Research lessons learned: Occupational therapy with culturally diverse mothers of premature infants

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Abstract

Background. *Evaluation studies of the effectiveness of home-based occupational therapy are scarce but are needed to justify the impact of occupational therapy intervention. When the intervention is for persons from diverse cultural backgrounds, additional research challenges arise.* **Purpose**. *To share lessons learned in conducting home-based occupational therapy research with Canadian, and immigrant South Asian and Chinese mothers of premature infants in a large Canadian city.* **Key issues**. *Lessons learned were to implement a culturally sensitive recruitment process, change the research design to include more interviews and focus groups, and be aware of the need for culturally appropriate instruments.* **Implications**. *Researchers need to be sensitized to the Western cultural values upon which most research designs and instrumentation are constructed. Involvement of a culturally diverse research team, openness to feedback, adaptability, and critical reflection on what is important to the cultural groups are among the suggestions for researchers planning home-based occupational therapy research with culturally diverse populations.*

Abrégé

Description. *Les études visant à évaluer l'efficacité de l'ergothérapie à domicile sont rares tout en étant essentielles pour déterminer les effets de l'intervention ergothérapique. Lorsque l'intervention s'adresse à des personnes ayant des antécédents culturels différents, d'autres difficultés se présentent en matière de recherche.* **But**. *Partager les leçons apprises d'une étude sur l'ergothérapie à domicile menée auprès de mères d'enfants prématurés d'origine canadienne, sud-asiatique et chinoise habitant dans une grande ville canadienne.* **Questions clés**. *Les leçons apprises étaient, notamment, de mettre en œuvre un processus de recrutement adapté à la culture, de modifier le plan expérimental afin d'ajouter plus d'entrevues et de groupes de discussion, et d'être sensibilisé au besoin de créer des instruments adaptés à la culture.* **Conséquences**. *Les chercheurs doivent être sensibilisés au fait que la plupart des plans expérimentaux et des instruments d'évaluation sont construits à partir des valeurs culturelles occidentales. Les chercheurs qui envisagent de faire des études sur l'ergothérapie à domicile auprès de populations de diverses cultures sont encouragés à former des équipes de recherche composées de personnes de diverses cultures, à être ouverts à la rétroaction, à faire preuve d'une grande capacité d'adaptation et à réfléchir de manière critique à ce qui est vraiment important pour les différents groupes culturels.*

The ethnic and cultural diversity of the populations in Canada has increased because of changes in Canadian immigration laws, which have allowed a greater number of immigrants from more countries (Maiter & George, 2003). In 2010 Canada accepted over 250,000 immigrants, up from over 80,000 in 1985 (Research and Evaluation Branch, Citizenship and Immigration Canada, 2009). By 2031, visible minorities will comprise 63% of the population of Toronto, a large urban centre (Statistics Canada, 2010). Important issues arise not only because of the rapid growth in diverse populations but also the incidence and management of health problems across diverse groups (Skaff, Chesla, de los Santos Mycue, & Fisher, 2002).

This article makes use of a recent mixed-methods research study with Canadian and immigrant South Asian and Chinese mothers of premature infants. We

offer suggestions based on our experience that may help other occupational therapists produce culturally appropriate research as they conduct research in the home context with diverse communities. The goal of this research study was to measure the quality of mother-infant interaction and infant motor development after receiving home-based occupational therapy.

The thesis of this paper is that conducting research with diverse populations requires an understanding and sensitivity to constructs and methods that are traditionally used in social and behavioral research based on Western European perspectives. Important concepts that are explored are cultural sensitivity, mother-infant interaction, parenting styles and beliefs, recruitment, research design, and cultural appropriateness of research methods.

Review of the Literature

Home Care Service Delivery

Home care has been defined as "an array of health and social support services provided to clients in their own residence. Such coordinated services may prevent, delay or be a substitute for temporary or long-term institutional care". (Thomé, Dykes, & Hallberg, (2003, p. 861). Culturally competent home care is proposed to include cultural sensitivity, knowledge, and skills (Kim-Godwin, Clarke, & Barton, 2001; Levine, 1984). Specific models of care have been proposed in the literature for diverse populations (Romeo, 2007). On the other hand, objections for a culturalist approach to home care (Culley, 1996) suggest that good quality care should be a product of every encounter between care provider and client.

