CULTURAL ADAPTATION OF A CHILDREN'S PARTICIPATION MEASURE

YOUNG CHILDREN'S PARTICIPATION AND ENVIRONMENT MEASURE (YC-PEM): CROSS-CULTURAL ADAPTATION AND PSYCHOMETRIC EVALUATION IN CHILDREN WITH AND WITHOUT DEVELOPMENTAL NEEDS IN SINGAPORE

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TITLE: Young Children's Participation and Environment Measure (YC-PEM): Cross-cultural adaptation and psychometric evaluation in children with and without developmental needs in Singapore

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Abstract

Young Children's Participation and Environment Measure (YC-PEM): Cross-cultural adaptation and psychometric evaluation in children with and without developmental needs in Singapore

Measuring the participation of young children is important in informing their health and well being and designing rehabilitation services. To our knowledge, there are no participation measures that have been developed or adapted to the Singapore context. The Young Children's Participation and Environment Measure (YC-PEM) was developed in North America and its content may not be relevant to the Singapore context. Three studies were conducted to culturally adapt and validate the YC-PEM with children with and without developmental needs in Singapore. These studies involved (1) adapting the YC-PEM culturally based on interviews with 10 service providers and 10 parents, (2) evaluating the psychometric properties of the adapted YC-PEM with 151 children with and without developmental needs in Singapore and, (3) examining the validity and utility of the YC-PEM to describe and compare the participation patterns between children with and without developmental needs in their childcare/preschool and community environments.

The outcome of this dissertation is a culturally relevant and validated YC-PEM (Singapore) for young children with and without developmental needs, aged 0 to 7 years old. The YC-PEM (Singapore) could be used by service providers to provide participation-focused intervention and researchers to implement population-based research to improve the participation of young children in Singapore. New knowledge has been developed through the cultural adaption process of the YC-PEM. Firstly, it is important to adapt instruments culturally before they are used in a new culture, even when language translation is not required. Secondly, cognitive interviews were found to be useful in the cultural adaption process. Thirdly, participation and perceived environmental support differences were found between children with and without developmental needs in Singapore as well as children between Singapore and America. Cultural influences such as the society's political agenda and parental beliefs were hypothesized to have potential influence on the participation of young children.

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Table of Contents

List of Tables

List of Figures

List of Abbreviations

ANOVA: Analysis of variance

ANCOVA: Analysis of covariance

CHIEF-CP: Craig Hospital Inventory of Environmental Factors for Children

DCD: Department of Child Development

DSP: Developmental Support Program

DSM: Developmental Systems Model

EIPIC: Early Intervention Programs for Infants and Children

ICF-CY: International Classification of Functioning, Disability and Health – Children and Youth

KK Hospital: KK Women's and Children's Hospital (Singapore)

KT: Knowledge translation

KTA Framework: Knowledge-To-Action Framework

LSEd: Learning Support Educators

OPC: Occupational Performance Coaching

PEO Model: Person-Environment-Occupation Model of Occupational Performance

PEM-CY: Participation and Environment Measure for Children and Youth

P4C Model: Partnering for Change Model

RtI Framework: Response to Intervention Framework

US: United States of America

VWO: Voluntary Welfare Organisations

WHO: World Health Organization

YC-PEM: Young Children's Participation and Environment Measure

Declaration of Academic Achievement

This thesis comprises three studies, each presented in a version of what will be submitted as a manuscript of publication.

For all three studies, Chun Yi Lim defined the research questions, developed the study designs, applied for ethical approval through the Faculty of Health Sciences Research Ethics Board at McMaster University and KK Hospital Institutional Review Board in Singapore, applied for funding to implement the research, implemented the data collection process, conducted the analyses and prepared the manuscripts.

Dr. Law assisted with the refinement of the research questions, provided suggestions on the proposed methods and advised on the data collection process. She also assisted in interpretation of analyses and provided ongoing editorial support during manuscript preparation.

The co-authors held the following roles when these studies were conducted: Dr. Mary Law, Ph.D., co-author, was Professor Emeritus in the School of Rehabilitation Science at McMaster University; Dr. Peter Rosenbaum, Ph.D., co-author, was Professor in the Department of Pediatrics at McMaster University; Prof. Nancy Pollock, O.T., M.Sc., co-author, was Associate Clinical Professor in the School of Rehabilitation Science at McMaster University; and Dr. Mary Khetani, Ph.D., co-author, was Assistant Professor in the Department of Occupational Therapy at Colorado State University.

Chapter 2

This chapter contains a manuscript entitled “Establishing the cultural equivalence of the Young Children’s Participation and Environment Measure (YC-PEM) for use in

Singapore". The authors are: C.Y. Lim, M. Law, M. Khetani, N. Pollock, and P. Rosenbaum. The design, data collection, data analysis, and writing were planned and conducted from January 2013 to July 2014.

Dr. Mary Khetani contributed to the refinement of the research question, contributed to the data collection and interpretation of findings, as well as provided editorial comments regarding the manuscript and its overall organization of content.

Prof. Nancy Pollock contributed to the refinement of the research question, interpretation of findings, provided editorial comments regarding the manuscript and its overall organization of content.

Dr. Peter Rosenbaum contributed to the refinement of the research question, interpretation of findings, and provided editorial comments regarding the manuscript.

Chapter 3

This chapter contains a manuscript entitled "Psychometric evaluation of the Singapore Young Children's Participation and Environment Measure (YC-PEM)". The authors are: C.Y. Lim, M. Law, P. Rosenbaum, M. Khetani, and N. Pollock. The design, data collection, data analysis, and writing were planned and conducted from January 2013 to November 2014.

Dr. Peter Rosenbaum contributed to the refinement of the research question, study design, provided editorial comments regarding the manuscript, its overall focus and structure to increase its chances of being published in an international, peer-reviewed journal.

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Chapter 4

This chapter contains a manuscript entitled "Participation in out-of-home environments for young children with and without developmental needs". The authors are: C.Y. Lim, M. Law, M. Khetani, N. Pollock, and P. Rosenbaum, The design, data collection, data analysis, and writing were planned and conducted from January 2013 to January 2015.

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Chapter One: Introduction

1. Introduction

The World Health Organization's International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY) (2007) and UNICEF's State of the World's Children Report (2013) indicate that *participation in activities* is a fundamental indicator of children's health and well-being. In Singapore, the Enabling Masterplan for the Disability Sector 2012-2016 was developed to guide policy and program development for people with disabilities in Singapore. One of its visions is to empower people with disabilities to achieve full *participation* as an indicator of inclusion in our society (EM 2012-2016 Steering Committee, 2012). A framework has also been proposed to improve the quality of early intervention services for young children with disabilities (EM 2012-2016 Steering Committee, 2012). Given the emphasis on participation both internationally and in Singapore, there is an apparent need to measure and understand the participation of young children with disabilities in Singapore as an indicator of their health and well-being.

