ commentary from the member check is intermeshed throughout the discussion section of this article.

Permeability of Themes

A categorical reliability check was performed by three of the authors (TKC, JMD, BVL) who independently sorted a random sample of 10% of the data into the six established categories. Reliability was found to be 79%, which indicated a degree of permeability between the themes. Overlap was considerable between Theme II (Doing and Being With Others: Expanding My Social Life) and Theme V (Balancing Work, Home, and Community Responsibilities). Occupational goals such as, “being involved with church/attending community events/and helping other parents” clearly involve participation with others within community settings and thus belong to both categories. Another example of a goal that falls within the rubric of multiple categories is “dealing with other people’s rejection.
of child.” This goal involves a need for personal time and space to process emotions (Theme I), interaction with others (Theme II), and, we may suppose, an aim of restoring inner balance for the sake of maintaining a positive relationship with the child (Theme III). The outcome of the reliability check was the recognition that certain goals could not be clearly pigeonholed into one descriptive category due to their multifaceted nature, but rather belonged within several of the themes.

Results

Our analysis ultimately yielded six themes that were able to circumscribe and describe the meanings associated with caring for a child with a disability (see Table 1). The lists of italicized goals in this section are taken at random and verbatim from the total data pool.

Theme I—Doing and Being Alone: Taking Care of My Own Health and Well-Being

For the sheer frequency of its appearance in the data, the first theme may be particularly salient. One of the mother’s goals, “wear hair down more often,” provides the general feeling of this theme: a desire to unwind and let down. The domain includes specific occupational goals to support personal health and well-being, including taking time to enjoy self-care rituals, exercise, recreation, relaxation, and sleep. Examples of goals include:

- go to the bathroom by myself / take a shower on own schedule / have more time for me (to get a haircut, to eat lunch) / jog / more consistent with fitness program / workout on daily basis for 30 minutes / go get lost in a bookstore / find ways to engage my brain / going to a movie / play Nintendo / get a massage occasionally / have time for solitude and peace / learn to relax and enjoy myself even when my regular responsibilities haven’t been met / adequate amount of sleep on a more consistent basis with fewer interruptions / getting a good night’s sleep (earlier bed time or later wake-up time).

On a more internal level, this category also includes goals related to spiritual renewal, emotional processing, building self-esteem, and feeling good. Examples include:

- opportunity to reevaluate priorities, clarify values / meditation and spirituality / decreased sense of being overwhelmed and increased sense of trust in my own capabilities / resolving grief issues about son / dealing with other people’s rejection of child / not feeling guilty when I go and do something I like (e.g., swimming) / desire more stamina, confidence, and focus / staying involved with my recovery program (not acting out through drugs and alcohol) / learn coping strategies—move out of fight/flight mode / time for myself to do things I enjoy.

As the title of the theme suggests, most of the goals were self-focused and included an aspect of being and doing alone. One of the mothers specifically wrote, “have time alone once a week,” and the goal, “time alone,” was frequently cited.

Theme II—Doing and Being With Others: Expanding My Social Life

The second theme centers around making, maintaining, and renewing relationships as well as keeping in touch, whether physically (visiting, traveling, getting together), by phone, or by writing letters and e-mail. These occupational goals entail bringing together nuclear family, extended family, and friends. Examples of goals include:

- going on picnics with family / spend more of my free time doing fun things with kids / go out with husband at least once a month / go to Boston for my cousin’s wedding / take initiative to do lunch, coffee, activity with girlfriends / time with other women like me.

Theme III—Improving My Child’s Quality of Life

The third theme could be summed up in the words of one mother: “find strategies, find solutions, find a way.” The occupational goals in this category are directed at the work a mother does, including advocacy, to help her child to meet his or her potential. Verbs used by the mothers to describe this process include help, facilitate, develop, establish, structure, discipline, and encourage. Examples of verbatim goals include:

- find solutions to help daughter overcome fears / develop new strategies for son’s toileting / arrange recreational activities for daughter and son like horseback riding and dancing / read to enhance my understanding of how to help son / keep children healthy and out of hospital.