In the city of Toronto, COTA Health provides home-based service to culturally diverse individuals (infancy to elderly) with rehabilitation and mental health needs. At the time of the study the service was provided at COTA Health and the same service is now provided by the VHA Rehab Solution, VHA Home HealthCare. COTA Health's global expected outcomes for occupational therapy service for mothers with premature infants include (1) an understanding of the strengths and the needs of the infant, (2) increased knowledge and skills to support the infant, (3) enhanced quality of interaction between parent and infant, (4) increased knowledge about relevant resources and better utilization of appropriate social supports and resources, and (5) increased competence in the care of the pre-term infant. The purpose of the occupational therapy service is to improve the infant's development (motor, sensory, social, cognitive) and improve functioning with feeding, and social interaction skills in the home setting and to enhance the quality of caregiver-infant interaction by building competence and self-efficacy.

Prematurity and Quality of Mother-infant Interaction

More than 350,000 premature infants are born every year in Canada and more than 480,000 in the United States (Canadian Institutes for Health Information, 2009; Hamilton, Martin, & Sutton, 2004; Statistics Canada, 2003). With the increased survival of preterm infants, there is a growing concern for their developmental and socio-emotional outcomes and their quality of life (Bregman, 1998).

There is a lack of studies of parents and infants with prematurity in immigrant groups. Most studies completed are based on Western infants' characteristics—that premature infants have more difficulties interacting with their mothers than healthy term infants (Goldberg & DiVitto, 1995), they initiate less interaction, show fewer positive affects, are less attentive, less organized, less alert, and less responsive than the full-term infant (Stevenson, Roach, ver Hoeve, & Leavitt, 1990), and have a poorer temperament throughout the first year of life (Hughes, Shults, McGrath, & Medoff-Cooper, 2002). Similarly, immigrant groups with premature infants have been relatively neglected in terms of studying issues related to parent-infant interaction. This is important because the varied cultural beliefs about child rearing make it a challenge to measure mother-infant interaction across groups.

Role of Culture and Parent-Infant Interaction

Culture refers to societal beliefs, values, and attitudes. Parent-infant interaction have been found to vary across ethnic groups (Bernstein, Harris, Long, Iida, & Hans, 2005). Cultural values inform parents' child-rearing beliefs and practices, which have important implications for child development and parenting practices (Kim & Wong, 2002; Tajima & Harachi, 2010). Parenting beliefs of immigrant families of infants with prematurity living in Canada are not well understood, nor is the role of acculturation on parents' child rearing practices (Foss, 1996; Johnson, 2007). Few studies have examined the parent-infant interaction and parenting approaches among immigrant South Asian and Chinese mothers. Studies that would address this gap in knowledge are important because Chinese is the largest immigrant group in Canada, followed by South Asians (Maiter & George, 2003).

The Chinese and South Asian parents have different beliefs on parenting. There is evidence of both cultural groups retaining their cultural beliefs after immigration. For instance, families from South Asia have maintained infant massage, a traditional child-rearing practice in South Asia (Darmstadt & Saha, 2002). In a study of parenting among immigrant Canadian mothers from South Asia, Maiter and George (2003) found that mothers' parenting goals and practices were particular to the context of immigration and were perceived to help their children adapt to the new social environment. Chao (2000) compared the Chinese and Euro-American mothers and found that Chinese mothers adopted the training, authoritarian and permissive parenting styles, and socialization goals for filial piety. Bernstein et al. (2005) developed the Parent-Child Observation Guide in a study to evaluate the effectiveness of integrating mental health services into early childhood settings in the U.S. with 683 diverse immigrant and American families. The authors reported that they rewrote the item "Does child make eye contact with the parent?" to "Does the child act connected to the parent?" based on the Chinese informants who said that interacting with eye contact is not

common in Chinese culture. The different parental practices set the cultural contexts in which immigrant parents of premature infants feed, play with, and interact with their children.