The Young Children's Participation and Environment Measure (YC-PEM) is a parent-report questionnaire developed in North America (Khetani et al., 2014a). The YC-PEM assesses for participation and environmental supports and barriers to participation for children 5 years and below in their home, childcare/preschool, and community environments. Since the types of activities in which children participate are dependent on the culture (Gallimore et al., 1993; Harkness et al., 2011), cultural adaptation and validation of the YC-PEM can help to ensure that survey content is relevant to parents of

young children residing in Singapore. Cross-cultural validation of measures typically includes language translation, content adaptation, and psychometric validation (Sousa & Rojjanasrirat, 2010; Guillemin et al., 1993). Since the first language of Singapore is English, the focus of this thesis was on YC-PEM adaptation and validation only.

In the remainder of this introductory chapter, I will provide a background and purpose of this thesis that includes description of the (1) concepts and theoretical assumptions underlying young children's participation and environment, (2) development of children's participation measures and the YC-PEM, (3) rationale for cross-cultural adaptation and validation of measures, (4) need for culturally relevant and validated participation and environment measures for use with young children in Singapore, (5) research objectives and thesis goals and (6) ethical considerations.

2. Young Children's Participation

Participation in activities and routines is important to the development of young children, as it provides them with opportunities to learn new skills, knowledge and build relationships that are meaningful and culturally valued (Larson & Verma, 1999; Harkness et al., 2011; Dunst et al., 2002; Weisner, 2002). Through participation, children also experience health and well-being, and develop a sense of personal identity (Law, 2002). Young children with developmental needs (i.e., motor skills, cognitive, language and social skills) participate less frequently and in fewer activities than typically developing children (LaVesser & Berg, 2011; Leung et al, 2011). Participation difficulties have been associated with several factors, including those related to the child (behavioural and social difficulties), the family (income, parental education levels, informal family support,

parents' confidence in managing child's behaviour) and the environment (social support, transportation) (Rosenburg et al., 2012; Khetani et al., 2012; Soref et al., 2011; Leung et al. 2011; LaVesser & Berg, 2011; Khetani et al., 2013). No studies have explored the participation levels of Singaporean children with developmental needs and the factors that influence their participation. A participation measure relevant to a cultural context can further enhance our understanding of the patterns and predictors of young children's participation in Singapore.

Culture has been related to children's development through the developmental niche theoretical framework that guides the understanding and analysis of how culture shapes child development (Harkness et al., 2007). The developmental niche has three subsystems (1) psychology of the caregivers (2) culturally regulated customs of childcare and child rearing, and (3) settings of daily life (Harkness & Super, 1992). Through the subsystems, the child learns the social, affective and cognitive rules of the culture (Super & Harkness, 1986). They form the cultural context of child development and mediate the child's developmental experience within the larger culture (Super & Harkness, 1986). Regular themes of the culture guide the development of a child from one culturally defined stage to the next (Harkness et al., 2007). Cultural forces predominantly determine parental preferences, values and beliefs about how children develop and these beliefs lead to opportunities or limitations on children's participation in activities (Harkness et al., 2011). This is particularly relevant for young children (whose parents typically organize their daily routines), the people they interact with, and the activities in which they participate (Law et al., 2006).

Through participation in these activities, children develop skills and learn the values and beliefs of the community (Harkness et al., 2011). For example, Lim et al. (2014) showed that Chinese children in Singapore, whose caregivers value having their child obtain a head start in academics, participate more in writing activities and were found to have higher visual-motor scores when compared to American children and children of other ethnic groups in Singapore. Similarly, Bartlett (1999) described that Bangladeshi children are expected to collect water from communal wells which are 30 minutes away, twice per day, because their homes do not have running water and indoor plumbing. Thus, collecting water is part of their daily routine and it affects their regular school attendance. Both examples illustrate how parental beliefs and family customs influence their primary occupations and how children participate in activities that shape the types of skills and knowledge that young children develop. The developmental niche theoretical framework recognizes that culture has an influence on children's participation and development, thus supporting the need to adapt the YC-PEM to the Singapore culture to ensure that its content is able to capture the participation patterns of young children in Singapore adequately.

3. Young Children's Environment

Participation in activities is closely linked to young children's environment, as participation occurs within a context that is heavily influenced by environmental factors ('participation in what, with who and where?') (King, 2013). Factors such as support from family and friends, availability of supplies, accessibility to information, weather conditions and the predictability of the setting have been associated with participation

restriction in young children (Khetani et al., 2012; Khetani et al., 2011; Rosenburg et al., 2012; Larson, 2000). The Person-Environment-Occupation (PEO) Model of Occupational Performance (Law et al., 1996) reflects the transactional nature of children, occupations and the environment, as they develop. Occupational performance is the act of *doing* an occupation, which is the outcome of an interaction between the person, environment and occupation to support the tasks, activities, and roles that define the person as an individual (Christiansen & Baum, 1997). Thus, occupational therapists think of participation as an individual's experience of participating in occupations that are personally significant and meaningful (Law et al., 2006). The outcome of participation is similar to the outcome of occupational therapy, that is, occupational performance (Law et al., 2006). There is a lack of literature examining the relationship between occupational therapy models of practice and the concept of participation despite enabling participation of our clients being the main objective of occupational therapy (Hemmingsson & Jonsson, 2005). As enablers of participation, it is essential that we deepen and broaden our knowledge of the process and outcome of participation within the environmental and cultural contexts in which children's activities occur (Law et al., 2006) and also how our existing models of practice support participation (Hemmingsson & Jonsson, 2005).

Since the concept of occupational performance is similar to participation, successful participation is an outcome of an adequate 'fit' between children, their occupations and environments (Law et al., 2006). Law et al. (2006) suggested that we use an ecological approach to facilitate children's participation because physical, social, cultural and institutional environments are important elements to enable participation.

Thus, it is important to measure participation together with environmental affordances and barriers to participation so that we can intervene and ensure a good 'fit' between children, their occupations and environment. Moreover, environments are often overlooked during interventions to support children's participation, so there is a need for a detailed assessment of environmental influences on participation (Anaby et al., 2013; Anaby et al., 2014).

4. Development of Children's Participation Measures

The ICF-CY regards participation as the most important functional outcome to children and their families and should be evaluated as an important goal of rehabilitation interventions (Coster & Khetani, 2008; Simeonsson et al., 2003). Despite its importance, Dunst et al. (1998) found that the majority of early intervention providers do not address goals related to participation in home and community activities. Khetani et al. (2013) suggested that this is because service providers do not know how to intervene to improve participation due to a lack of knowledge and tools to inform factors that influence the participation of children. Existing measures used in paediatric rehabilitation focused more on body functions and activity limitations and less on participation (Brown & Bourke-Taylor, 2014; Simeonsson et al., 2003; Adolfsson et al., 2011). Since the introduction of participation within the ICF framework, the number of participation measures has increased. However, they may not be consistent and accurate in measuring participation due to the ambiguity of ICF's definition of participation. The ICF defines participation as "a person's involvement in life situation (WHO, 2007, p. 213)" and the ambiguity of the definition of "life situation" has made it a challenge to ensure that instruments are

measuring the construct of participation in a valid manner (Coster & Khetani, 2008). There is consensus that the ICF-CY cannot be easily used to guide measurement development in this area (King, 2013). In response, researchers have attempted to differentiate the constructs of participation and activity in children but uniform consensus has yet been achieved (Granlund, 2012, 2013; King, Rigby & Batorowicz, 2013; Coster & Khetani, 2008).