Table 1. Occupational Goal Themes

| I. | Doing and Being Alone: Taking Care of My Own Health and Well-Being |
| II. | Doing and Being With Others: Expanding My Social Life |
| III. | Improving My Child’s Quality of Life |
| IV. | Household Management: Organizing Time and Resources |
| V. | Balancing Work, Home, and Community Responsibilities |
| VI. | Sharing the Workload |

Theme IV—Household Management: Organizing Time and Resources

Theme IV involves tasks that comprise the daily routine. The “to do” list for these mothers includes: cook, clean, weed out clothes in the closet, do laundry, fix and mend, iron, budget, pay bills, shop, run errands, get hair done, vacuum, landscape, mow, repaint, and redecorate. Mothers strive for...
efficiency in performance of chores through improved (time) management skills. A list of common verbs used in this category includes develop strategies, schedule, form routines, systematize, plan, and organize. Examples of goals include:
- rely on consistent shopping schedule/staying on top of laundry / maintaining vegetable garden / cooking a good meal / establish a budget / meeting ongoing demands for receiving financial assistance / accomplishing household tasks in efficient manner (free time vs. with kids) / get a weekly schedule for household chores / be more efficient and organized (paper management and to-do lists).

Theme V—Balancing Work, Home, and Community Responsibilities

The fifth theme focuses on getting out into the bigger world to advance professionally, improve the family’s financial situation, and contribute to society through volunteer and advocacy work. In pursuing desires and actions inherent to this category, some of the mothers’ goals displayed explicit recognition that sustainable participation in work and community-related occupations was dependent on interweaving activities within the home/family routine. Examples within this domain include:
- go back to school and get my degree / be able to advance in my profession / helping other parents / increase involvement with social and political issues / coordinating work responsibilities with caring for baby / find a way to get out of the red and still find time and money to provide for children’s economic and social needs.

Theme VI—Sharing the Workload

The sixth category relates to mothers’ desires to relinquish responsibilities by having other persons assume them. Finding a trustworthy and reliable childcare helper was the top, oft repeated, goal in this domain followed by a desire for husbands, significant others, and children to meet more of their own needs independently and to assume more active roles in helping to maintain the household. Goals include:
- finding a dependable babysitter who has the skills and knowledge to meet son’s needs / would like husband to find more flexible, understanding job / reach a compromise with spouse—each sharing responsibility / would like children to be more independent in self-care activities / being able to delegate without feeling like I have to be the one in control.

Overarching Themes

Beyond Traditional Performance Areas: Overarching Temporal, Social, and Emotional Contexts

Although the COPM organizes information around the performance areas of self-care, productivity, and leisure, our desire was to look beyond this conventional triumvirate with the hope of gaining new insights into occupation and occupational performance, its affordances and constraints, and its meaning in the lives of mothers of children with disabilities.

The integral role of context in forming occupation and enabling occupational performance has been recognized for some time within the profession and is reflected in the Occupational Therapy Practice Framework: Domain and Process (American Occupational Therapy Association, 2002). Context may be considered as all-inclusive, ranging from the internal lived experience (Merleau-Ponty, 1962), to specific materials and settings necessary for participation in a particular occupation (Nelson, 1988), to broad ecological variables that include social, political, institutional, and cultural factors (Bronfenbrenner, 1979). Contextual elements that stood out as being particularly meaningful to the occupational performance of mothers of children with disabilities include the temporal, social, and emotional.

Importance of Time

The mothers referred over and over to a desire to find time, make time, and to have more time. The profound difficulty with time demands experienced by mothers of children with special needs is well-supported by the literature (Beckman, 1991; Erickson & Upshur, 1989; Harris & McHale, 1989; Hinojosa & Anderson, 1991; Kellegrew, 2000; McLinden, 1990). One participant in the member check stated, “It’s a powerful sense of there’s never enough time.” Examples include:
- have time to do housework without distractions / more time to do volunteer work in the community / would like to spend less time in the car (driving to therapy, grocery) / find an optimal time to go grocery shopping by myself / time for myself to do things I enjoy.