The Study

To set the context, we review the design of the study prior to discussing its findings in relation to lessons learned. The impetus for the study was the uncertainty about how quality of interaction between preterm infants and mothers is influenced by the contextual elements in a home setting, such as the cultural background, family composition, and child-rearing beliefs, and how these contextual elements interact with the process and outcomes of home care professional services.

Design and Sample

Ethics approvals were obtained from the Community Care Access Centres in Toronto, COTA Health, and the University of Toronto. Community Care Access Centres have been integrated into the Local Health Integrated Networks in Ontario. This study was a mixed-methods study. Interviews, videotaping, and the use of rating scales were used to explore the experiences of mothers of preterms and to measure changes in the quality of mother-infant interaction and motor development of the infant. Using a convenience sampling strategy, we selected eligible preterm infants and their mothers from five Community Care Access Centres (CCACs) in Toronto. Eligible infants were between 0 and 12 months corrected age at the time of referral to receive occupational therapy services in the home by COTA Health occupational therapists. Infants who were medically unstable, that is, those with uncontrolled asthma; who were in and out of hospital frequently, on cardiovascular monitoring, or on a ventilator; and infants with uncontrolled seizure or a history of uncontrolled seizure were not included in this study.

For the purposes of this study, prematurity was defined as less than 37 weeks gestation at birth (World Health Organization, 2005). We included South Asian and Chinese immigrant mothers and Canadian mothers whose primary home language was English, Chinese, or Tamil.

Procedures

We held discussions with home visiting occupational therapists who worked for COTA Health and asked them to distribute a flyer about the study to eligible families as they made their home visits. Interested mothers phoned the project coordinator or a Tamil- or Chinese-speaking research assistant for more details or to volunteer to participate. Because there was a research assistant who spoke the same language, from the same cultural community as the participants, mothers were more apt to share their stories. Skaff et al. (2002) and Marin and Marin (1991) also found this to be true when doing research with other cultural groups. Informed, signed consent was obtained prior to commencing the study. The researchers had three consent forms: one translated into Chinese, one translated into Tamil, and one in English. We believe that having separate consent forms played an important role in recruitment.

Each mother-infant dyad was interviewed twice and videotaped twice, initially and at six months. The project coordinator followed a videotape protocol to instruct the mothers to perform three activities: (a) 5 minutes of mother-infant free play, (b) 5 to 10 minutes of the mother positioning the infant in different positions, and (c) 20 minutes of the mother feeding the infant. In order to explore the relationship between the natural environment and mother-infant interaction, mothers were encouraged to (a) use the usual toys to play with their babies in a place they normally played and (b) feed their babies in their usual way (i.e., breast feeding or bottle feeding) in a place and time they usually fed the babies. A videographer assisted with setting up and videotaping the sessions. Two research assistants, one fluent in Chinese, the other in Tamil, assisted with each interview and videotape visit made to Chinese- or Tamil-speaking participants. The research assistants also scheduled the visits and acted as interpreters if needed. The tapes were later rated by two trained raters. Between research visits, the infants and mothers continued receiving their regular occupational therapy services in the home. The duration and frequency of these visits were determined by the service funder (i.e., the local CCAC) and the occupational therapist from COTA Health.

Quantitative Data Collection

Alberta Infant Motor Scale (AIMS).

In this study, the AIMS (Piper & Darrah, 1994) was used to measure infant movement performance. The AIMS is an assessment designed to measure motor development of infants aged 0 to 18 months. The psychometric properties of the AIMS are well established. It was tested with a group of Chinese preterm infants in Taiwan and showed good intra-rater and inter-rater reliabilities (Jeng, Yau, Chen & Hsiao, 2000).

Parent-Child Early Relational Assessment (PCERA).