Ambiguity about the ICF concept of participation has resulted in an alternative approach to develop participation instruments. This approach includes (1) gaining the perspectives of stakeholders to propose a working definition for children's participation (Hammel, et al., 2008; Coster et al., 2012; Khetani et al., 2013) and to inform the initial design of the new measure (Coster & Khetani, 2008; McConachie et al., 2006), (2) clearly documenting the measure development process (Coster et al., 2012) and, (3) after its initial validation, systematically linking items in the new measure to the ICF on an item-by-item basis for conceptual clarification and comparison of content coverage among measures (Coster & Khetani, 2008; Simeonsson et al., 2003). Coster et al. (2012) used this alternative approach to develop the Participation and Environment Measure for Children and Youth (PEM-CY). A working definition of the concept of children's participation, "involvement in sets and sequences of organized activities directed towards a personally or socially meaningful goal (Coster & Khetani, 2008, p. 643)" was first proposed based on prior literature and parent input (Coster et al., 2012). Parent input also helped to (1) identify relevant sets and sequences of activities and environmental factors, (2) identify dimensions to include in the measure, and (3) affirm that the measure should

include the concept of environment as the concepts of participation and environment have a strong interrelationship (Bedell et al., 2011). The decisions made during the measure development process, including the validation process, were clearly communicated through publications (Coster et al., 2012; Coster et al., 2011). Chien et al. (2014) then compared the items of 16 children's participation measures in terms of their fit with the ICF-CY and the PEM-CY was assessed to have an 88% fit.

5. Development of the YC-PEM

Researchers have developed some young children's participation measures, mostly for clinical assessment. However, they do not meet the criteria of consistency with ICF concepts and are either limited in age range (Assessment of Preschool Children's Participation) or are time-consuming (Preschool Activity Card Sort, Routines Based Interview). Existing measures focus on either participation (Child Participation Questionnaire) or environment (Environmental Restriction Questionnaire) and do not relate them together, despite their interrelatedness. Tables 1 and 2 briefly describe current participation and environment measures for young children.

Table 1: Description of Measures Related to Participation for Young Children

Measure	**Description**	**Administration**	**Age Range**	**Psychometric Properties**
Assessment of Preschool Children Participation (APCP) (Law et al., 2012)	Measures participation of preschoolers in the areas of play, skill development, active physical recreation and social activities	Parent-report questionnaire	2 to 5 years and 11 months	Internal consistency: 0.73-0.85 for diversity scores and 0.52-0.70 for intensity scores Construct validity: established for preschoolers with cerebral palsy

Child Participation Questionnaire (CPQ) (Rosenburg et al., 2010a)	Measures child's participation pattern in six areas of occupations	Parent-report questionnaire	4-6 years	Internal reliability: 0.79-0.90 Test retest reliability: 0.84-0.89 Convergent and divergent validity: established for children with developmental disabilities
Preschool Activity Card Sort (PACS) (Berg & LaVesser, 2006)	Measures participation in home, school and community activities	Parents/Child semi-structured interview with visual aid	3-6 years	Inter-rater and test retest reliability: studies completed and additional studies are in the process (LaVesser & Berg, 2011) Content validity: established
Routines Based Interview (RBS) (McWilliam et al., 2009)	Gathers information on the everyday activities, and events of children and families for early intervention planning	Semi-structured but detailed interview with specific steps with Parents Interviewer has to be trained	0-5 years	Validity: face validity established Lack empirical validity and reliability
Young Children's Participation and Environment Measure (YC-PEM) (Khetani et al., 2013)	Measures the child's participation in home, school/daycare and community activities and its environmental factors	Caregiver report questionnaire	0-5 years	Not known yet

Table 2: Description of Measures Related to Environment for Young Children

Measure	**Description**	**Administration**	**Age Range**	**Psychometric Properties**
Affordances in the Home Environment for Motor Development (AHEMD) (Gabbard et al., 2008)	Addresses the quality and quantity of factors in the home that are conducive to enhancing motor development	Parent report questionnaire	18-42 months	Internal consistency: 0.85 Construct validity: established with Portuguese and US families
Craig Hospital Inventory of Environmental Factors – Children and Parent Version (CHIEF-CP) (McCauley et al., 2013)	Measures environmental factors that influence activity and participation for children with disabilities	Parent reported questionnaire	2-12 years	Internal consistency: 0.76-0.78 Test retest reliability: 0.73
Environmental Opportunities Questionnaire (EOQ) (Doralp & Bartlett, 2013)	Measures the quality and variability in the home environment as it relates to the motor development of infants	Parent interview	0-12 months	Internal consistency: 0.79 Test retest reliability: 0.92
Environmental Restriction Questionnaire (Rosenburg et al., 2010b)	Measures parental perception of environmental restricting aspects to their children's participation	Parent report questionnaire	4-6 years	Internal consistency: 0.88 Construct validity: established with children with developmental disabilities

There appears to be a lack of measures that include the broad range of home, preschool and community activities, cover the 0 to 5 age range, combine assessment of

participation and environment, and can be easily completed within a shorter time frame (Khetani et al., 2014a). Such measures are required to conduct large-scale population-based research to determine the effectiveness of early intervention programs in improving the participation of young children with disabilities (Khetani et al., 2014a).

The YC-PEM (Khetani et al., 2014a) is a promising new instrument that was developed to address the issues described above. The ICF-CY (WHO, 2007) and the Developmental Systems Model (DSM) (Guralnick, 2005) emphasized participation as an important outcome for young children and they guided the decision to develop the YC-PEM. The DSM was developed to guide early intervention programs using principles of developmental framework, integration, and inclusion in the context of a multicomponent interactive system (Guralnick, 2005). The ICF-CY provides a common language to ease interdisciplinary understanding around participation and the DSM references participation as an outcome and provides guidance for early intervention service delivery (Khetani et al., 2011). The YC-PEM was modelled after the PEM-CY but for younger children 0 to 5 years (Khetani et al., 2014a). Similar to the PEM-CY, the alternative 4-step participation and environment approach mentioned above was used to develop the YC-PEM.

First, the working definition of young children's participation was proposed, "For infants and young children, participation as outcome is characterized by involvement in organized sets and sequences of activities that typically involve the presence and engagement of others. These life situations are setting-specific (e.g. home, community) and, in addition to promoting the learning and development of skills and capacities, may

serve an overarching goal of achieving health and sustenance and enjoyment and well-being (Khetani & Coster, 2008, p.2)."