Parental time constraints may differ as a result of child-specific variables; some studies indicate a correlation between time costs, the degree of the child’s disability, and the presence of behavioral problems in the child (Curran, Sharples, White, & Knapp, 2001; Floyd & Gallagher, 1997).

Time considerations seem to have a considerable impact on quieter, more reflective, occupations, which may be the first to go when “push comes to shove” in the daily routine. Although the majority of goals identified by the women in this study could be classified as those that involve active doing, a substantial number, particularly within the domains of Themes I and II, were oriented around time and space for just being alone or being with others. Being has been described as “time for [people] to discover themselves, to think, to reflect and, to simply exist” (Wilcock, 1998, p. 250). These goals encompassed time for “dealing”
with emotions, time for mental reflection and clarification, and time for being together with others, including:

- dealing with anger and depression / time for solitude and peace / more time to reflect on future / private time with just my family doing something fun / spending one-on-one time with [husband] without sacrificing my own time / being alone with younger son / go away for weekends with my friends / make time to socialize with friends / more time to play with children.

In addition to the scarcity of time experienced by mothers of children with special needs for doing and being, the quality of their time when engaged in occupations appears to be fragmented. The choppy, stop-and-go quality of their routines may prevent these women from realizing a satisfying rhythm, or tempo, during performance of occupations (Clark, 1997) and preclude them from having optimal flow experiences (Csikszentmihalyi, 1990). This may result from alternating back and forth between two or more activities when multitasking, and the need to frequently stop what they are doing in order to attend to their child’s demands (Kreiger, 1996). This quality, as reflected in the mothers’ goals, is characterized by interruption, disruption, distraction, and rushing. The goals express the mothers’ tandem desire to do things at their own personally satisfying pace, as well as to separate occupations so that they may concentrate on one thing at a time:

- getting enough uninterrupted sleep / have time to do housework without distractions / getting children to therapy, doctor without rushing or stress / be able to shop for clothes in a relaxed manner / take a shower on own schedule / taking time to get ready (nice) / have a good restful night’s sleep and wake up when I wake up / have a day each week to clean and work outside when every- one else is out of the house / doing housework while son is occupied (playing or sleeping).

The literature identifies various time-use strategies that have been used by mothers to different ends. Bateson (1996) coined the term “enfolded activities” as a description of women’s work that includes all that can be done while caring for a child. Although the strategy of enfolding occupation often results from multitasking and may lead to exhaustion, Primeau (1996) showed positive effects from the use of this strategy; she found that mothers of typically developing preschool aged children had fun when doing household chores that embedded play activities with their child. Building on the idea of enfolded activity, Segal (2000) identified the use of “temporal unfolding,” or doing only one thing at a time, by mothers of children with attention deficit hyperactivity disorder; she noted that mothers used this strategy to give full attention to their child in order to facilitate the child’s success in reaching a developmental goal. Outcomes from the use of strategies to enfold and unfold activities are varied and require more study to determine how they may be affected by complex personal and familial factors.

Our data also reflects the use of additional strategies by mothers of children with disabilities to compensate for time constraints. One of these is a straightforward attempt to stretch the wakeful hours of the day: “get up earlier and be completely ready for my day before kids wake up.” Another strategy is to form organized and efficient schedules and routines: “develop more organized system of filing, toy management/establish daily household management routine/maintaining a morning routine.” Helitzer et al. (2002) described how mothers of children with disabilities use routines and schedules to maintain a sense of control. Finally, some mothers interweave public and private work in order to support the family routine: “need family-friendly position (individualized work plan)/work as much as possible from home/finding a job (that will fit family’s schedule)/ balancing work and home responsibilities.” An ecocultural framework (Bernheimer, Gallimore, & Weisner, 1990) has been used in numerous studies of families that include children with disabilities to explain accommodations family members make to sustain the family routine (Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Kellecgrew, 2000; VanLeit & Crowe, 2002). Clearly the influence of time on the occupations of mothers who care for children with disabilities is quite significant and a constellation of strategies may be used, with more or less success, in the hope of supporting healthy family functioning.