The PCERA (Clark, 1985, 1999; Clark, Paulson, & Conlin, 1993) is an observational assessment that measures the quality of interaction between an infant and his or her caregiver. It was theoretically constructed with factor analyses on 379 healthy 4-month-old and 359 healthy 12-month-old infants (Clark, 1985, 1999). It consists of parent subscales, infant/child subscales, and dyad subscales. The psychometrics of the instrument are reported to be good. The PCERA has been used primarily in studies of African American families (Black, Dubowitz, Hutcheson, Berenson-Howard, & Starr, 1995).

Mother–Infant/Toddler Feeding Scale (MITFS).

The MITFS (Chatoor et al., 1997) is an observational scale designed to assess feeding problems during infant-mother interaction for children aged one month to three years old. The MITFS identifies parenting performance problems, infant-feeding performance, and malfunctioning interactions in the pair. The MITFS was used in this study to measure caregiver-infant interaction during infant-feeding performance. Inter-rater reliability was tested in a study of 40 infants ranging in age from 7 months to 3 years. There is good reliability and pre-

dictive validity reported for this tool. The scale was validated on a sample of 97% Caucasians and African Americans and 3% Asians or Hispanics.

Qualitative Data Collection

One week after the mothers were videotaped with their infants, a research member showed the mothers the clips of the video and interviewed them. The in-depth interviews took place in the home in a place chosen by the mother and lasted approximately one hour. They were asked about their thoughts and feelings while they watched the clips. After the video viewing, the mothers were asked to tell stories about their cultural values and family beliefs, what they thought about their role in caregiving and child rearing, and what they thought of the occupational therapy and other services they received. The interviews were audio-taped.

Reflective memos were written following each visit to record the contextual base of the interviews, including the physical surroundings, profile of mother and infant, and observed interactions between the infant and mother. After each visit, the interviewers met with the second author (TC) to debrief and reflect on the interview contents, mothers' responses, and interviewers' reactions pertinent to the research questions. The audiotapes of interviews were transcribed (and translated) verbatim. The qualitative data analysis software program Atlas.ti version 5.2 was used to analyze the interview transcripts, videotapes, and memos. Across cases, we looked for recurrent themes, emerging patterns, and negative cases. The research team generated thematic codes at reflection meetings, refined the codes, interpreted the recurring themes, and defined meanings.

Strategies That Worked and Lessons Learned

Study Approach

We used a mixed-method design. To collect quantitative data, we used a pretest-posttest design and validated instruments to measure the change of scores over time. We also used qualitative interviews and focus groups to understand the experiences and perspectives of the mothers of preterm infants. Fitzgerald (2006) suggested that when conducting cross-cultural research with infants, we need to address the issue of the observer's culturally constructed theory of mind. (p. 613)When the observers are trained to observe based on a theory generated from the Western cultural context, they may not be sensitive to the different set of cultural values and beliefs of the individuals being observed. Cross-cultural studies of cognitive development addressed this issue by acquiring ethnographic knowledge to help the researcher to understand "why certain cognitive skills are valued by particular cultural groups in particular ways" (Maynard, 2008, p. 61) instead of imposing the value of the Western culture. The use of a qualitative inquiry approach has enriched our understanding of children's development in their cultural context (Fitzgerald, 2006).

In this study, the qualitative approach has allowed us to gain a deeper understanding of the relationship between cultural context and the mother-infant interaction of preterm infants and their mothers. We used an interpretive grounded theory approach to critically inquire about the mother-infant interaction and the cultural context. Analytic tools included interview transcripts, focus group transcripts, analytic memos, and debriefing meetings. The thematic analysis focused on the meaning of cultural influences on the quality of infant-mother interaction in the family context. Key themes were the occupational therapist's role, the cultural beliefs of the family, the transformation process of the mother and the infant, and the home context. A conceptual model that theorized the relationship among these themes has been reported elsewhere (Reid, Chiu, Sinclair, Wehrmann, 2007a, 2007b).