The definition was formulated by drawing on four themes derived from interdisciplinary literature. These themes include (1) participation being setting-specific, (2) participation being temporal, (3) the outcome of participation is orientated towards three overarching goals (e.g. health and sustenance, learning and the development of skills and capacities, and enjoyment and well being), and (4) four factors of participation, which include organizational and staff attitudes and parent belief systems, activity settings or participatory learning opportunities, available resources and developmentally appropriate and family-centred practices (Khetani et al., 2011). Parents' perspectives then informed the initial design (content, scaling and layout) of the YC-PEM and they also suggested including activities and setting-specific qualities in environmental influences (Khetani et al., 2011). The study also found that parents use different strategies to promote participation and the strategies are direct ways to understand how environments influence participation. This supported the design of the YC-PEM to elicit information on parent strategy use specific to each setting, and this information may improve its clinical utility (Khetani et al., 2011).

Subsequent studies using data from a national longitudinal study of preschoolers with disabilities (Khetani et al., 2012; Khetani et al., 2013) further validated the decisions (1) about whether to combine assessment of participation and environment or (2) assess for environmental impact at the setting level; (3) it also identified the types of child, family and environmental factors that discriminated levels of participation. To prepare the

newly developed YC-PEM for field-testing, it underwent several rounds of testing using cognitive interviews to understand how respondents understood and interpreted the items (Khetani et al., 2014). The YC-PEM was then subjected to psychometric evaluation and results lend initial support for use of the YC-PEM in research to assess participation and environment of young children in their home, daycare/preschool and community settings (Khetani et al., 2014).

6. Strengths and Limitations of the YC-PEM

A unique feature of the YC-PEM is that it assesses young children's participation together with physical, social, attitudinal and institutional features of their home, childcare/preschool and community environments (Khetani et al., 2014a). It informs environmental affordances and challenges to participation in specific activities in a particular setting. Information about environmental influences on participation may provide essential information to service providers, preschool educators and policy-makers who are well positioned to help modify the environments to facilitate young children's participation outcomes. Another unique strength of the YC-PEM is its ability to elicit information about parent strategies in supporting young children's participation in a specific setting. Information about parent strategies provides insights about parenting practices and beliefs, thus offering service providers a starting point for intervention and better allowing them to encourage the integration of intervention into the daily routines and cultural context of families (Bernheimer & Weisner, 2007; Weisner, 2002). This enhances family-centred practice, which is an integral part of early intervention for children (Bailey et al., 2006; Guralnick, 2005; Carpenter, 2007).

The YC-PEM has been evaluated psychometrically (Khetani et al., 2014a). Internal consistency ranged from .68 to .96 for participation scales and .92 to .96 for environment scales for children with and without developmental disabilities and delay. Test-retest reliability ranged from .31 to .93 for participation scales and .91 to .94 for environment scales within a 2-4 week period. One of 3 participation scales and the environment scale demonstrated significant disability group differences across all 3 settings and all 4 scales discriminated between disability groups for the daycare/preschool setting. The YC-PEM was also found to be a valid caregiver assessment of the environment when significant associations were found for all items in all 5 ICF-CY environmental domains and small to moderate negative associations were found for 51 of 66 pairwise comparisons involving Craig Hospital Inventory of Environmental Factors – Child and Parent Version (CHIEF-CP) and YC-PEM environment items ($r=-.13$ to $-.39$; $P<.01$) (Khetani et al., 2014d). Because the YC-PEM has only been developed recently, evidence of its ability to differentiate patterns of groups of young children with and without disabilities in the home, childcare/preschool and community setting is emerging. There is evidence that the more established PEM-CY is able to differentiate patterns of groups of school-age children with and without disabilities in the three settings (Law et al., 2013; Coster et al., 2013; Bedall et al., 2013). The PEM-CY is beginning to produce evidence of its clinical utility at both the individual and group level. At the individual level, service providers suggested a decisional support algorithm for collaborative care planning using the PEM-CY (Khetani et al., 2014b). At the group level, the PEM-CY may hold utility for Health Impact Assessment to look for environmental impacts on

children's participation and thus guide decision-making in non-urban sustainable development projects (Khetani et al., 2014c).

7. Cross-cultural adaptation and validation of measures

Measuring the concept of participation and environment is important and the YC-PEM is a potential instrument to use to measure participation and environment of young children. However, measures cannot be automatically applied in another culture, as they may fail to reflect local customs, cultural understanding, language or expressions, resulting in inaccurate assessment of the population (UNICEF, 2013). For example, activities such as playing board games that are typically found in questionnaires to evaluate child development may not be appropriate in places where children do not routinely engage in these activities (UNICEF, 2013). Specific to participation measures, Stevelink & Brackel (2013) systematically reviewed the process of cross-cultural equivalence testing of participation measures and found that conceptualizations of participation vary across cultures. They concluded that participation instruments have to be culturally validated before they are used in a different context. The content and scaling of the YC-PEM was developed from the perspectives of American parents (Khetani et al., 2011). Since studies have shown that the types of activities in which children participate, and their environments, vary across cultures (Ullenhag et al., 2012; Harkness et al., 2011; Gallimore et al., 1993), it is important to adapt the YC-PEM to the cultural context to ensure that it accurately reflects the participation and environment of the young children in Singapore. Moreover, using measures that are similar conceptually and that are well-