**Importance of Social Contact**

Mothers of children with special needs also seem to be at high risk for social isolation (Crowe, 1993; Esdaile, 1994; Olson & Esdaile, 2000; Segal, 2001). Multiple factors related to being the primary caregiver may deter participation in social activities for mothers of children with disabilities including volume of daily caregiving activities, physical and emotional exhaustion, social stigma due to child’s inappropriate behaviors in public places, and practical concerns related to transporting the child such as physical access and medical need. Four subgroups related to socialization and a desire to be in closer contact with others comprise this theme, (a) being together as a family, (b) spending time with kids or with husband, (c) staying in touch with extended family, and (d) making, communicating with, and getting together with friends. Examples include:

- find other families that we can get together with / weekly family walk on the mesa / going out with son (movies, zoo, swimming) / go on a date with husband / be more open to invitations from in-laws / 2-week vacation in Sweden to see father / find and create friendships with

---

*The American Journal of Occupational Therapy*
people who understand what it is like to have a child with a disability / doing spontaneous activities with friends / talk with friends on the phone.

A large number of goals in subgroup (a), being together as a family, related to the desire to plan and take a family vacation. This may be partly indicative of the social-economic status and aspirations of this specific group of women, but may also reflect the complexities inherent to caring for a child with functional disabilities for whom particular contextual supports (often provided in the home environment) are necessary to support the child’s task performance. A mother in the member-check phase of the study recounted a story of losing her family’s vacation cabin to a forest fire and how this complicated getting away due to her son’s medical need. One of the goals was specifically worded: “take a family vacation without it being an ordeal.”

The data strongly suggested that occupational goals related to finding and making compassionate friends as well as staying in touch with them are a challenge for mothers of children with disabilities. As a mother in the member check said, “People call—do you want to go to [popular restaurant]? We can’t do it.” Segal (2001) described how social events that include children with special needs are often disastrous. Heiman (2002) found that new parents of children with disabilities experienced changes in socialization that led to increased frustration and dissatisfaction. However, not all studies show differences in the level of social support for parents of children with special needs. Dyson (1997) compared 32 couples of parents of children with disabilities to 32 couples of parents of typically developing children and found no differences in social support between the two groups; however, the parents of children with disabilities showed higher stress levels.

The high risk for loss of social support is of particular concern as socialization has been shown to positively mediate psychological distress and influence personal well-being (Friedrich & Friedrich, 1981; Horton & Wallander, 2001). Mothers of children with disabilities may be at high risk for distress due to limited opportunities for socialization combined with the presence of unremitting difficult emotions.

Dealing With Emotions

Both the interviews and the member check highlighted the prominence of painful emotions for these mothers. A story was told in the member check about a family with two daughters, the elder of whom had a disability and, at 7 years of age, had never been invited to celebrate a peer’s birthday; her typically developing sister, at the same age, had a history of invitations to 55 birthday parties. The mother who related this story talked about the feelings of anguish, dis-

appointment, and grief this brought up for her. The mothers’ occupational goals made reference to a variety of hassles and difficult emotions, including anger, depression, embarrassment, rejection, guilt, overwhelmed, grief, fight-flight mode, stress, worry, exhaustion, and ordeal. Examples of goals include:

be able to sleep without worrying about daughter / sit and draw when I am not exhausted / resolving grief issues about son / dealing with feelings of other children / decreased sense of being overwhelmed and increased sense of trust in my capabilities / dealing with feeling guilty about missing work / dealing with advice of in-laws / dealing with other people’s rejection of child / dealing with embarrassment about son.