Team Members

Assembling an ethnically diverse research team allows cultural sensitivity and competence to be built into the planning stages and study design. One investigator (TC) is a Canadian Chinese and another investigator (DR) had the experience working with the local Tamil community. We recruited one-Tamil speaking and one Chinese-speaking research assistant to be the interpreter during the assessment, conduct the qualitative interview, and act as the cultural advisor. We provided training and supervision to the ethnic research assistants to sensitize them to the importance of linguistic and cultural translation when interpreting the findings. Because we did not have an investigator with Tamil background in our team, we formed a Tamil Advisory Committee to provide consultation in the procedure and assist with the interpretation of the findings. The Advisory Committee consisted of three Tamil-speaking occupational therapists at COTA Health and the Tamil-speaking research assistant on this study.

Recruitment and Sampling

Recruitment was a challenge. A sample size calculation was performed and the results showed that recruiting 30 families (10 Chinese, 10 Caucasian, and 10 Tamil) was sufficient. However, by the midpoint of the study the sample obtained was small (8 Caucasian and 2 Chinese mother-infant dyads) due to difficulties in recruiting Chinese and Tamil families. The primary caregivers within the dyads were all the biological mothers of the infants.

The recruitment strategy and planned procedures with the families was reexamined. One of the first important lessons was to communicate with the ethics committee that the diverse cultural groups would not all respond to our recruitment methods in the same way. Although when we designed the study we were aware of the reluctance of the Tamil families to provide consent without prior contacts with the researcher, the Ethics Committee did not approve our design to approach potential participants before obtaining their consent. As the study progressed and more evidence was available to show that the proposed recruitment strategy was not working, several changes to the ethics protocols were made to modify our procedures to address the cultural sensitivity issues with the Tamil and Chinese communities. The Ethics Committee approved the revised protocol.

Procedure

Several modifications of the procedure were undertaken to improve the reluctance of the Tamil community to take part in the study. Firstly, we removed the videotaping procedure for the Tamil families because it was not considered culturally appropriate. Tamil families of premature infants did not feel comfortable with exposing the realities of having and caring for their babies on a video camera. Second, the Tamil-speaking research assistant was introduced by the attending occupational therapist to the participants. The Tamil Advisory Committee suggested that Tamil-speaking Canadians required personal contact with someone from their community before they would be willing to be interviewed. In the revised procedure, we invited the Tamil-speaking occupational therapists to approach potential participants by phone. If the families agreed to participate, the occupational therapist and the Tamil-speaking research assistant jointly made a befriending visit. During the befriending visit, the occupational therapist introduced the research assistant to the family and obtained their consent. Third, we engaged the participants through the use of "gentle talks" at a pace that was appropriate to their culture. During the visit, the research assistant explained the study to the family and answered any questions they might have had, obtained a written consent, and collected nonsensitive, concrete information such as sociodemographic information about the infant and parents. The "gentle talks," described by the Advisory Committee as an important engagement process, helped the research participants to develop trust in the researchers. The visit lasted for about 30 minutes. Three Tamil families agreed to these interviews.

Although the revised protocol was successful in recruiting more Tamil families, there were not sufficient data to answer the research question. We decided to conduct focus groups with mothers of healthy babies from the Tamil and Chinese communities to explore the mother-infant interaction during play in each ethnic group. In the Tamil community, nine families with infants between 6 and 24 months participated. The focus group participants viewed a 5-min video clip of a Caucasian infant playing with his mother and another 5-min clip of a Tamil baby playing with his mother. They were facilitated to share their stories of child-rearing practices, comparing and exploring the similarities and differences in play between the two cultures. Similar focus groups were conducted in the Chinese community using the same procedure, but the Tamil baby video clip was replaced by a Chinese baby video clip. Ethics approval was obtained. The modified procedure provided valuable information about the characteristics of play behaviours in each cultural group.

Quantitative Instruments

Care was taken to select measures that would be appropriate across diverse groups of participants. We selected the PCERA (Clark, 1998, 1999; Clark et al., 1993), and the MITFS (Chatoor et al., 1997) as parent-infant interaction measures. We also used the AIMS (Piper & Darrah, 1994) for rating motor development. These outcome tools were selected as they had included preterm or term infants with different ethnic backgrounds in the sample (Black et al., 1995; Burns, Chethik, Burns & Clark, 1998; Clark et al., 1993; Grych & Clark, 1999; Kivijärvi et al., 2001). These instruments were considered the best available to evaluate the variables of interest.