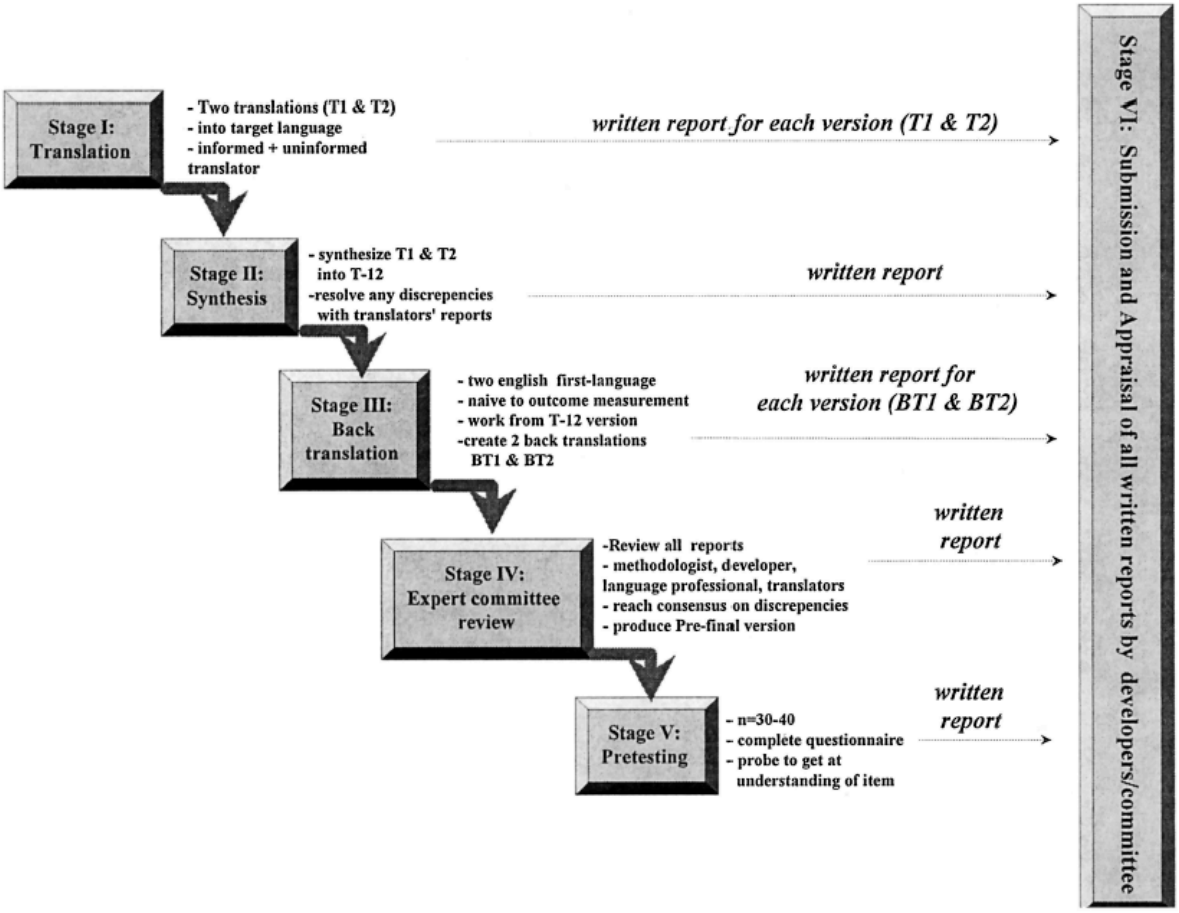
validated can lead to cross-cultural research to help us understand differences in participation between countries (Ullenhag et al., 2012; Sousa & Rojjanasrirat, 2010).

8. Methodological approaches to cross-cultural adaptation and validation

Cross-cultural adaptation and validation improves consistency in the face and content validity of the original and culturally adapted versions of a measure (Guillemin et al., 1993). The process of culturally validating an existing measure is often more efficient than generating a new measure (Guillemin et al., 1993) and a common approach has been developed to adapt and validate the content of existing measures so as to ensure its relevance for the new culture (Sousa & Rojjanasrirat, 2011). A review of 47 methodological studies focusing on the translation and validation of existing instruments for cross-cultural research found that there was a great discrepancy in the quality and methodological approaches of the reviewed studies (Maneesriwongul & Dixon, 2004). Sperber (2004) indicated that researchers have viewed cross-cultural validation of measures as an insignificant step of studies and few described the processes for the adaption and/or validation of the measures. Cross-cultural validation should be a comprehensive process that is clearly documented (Sousa & Rojjanasrirat, 2010).

For this dissertation, I used 'Guidelines of the Process of Cross-Cultural Adaption of Self-Report Measures' developed by Beaton et al. (2000) to guide the methodology (see Figure 1).

Figure 1: Graphic Representation of the Stages of Cross-cultural Adaptation (Beaton et al., 2000)



As translation was not required, I used only Stages IV (Expert Committee Review) and V (Test of the Prefinal Version and Further Testing of the Adapted Version). Stage V (Test of the Prefinal Version) has been modified from administering the questionnaire to 30-40 people using a probe technique to cognitive interviews with 10 people. Price et al. (2009) did a similar modification to the Beaton et al. (2002) guideline and found cognitive debriefing useful in cross-cultural translation and adaptation of disease-specific quality of life measures, as it improves the rigor of the methodology by assessing respondents' understanding and interpretation of questionnaire items. The

Beaton et al. (2002) guideline was chosen because (1) it was developed specifically for self-report measures; (2) it is based on a review of cross-cultural adaption in the medical, sociological and psychological literature, which is similar to the interdisciplinary literature from which the YC-PEM was developed; (3) it is designed to achieve semantic, idiomatic, experiential and conceptual equivalence between the source and target measures, and (4) it has been refined by research groups that utilized the guidelines to culturally adapt health-related measures, which provides evidence of rigor and effectiveness (Beaton et al., 2000).

9. The Singapore Context

This thesis reports on the work done to culturally adapt and validate the YC-PEM to the Singapore context. A locally developed participation measure is required to address the health challenges of young children in Singapore. The two main health challenges related to children in Singapore are myopia and obesity (Ministry of Health [MOH], 2012). Singapore has one of the highest rates of myopia in the world (MOH, 2012). In 2010, about 25% of children aged 6-7 had myopia (MOH, 2012). Obesity is also on the rise amongst school children in Singapore (MOH, 2012). In 2010, 7.4% aged 6-7 were overweight (MOH, 2012). These health challenges are often attributed to the high regard that parents and the education system place on scholastic achievement. Singaporean children spend more time participating in academic near-work activities (e.g. reading, screen time, etc.), which has been associated with myopia (Rose et al., 2008; Dirani et al., 2010). More time on academic activities may also lead to sedentary lifestyles and lack of physical activity amongst Singaporean children, resulting in obesity (Low et al., 2010;

Rose et al., 2008; Dirani et al., 2010; Schmidt et al., 1998). Evidently, these are health challenges faced by younger children, and these are linked to lifestyle, but we know little about lifestyle because we need valid measures to evaluate it. New tools are needed to build new knowledge about patterns in participation and environmental influences on participation and this dissertation validates the tool to build that knowledge.

Besides health challenges faced by all children in Singapore, the incidence of developmental needs among children younger than seven years in Singapore was estimated at about 7,000 (or 3.2% of the child population) in 2010 (Enabling Masterplan [EM] 2012-2016 Steering Committee, 2012). Between 2004 and 2010, the majority of young children who accessed early intervention services from the national Child Development Program were diagnosed with speech and language disorders (24-37%) and autism spectrum disorders (21-29%). Focus groups were conducted with parents of children with developmental issues to understand their needs (EM 2012-2016 Steering Committee, 2012). The parents raised concerns such as lack of knowledge, information, resources and services to support their children and the lack of public awareness and acceptance from society (EM 2012-2016 Steering Committee, 2012). These environmental barriers to inclusion appear to be of pronounced importance to parents and should be understood in greater depth and on a larger-scale. The development of a Singapore YC-PEM could measure parental perception of environmental barriers in the home and community, including policies, public acceptance and accessibility to various community supports on a larger scale (Khetani et al., 2014a). This can inform decision-

making amongst policy makers to provide an inclusive environment for young children with developmental needs in Singapore.