Mothers in the member-check group reiterated the terms “dealing with emotions” and “ongoing grieving” and spoke of the importance of counseling and psychotherapy to help them balance their emotions. Some researchers have found that mothers of children with disabilities experience recurring cycles of sorrow and grief with each new developmental stage their child reaches (Bruce, Schultz, & Smyrnios, 1996; Schultz & Schultz, 1997). Larson (1998) used the phrase “the embrace of paradox” to illustrate the emotional duality experienced by mothers of children with special needs, which she describes as, “the management of the internal tension of opposing forces between loving the child as he or she was and wanting to erase the disability, between dealing with the incurability while pursuing solutions, and between maintaining hopefulness for the child’s future while being given negative information and battling their own fears” (p. 873). The literature supports the high incidence of emotional stress found in mothers of children with disabilities (Beckman, 1991; Breslau, Staruch, et al., 1982; Crnic et al., 1983; Dyson, 1991; Goldberg et al., 1986; McCubbin et al., 1983; Shapiro & Tittle, 1990). Emotional issues may be compounded for mothers who care for children with disabilities by physical exhaustion due to their increased housework and caregiving demands (Breslau, 1983; Crowe, 1993; Crowe et al., 2000; Johnson & Dierz, 1985), by the loss of mediating social factors, and by restricted opportunities to pursue meaningful and restorative discretionary occupations (Breslau, Salkever, et al., 1982; Crowe et al., 1997).

Discussion

Limitations

Limitations to this study include a sample composed of women in a predominantly middle-upper income bracket situated in one metropolitan area of the southwestern
United States. Use of retrospective data, although adequate for descriptive purposes, involves interpretation of textual artifacts removed from their contextual moorings by an objectifying researcher. Research conducted in the field in the true tradition of qualitative research, and through the use of an intersubjective methodology, would provide a richer understanding of the meaning of occupation in the lives of mothers of children with disabilities.

**Implications for Practice**

A strong plea was made by mothers who participated in the member-check phase of this study for therapists to confront their own imperfections, to put energy into their own emotional and spiritual growth, and to practice with heart. They expressed higher value and appreciation for therapists who touch their children, who look for the spirit behind the disability, and who provide social support than for therapists who maintain an aloof stance as technical experts. The importance of therapists’ social support for mothers of children with special needs has been documented in the literature (Case-Smith & Nastro, 1993; Esdaile & Olson, 2004; Hinojosa, 1990; Olson & Esdaile, 2000).

In addition to providing social support, therapists need to maintain awareness of the power differential within the therapeutic relationship when working with these women and to put energy into creating a more equal playing field. Although mothers of children with disabilities are a diverse group, they are at high risk for social disenfranchisement and occupational marginalization (Townsend & Wilcock, 2004) due a variety of factors, including gender and loss of discretionary occupations that may lead to restricted participation in professional and community affairs. By enabling collaboration throughout all phases of the therapeutic process, including during assessment, problem identification, goal setting, critique of treatment options, and determination of intervention efficacy (Lawlor & Mattingly, 1998), therapists increase their clients’ participation and socially empower them in the process. Doing this effectively in practice may be facilitated by the use of client-centered tools that support an enabling process.

The authors of this study discovered the power of using the COPM to increase equality in the therapeutic relationship and for building understanding of the mothers’ individual perspectives. The COPM was able to elicit a sense of each mother’s personal history as she described her daily routine and self-perceived occupational concerns; this information then led easily into collaborative goal formation. The literature supports the use of interviewing as an important method for increasing understanding of a person’s subjective experience, especially when combined with narrative reasoning (Mallinson, Kielhofner, & Mattingly, 1996; Polkinghorne, 1996) and in conjunction with an ethnographic interpretive framework (Gitlin, Corcoran, & Leinmiller-Eckhardt, 1995; Spencer, Krefting, & Mattingly, 1993).

We also found that using the COPM was a simple way to shift perceptions, attitudes, and behavior toward occupation. Simply verbalizing one’s intent to improve occupational performance and satisfaction in targeted occupations, without any other intervention, may lead to improved satisfaction with occupational performance over time (VanLeit & Crowe, 2002); Tryssenaar, Jones, and Lee (1999) reported similar findings.