In this study, the raters did not report any issues that was caused by the child's cultural background when rating the motor development (measured using the AIMS). Early cross-cultural Piagetian studies have found that the sensorimotor developmental period of the infants was likely to be universal (Maynard, 2008). However, the PCERA and the MITFS, which measure mother-infant interaction, were less satisfactory. During the team meetings, the research team (including the raters, research assistants, project coordinator, and the investigators) discussed the validity of many items and issues related to cultural norms that were possible confounds in the rating of specific items. We reflected on which cultural perspective we should use when rating the items and questioned whether the administration methods were linked to the cultural practices. We also reviewed current literature to assist with the interpretation. Recent approaches with cross-cultural children focus on studying which concepts and skills are useful and important in a particular culture instead of imposing a Western theoretical construct to interpret the observations (Maynard, 2008). After much reflection, we decided not to interpret the findings according to the rating scales that were constructed based on a Western cultural context. Instead, we focused on the interpretation of the meaning and experience of mother-infant interaction using a critical qualitative inquiry approach. The finding of the qualitative inquiry has been reported elsewhere (Reid et al., 2007a), and the qualitative approach has yielded useful and important concepts of mother-infant interaction.

Conclusion and Implications

This article reinforces the importance of being culturally sensitive when doing research with diverse samples. We have demonstrated how to be critically reflective in the research design and in changing the protocol midstream to improve the engagement of cultural groups. Openness, flexibility, and willingness to learn various points of view have strengthened our understanding of how culturally diverse mothers spent time caring for their premature and term babies and how their beliefs shaped their behaviors. We have proposed seven methodological considerations in Table 1 on the basis of the strategies that have worked in this study and the lessons we have learned. The consideration begins with choosing an appropriate design approach to the formation of the research team, continuing with a clear understanding of the research constructs, methodological awareness, and ethical considerations. Experimental design alone cannot produce credible findings if the instrument has not been validated with the cultural group being studied. A qualitative research approach or mixed method design allows researchers to learn what is important to the study participants and use what they have learned to design the study, engage the participants, and interpret the findings in a culturally appropriate way.

Table 1
Methodological Considerations When Designing a Study That Involves Culturally Diverse Families

1. Study approach
   - Is the study approach appropriate for the particular cultural context?
   - How do we appraise the influence of the cultural context?
2. Team members
   - How knowledgeable are the investigators with the cultural group?
   - Are the investigators open to cultural values that are different from theirs?
   - Are additional team members or an advisory committee needed to contribute to the design, implementation, and interpretation?
   - Are the ethnic team members aware of the differences between linguistic and cultural translation?
3. Recruitment and sampling
   - How do the participants perceive the researcher(s) and research process?
   - What variations of sample can be recruited to answer the questions of cultural characteristics?
4. Procedure
   - What needs to be modified in the research procedure on the basis of the cultural meaning experienced by the participants when participating in the study?
   - How does one engage the participants by showing respect and understanding of their cultural values?
5. Measurement tool (quantitative measures)
   - Has the instrument been validated with the cultural group in the study?
   - If the best available instrument has not been validated with a particular cultural group, how would the administration procedure and scoring method be influenced when used in the cultural group?
6. Analysis and Interpretation
   - Have we imposed our own cultural values in the interpretation of the findings?
   - Have we fairly represented the cultural picture without overgeneralization?
7. Ethical considerations
   - What culturally sensitive adaptation is required in the consent procedure to ensure different cultural groups are fairly represented in the study?
   - How to present the cultural characteristics that require special arrangement of consent procedure to the ethics review boards?

Key Messages

- Qualitative research can complement quantitative findings and sensitize researchers to the potential influence of cultural background on findings.
- Using parent-infant interaction instruments validated with a Western cultural construct is problematic with cultural groups who have different views of important interaction.
- Including researchers from the same ethnic group as the study participants helps to connect the participants throughout the study and ensures the cultural relevance of the study design and findings.

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