To empower families with children with developmental needs, the EM 2012-2016 Steering Committee (2012) highlighted the importance of family-centred care within early intervention. Ho (2007) also described Singapore's healthcare paradigm shift towards family-centred service and community-based care. Both acknowledged that empowering the community and families to support young children with developmental needs is essential to effective early intervention. Tang et al. (2012) also found that service providers in Singapore felt that they were not implementing family-centred service even though their beliefs and attitudes were family-centred. This may be due, in part, to the lack of culturally relevant, family-centred instruments in Singapore. The Singapore YC-PEM has the potential to enhance family-centred care, as it directly considers the viewpoints of parents and increases our understanding of the child's environment. Community-based service providers have found the PEM-CY useful in formulating care plans with families using a decisional support algorithm (Khetani et al., 2014b). The YC-PEM has potential to guide intervention planning with the family's needs as priority.

10. Research Objective

The objective of this thesis is to undertake a cultural adaptation of the YC-PEM to the Singapore context, evaluate its psychometric properties with children with and without developmental needs in Singapore, and use it to describe the childcare/preschool as well as community participation patterns of children in Singapore.

11. Thesis Goals

This introductory chapter provides the background and purpose of a thesis that describes the cultural adaptation and validation of the YC-PEM. The chapters in this thesis provide new knowledge about cultural adaptation of self-report participation measures, build on each other to develop the Singapore version of the YC-PEM and provide information about the participation patterns of young children with and without developmental needs in Singapore. Chapter 2 describes the cultural adaptation of the YC-PEM to the Singapore context using qualitative interviews with service providers and cognitive interviews with parents. Chapter 3 provides initial evidence of the reliability and validity of the Singapore YC-PEM when evaluated with children with and without developmental needs. Chapter 4 describes the ability of the Singapore YC-PEM to differentiate patterns of groups of young children with and without developmental needs in the childcare/preschool and community settings. It also describes their participation patterns and environmental barriers/supports in the settings.

12. Ethical Considerations

To conduct the work reported in Chapters 2, 3 and 4 of this thesis, ethical approval was obtained from Hamilton Health Science Faculty of Health Sciences Research Ethics Board at McMaster University and KK Hospital Institutional Review Board in Singapore. For the work reported in Chapter 2, involving interviews as part of the methodology, pseudonyms were used in transcriptions of the participants'

contributions to protect confidentiality. The original audiotapes as well as the contact information for the participants were stored in a locked cabinet in the project office to which only the investigators have access. For all the work described in Chapters 2, 3 and 4, a numeric ID was assigned to all participant materials for investigators to identify them and to protect confidentiality. Upon return of the forms, the investigator immediately separated the signed consent form from the number coded survey form, which ensured that the form could no longer be matched up with the data. The signed consent forms were stored in a locked cabinet in the project office, to which only the investigators have access. Informed consent was sought from all participants described in Chapters 2, 3 and 4 by ensuring that participants read and signed the informed consent forms.

13. References

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Chapter Two

Establishing the cultural equivalence of the Young Children's Participation and Environment Measure (YC-PEM) for use in Singapore

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This chapter contains a manuscript entitled "Establishing the cultural equivalence of the Young Children's Participation and Environment Measure (YC-PEM) for use in Singapore". This manuscript has been submitted to the Journal of Physical and Occupational Therapy in Pediatrics on 13 January 2015 and is currently under review.

Abstract

Aims: Establishing the cultural equivalence of clinical assessments is critical to ensuring culturally competent care. Developed in North America, the Young Children's Participation and Environment Measure (YC-PEM) is a caregiver questionnaire of participation in home, preschool, and community activities and perceptions of environmental impact on participation. The purpose of this study is to establish the cultural equivalence of YC-PEM content for use in Singapore.

Methods: We conducted semi-structured interviews with 10 early childhood and healthcare providers and cognitive interviews with 10 parents in Singapore to examine the relevance of original YC-PEM content (activities, environmental factors, item wording). Interviews were transcribed, summarized and categorized according to item, semantic, conceptual, and operational dimensions of the Applied Cultural Framework that served as a decision-making guide to keep, modify or delete the items.

Results: Providers and parents agreed on conceptual, item and semantic changes but less on operational changes. Significant changes were made to improve comprehension of the YC-PEM.

Conclusions: Despite using the same language, the majority of the YC-PEM items needed modification to be relevant to the Singapore culture. Cultural adaptation of the YC-PEM is important because there are cultural differences in children's participation, their environments as well as the way people understand words.

Keywords

Participation, environment, children, culture, adaptation, assessment

Main Text

Introduction

The incidence of disability among children younger than seven years in Singapore was estimated at about 7,000 (or 3.2%) in 2010 (Enabling Masterplan [EM] 2012-2016 Steering Committee, 2012). Between 2004 and 2010, the majority of young children who accessed early intervention services from the national Child Development Program were diagnosed with speech and language disorders (24-37%) and autism spectrum disorders (21-29%). The Enabling Masterplan for the Disability Sector 2012-2016 was recently developed to guide policy and program development for people with disabilities in Singapore, with the vision of empowering people with disabilities to achieve full participation as an indicator of societal inclusion (EM 2012-2016 Steering Committee, 2012). Toward this end, a framework has been proposed to improve the effectiveness of early intervention services in achieving full participation of young children with disabilities (EM 2012-2016 Steering Committee, 2012). However, little is known about the participation of young children with disabilities in Singapore and the effectiveness of early intervention services in helping them to achieve full participation. This may be due to the lack of participation measures in Singapore. There is a need for a participation measure that is relevant to the Singapore context to inform the participation patterns of young children with disabilities in Singapore. It could also be used as one of the outcome measures to ensure the effectiveness of early intervention services in Singapore.

Although English is the primary language in Singapore, Poon & Lim (2012) recommend that assessment content be culturally adapted to the Singapore context in

order to adequately measure the effectiveness of early intervention services on participation within this framework. To our knowledge, there are no children's participation measures that have been developed or adapted for use in a Singaporean context. The Young Children's Participation and Environment Measure (YC-PEM) is the first caregiver questionnaire to combine the assessment of both participation and environmental supports and barriers to participation for children 0 to 5 years with and without disabilities (Khetani et al., 2013b). The YC-PEM is a newly validated caregiver-report questionnaire for use in large-scale research in North America (Khetani et al., 2014a). Prior studies informed the design of the YC-PEM in terms of content (i.e., activities, environmental factors) and scaling (Khetani et al., 2012; Khetani et al., 2013; Khetani et al., 2011).