In addition, however, the tremendous amount of information generated by the COPM is very useful in intervention. Clients come up with many types of goals using the COPM, some that are specific and others that are less well-defined. This information may be used as a point of entry for therapists. For instance, to facilitate a fuzzy goal, such as “eventually would like a reliable job,” a therapist might begin by establishing the person’s motivation for and commitment to the goal. This could be accomplished by assessing the person’s occupational history in more depth, including past and present roles, employment history, skills, and interests. By engaging in this process of clarification, the client might decide to forsake the goal as unimportant for the time being, to change the goal to more accurately reflect his or her occupational concern, or to continue realizing the original goal. If the goal were to be continued, the therapist might provide skill training or identify community resources for the client’s use.

A therapist addressing a goal such as “transporting children to complete errands (if fuzzy cannot go),” might begin by exploring the importance of the desired outcome to the client as well as alternative means for reaching the end goal that could be more effective. In this case, a therapist might need to know the family’s routine, shopping schedule, childcare help (if any), children’s behaviors, etc. to help identify areas for modification and change. To address a very specific goal, such as “hiking/outdoor activities” the therapist might begin by assessing practical environmental constraints and affordances. Questions might include: Does the mother know about accessible and safe recreational areas? Would she like to be part of a hiking group? Can her schedule flexibly accommodate the occupation? Answers to these questions might reveal that the client doesn’t perform the occupation because of a low value placed on her own participation in self-care leisure activities. At this point the therapist might need to address self-perceptions and coping skills to enable occupational participation. Goals from the
COPM are a practical jumping off place for enacting meaningful client-centered interventions.

Implications for Research

Employing qualitative methods in research, similar to those described above for use in practice, is a way of increasing our understanding of the experience of mothering a child with a disability. Phenomenology and ethnography conducted through observation and interview in real-life settings (home, clinic, grocery, etc.) and interpreted through multivoiced texts and narratives can be a powerful vehicle for making these mothers’ voices heard. Narrative interpretation of ethnography is a particularly suitable vehicle for “creating meaning that attends to the temporal dimension of human nature” (Tedlock, 2000, p. 471). Texts of this nature could contribute to our understanding of the distinct temporal experiences of mothers who care for children with special needs.

Another important consideration is how information is shared. To enlarge the arena for sharing knowledge beyond professional journals, information may be more accessible, interesting, and useful if it is presented in traditional literary forms (e.g., story, narrative, novel) and/or alternative media, including film, visual, and/or performing arts and presented through a variety of community-based venues.

Action, or participatory, research (Kemmis & McTaggart, 2000; Letts, 2003; Townsend, Birch, Langley, & Langille, 2000) is a vehicle for shifting power relations and has received considerable attention in the occupational therapy literature due to the close fit between its principles and those of client-centered care (Cockburn & Trentham, 2002). This form of investigation brings together activism, advocacy, and research under one roof. Active collaboration with mothers of children with disabilities on all aspects of a research design from community needs assessment to application of results would provide an opportunity for a researcher or facilitator to access experiential knowledge and explore distinct temporal experiences of mothers who care for children with special needs.

In our roles as therapists and researchers we may be most efficacious if we are able to socially empower our clients and bring them into participation within the wider community as well as to cultivate caring therapeutic relationships in the process. As a mother in the member-check phase of the study stated, “The therapists made or broke me. . . . One made me cry every time, and then I had [therapist] who had so much heart . . . she was incredible . . . she cared.”

Acknowledgments

We thank all the women who participated in Project Bien Estar. Special thanks to those mothers who took part in the member check whose personal stories brought a life spark to the retrospective data employed in this article. Funding for Project Bien Estar was provided by a grant from the American Occupational Therapy Foundation. This work was based on a thesis completed by the first author in partial fulfillment of a Master of Occupational Therapy degree at the University of New Mexico.

References


Case-Smith, J., & Nastro, M. A. (1993). The effect of occupational therapy intervention on mothers of children with...


Horton, T. V., & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of...


---

**Coming in July/August 2005**

▲ **Visual Perception and Visual Factors**

▲ **Adjustments to Disability in Daily Occupations**

▲ **Occupational Patterns and Skills of Children**

▲ **Professional Workforce and Development Issues**

Turn to *AJOT®* for the latest information on occupational therapy treatment modalities, aids and equipment, legal and social issues, education, and research.