Psychometric evaluation of the YC-PEM revealed internal consistency of .68 to .96 for participation scales and .92 to .96 for environment scales for children with and without developmental delay (Khetani et al., 2014a). Test-retest reliability ranged from .31 to .93 for participation scales and .91 to .94 for environment scales within a 2-4 week period (Khetani et al., 2014a). Majority of the participation and environment scales discriminated between disability groups for all three settings and the participation scales demonstrated small to moderate correlations with functional performance scores (Khetani et al., 2014a). The YC-PEM can be filled out independently by caregivers, and captures a broad range of relevant settings (i.e., home, daycare/preschool, community) and environmental factors (e.g., physical layout, sensory qualities, time, money) that impact participation. The measurement approach of the YC-PEM is similar to the Participation

and Environment Measure for Children and Youth (PEM-CY) (Coster et al., 2011) in that participation and environment are assessed together in the same questionnaire, to afford for greater specificity in examining environmental impact on participation in the home, preschool and community settings (Khetani et al., 2014a). The YC-PEM is a relatively new measure compared to the PEM-CY, which was developed earlier and has been found to be useful in practice (Khetani et al., 2014b), research (Law et al., 2013; Coster et al., 2013; Bedall et al., 2013) and policy making (Khetani et al., 2014c). There is evidence that the more established PEM-CY is able to differentiate patterns of groups of school-age children with and without disabilities in the three settings (Law et al., 2013; Coster et al., 2013; Bedall et al., 2013). The PEM-CY has shown beginning evidence in its clinical utility at both the individual and group level. At the individual level, service providers suggested a decisional support algorithm for collaborative care planning using the PEM-CY (Khetani et al., 2014b). At the group level, the PEM-CY may hold utility for Health Impact Assessment to assess for environmental impact on children's participation and thus guide decision-making in non-urban sustainable development projects (Khetani et al., 2014c).

The Singaporean YC-PEM was the first to be culturally adapted from the original North American version. While the YC-PEM was developed to consider the viewpoints of parents of children of diverse ages, disabilities, and background, the content and scaling of the YC-PEM were based on the perspectives of North American parents (Khetani et al., 2011) and may not be relevant for Singaporean parents with young children. In a systematic review of cross-cultural equivalence testing of participation

measures for adults, Stevelink & Brackel (2013) found that it is important to understand variability in the conceptualization of participation across cultures and that cultural validation of participation measures is essential before they are used in a new culture. They used an adapted version of the Applied Cultural Equivalence Framework to guide the process of cultural equivalence testing of several participation measures for adults. This framework includes five categories of equivalence (conceptual, item, semantic, operational and measurement) and can be used to determine how equally suitable an instrument is for use in two or more cultures. This study used the adapted version of the Applied Cultural Equivalence Framework proposed by Stevelink & Brackel (2013) to guide the process of establishing the cultural equivalence of the Singapore YC-PEM. This framework was chosen because it was found to be useful in testing the cultural equivalence of participation instruments. This study focused on establishing conceptual, item, semantic, and operational equivalence. Future studies are underway to establish measurement equivalence.

[Insert Table 1]

Studies have also shown that culture shapes parental beliefs that shape the types of activities that children participate in at home and in the community (Ullenhag et al., 2012; Harkness et al., 2011; Gallimore et al., 1993). Several children's participation and activity measures have been culturally adapted to ensure the relevance of the measure to a specific culture (Costa, 2014; Bult et al., 2010; Ullenghag et al., 2012a; Ullenghag et al., 2012b; Stofel & Berg, 2008; Nordtorp et al., 2013). Cultural adaptation improves consistency in the face and content validity between the original and culturally adapted versions of a

measure (Guillemin et al., 1993). Adapting the YC-PEM to the Singapore cultural context may help to ensure that it accurately reflects the participation and environment of young children in Singapore. The objective of this study is therefore to develop a Singaporean version of the YC-PEM by establishing its cultural equivalence. This study is the first phase of a larger study that includes psychometric testing of the adapted version and exploring its utility.

Methods

Study Design. To establish the cultural equivalence of the YC-PEM, qualitative interviews were conducted with the original version of the YC-PEM to elicit provider and parent perspectives about the clarity and comprehensiveness of items. The purpose of the interviews was to improve on the cultural relevance of the questionnaire for use in clinical practice, so we engaged with providers and parents in Singapore who would likely be the primary users of the YC-PEM during baseline assessment in clinical practice. Face-to-face semi-structured interviews were conducted with providers in Singapore to gather item-by-item feedback. Face-to-face cognitive interviews were also conducted with caregivers of young children with developmental needs. Cognitive interviews assess respondents' interpretation and understanding of the items in self-report questionnaires, improving its content validity and reliability (Irwin et al., 2009; Knafl et al., 2007). The purpose of the cognitive interviews with the parents was to ensure that the content of the YC-PEM retained its equivalence to the original version from the perspectives of the study population.

Participants. Purposive and snowball sampling techniques were used to sample providers with diverse experience in terms of practice settings (e.g. acute, community), discipline (e.g. occupational therapist, psychologist, social worker, etc.) and professional background (e.g. educator, researcher, practitioner, etc.) We first approached providers from Singapore's leading referral centre for children with developmental needs, the Department of Child Development (the DCD) at KK Women's and Children's Hospital. Recruited providers then referred us to other providers with whom they work, from community agencies, universities and preschools. The inclusion criteria for the providers were at least 5 years of clinical, research or teaching experience in the field of early childhood. Table 2 describes the characteristics of the providers sampled.

[Insert Table 2 here]

Willis (1999) stated that cognitive interviews to improve on survey questions should focus on the diversity of individuals and not quantity. Parents were recruited through a series of sampling methods. First we used maximum variation sampling to accomplish diversity in the sample in terms of socioeconomic status (low, middle and high income) and child's age (0-2, 2-4, 4-6 years old). We then used snowball sampling to expand the recruitment. For this study, children with a presence of disability are children with developmental needs enrolled in early intervention programs. For parents of typically developing children, we approached providers from the DCD who knew of parents that fit our inclusion criteria. For parents of children with developmental needs, we distributed recruitment flyers at parent support groups, early intervention centers and the waiting areas of the DCD. Recruited parents then referred us to additional parents

who they thought would be willing to participate in the study. Finally, we used quota sampling by recruiting specific characteristics of participants whom socioeconomic status and age have not been represented for. The inclusion criteria for the parents were (i) they identified themselves as a parent or legal guardian of the child who was the focus of the survey; and (ii) they were able to read and write English; (iii) their child was between 0 and 7 years old at the time of the study. The YC-PEM was developed for children aged 0 to 5 in North America (Khetani et al., 2013b). However, in Singapore, young children who access early intervention services range from 0 to 7 years old. Therefore, our sample included children 0 to 7 years old. Table 3 lists the demographic characteristics of the parents.

[Insert Table 3 here]

Most parents identified two main caregivers of the child who was the focus of the survey. The parents who participated in this study were one of the main caregivers of the child. In Singapore, caregiving is often shared by the extended family (e.g. grandparents) and domestic helpers, who live together with the family.

Measure. Providers completed a demographic questionnaire and parents completed both the demographic questionnaire and the original version of the YC-PEM. The YC-PEM assessed caregiver perceptions of their young child's participation in broad types of activities that take place in the home (13 items, e.g., mealtime, cleaning up, indoor play and games, celebrations at home), daycare/preschool (3 items, e.g., group learning, socializing with friends, field trips and events), and community (12 items, e.g., dining out, classes and lessons, community attractions, overnight visits or trips) settings. The

caregiver was provided with examples of each type of activity. For each type of activity, the caregiver assessed three dimensions of their child's participation: 1) frequency (8-point scale, from never [0] to once or more each day [7]); 2) level of involvement (5-point scale, from not very involved [1] to very involved [5]; participants skipped this step if they selected "never" for frequency); and 3) their desire for change in the child's participation (yes [1] vs. no [0]). If yes, the caregiver clarified if change is desired in terms of frequency (i.e., more often or less often), level of involvement (i.e., more interactive and/or more helpful), and/or participation in a broader variety of activities of that type.

After completing participation items for a setting, caregivers evaluated the impact of types of environmental features (e.g., physical layout, sensory qualities, activity demands, social relationships, attitudes, safety, weather, policies) and resources (e.g., transportation, equipment and supplies, information, time, money) on the child's participation in that setting (13 items for home, 16 items for daycare/preschool, and 17 items for community). The caregiver was provided with examples of environmental features and resources. Perceived impact of environmental features on participation was assessed on a 3-point scale (no impact/usually helps [3] to usually makes harder [1]). Perceived impact of environmental resources on participation was assessed on a 3-point scale (not needed/usually yes [3] to usually no [1]).

YC-PEM summary scores are calculated for each setting: (1) *Frequency* is calculated as the average of all ratings within a setting (range = 0-7); (2) *Level of Involvement* is calculated as the average of all ratings within a setting (range = 1-5); (3)

Desire for change was calculated by summing the number of items scored as 'yes, change desired', divided by the total number of items, and multiplied by 100 (range = 0-100); and (4) *Environment support* was calculated by summing ratings across all environmental features and resources items and dividing by the maximum possible score, and multiplied by 100 (range = 0-100).

Procedures. Institutional Review Board approval was obtained prior to participant recruitment and data collection. Interested participants contacted the investigator who ensured that they fit the inclusion criteria before they signed the informed consent form to participate in the study. The participants decided on the date, time and venue of the interview. The providers' interviews were conducted first. Two weeks before the interview, the providers were emailed the interview questions, and the YC-PEM. They were encouraged to prepare before the interview by reading the questions and the YC-PEM. Interviews were conducted at the respective workplaces of seven providers and at the respective homes of three providers. After all the providers' interviews were conducted, cognitive interviews with parents were conducted with the original version of the YC-PEM. Two weeks before the interview, parents were emailed the interview questions, and the YC-PEM. On the day of the interview, parents completed the family demographic questionnaire, followed by the YC-PEM. After completing each page of the YC-PEM, the principal investigator utilized the verbal probing technique of cognitive interview (Knalf et al., 2007). Parents were probed to verbalize their interpretation of items and to paraphrase/comment on the wording of items to identify unclear or irrelevant questions. Interviews were conducted at the respective homes of eight parents, the

workplace of one parent and one parent was interviewed at the investigator's office. The principal investigator, who attended a class about cognitive interview as part of her PhD training, conducted all the interviews. Both providers and parents interviews were audiotaped and each interview took about 60-90 minutes. All parents were given a $10 shopping voucher after the interview. Table 4 describes the interview guide for providers and parents.

[Insert Table 4 here]

Data analysis. The guideline proposed by Knafl et al. (2007) was used to analyze the interviews and it included transcription of interview data, summarization of participants' interpretation of items and identification of types of problems, analysis of item summaries, and decision-making about items. All interviews were audiotaped and transcribed verbatim with the individual YC-PEM item as a unit of analysis. For each item, data was summarized across providers and parents with similar problems coded then mapped to the four dimensions of the Applied Cultural Equivalence Framework: Conceptual, Item, Semantic and Operational (Stevelink & Brackel, 2013). Summarized data from provider and parents for each item was systematically compared according to 1) areas of overlap between provider and parent perspectives; 2) item where one but not both, raised concern and; 3) items without any concern. The final analysis of each item provided an overview of range of interpretations, type of equivalence and supported the decision-making process to keep, delete or modify the items. The investigators, which included the author of the YC-PEM, reviewed and discussed the analysis of each item

until consensus was reached as to whether the item should be retained, deleted, or modified. Table 5 illustrates how an item was analysed.

[Insert Table 5 here]

Results

Results are organized according to the Applied Cultural Framework, namely conceptual, item, semantic and operational. In general, the participants understood the concepts of participation and environment. They also understood the main domains and categorizations of the YC-PEM.

[Insert Table 6 here]

Most content revisions were to establish item equivalence. Thirteen out of 28 participation items and thirteen out of 36 environmental items were modified. Most of the modifications were made to the examples of the activities that were perceived to be irrelevant to our context.

[Insert Table 7 here]

Despite using the same English language, 8 words and 4 phrases in the YC-PEM had to be modified to achieve sematic equivalence.

[Insert Table 8 here]

For operational equivalence, nine out of 10 providers commented that the YC-PEM's format and instructions were too lengthy and may be difficult for parents to understand. However, all parents could understand the instructions so there were no modifications made. For format, all parents felt that the presentation of some items was confusing and with their suggestions, we changed the sequence of some items to enhance

their understanding. For example, instead of starting the questionnaire with the activity 'getting rest' which parents were confused because it was difficult to quantify, we started with the activity 'mealtime' which has a frequency that is easier to quantify. For response options, specific to type of change desired, five out of 10 parents felt that they could relate more easily to 'more cooperative' than to 'more helpful' and we modified the response option as suggested. Other operational modifications made were increasing the font size and making some words bolder.

Discussion

Importance of cultural adaption of measures

Our study found that it is important to establish cultural equivalence of participation measures before they are used in another culture even without translation. Despite using the same language, most parents in this study had difficulty understanding some parts of the original YC-PEM. Evidently, some words and phrases were understood differently in different contexts. Singaporean parents also required more explicit examples to facilitate their understanding of items. Costa (2014) found that although there are many cultural commonalities in Western societies such as Canada, Australia and Europe, regarding cultural relevant activities for children, there were still a number of cultural adaptations required from the original version of the measure. Our study demonstrated that the types and emphasis of participation varied between Singapore and North America. For example, Singaporean parents in this study would like their children to be more 'cooperative' instead of more 'helpful'. This is aligned with Eastern cultures' emphasis on self-control and obedience (Lim, Rodger & Brown, 2013; Wong, 2008). The

addition of the item 'structured learning time' is aligned with Singapore's culture of introduction of learning tasks at an early age (Lim, Rodger & Brown, 2013). If the YC-PEM was not culturally adapted, essential information on Singaporean children's participation in structured learning time would not be captured, when it is such an integral part of their daily routine. The YC-PEM will thus be an invalid measure and the potential of the YC-PEM as a tool in assessing young children's participation and environment effectively will be lost.

To our knowledge, this is the first study that culturally adapted a participation and environment measure without language translation and documented its cultural adaptation process. Cultural adaptation studies often present psychometric properties of the translated version of the questionnaire but not results of the translation or how the items were culturally adapted (Ullenhag et al., 2012a; Nordtorp et al., 2013, Bult et al., 2010; Stofel & Berg, 2008). An exception is a study by Costa (2014) that translated and culturally adapted the Austrian-German Perceived Efficacy and Goal Setting System (PEGS) by interviewing 23 occupational therapists and a 14 year-old boy. Certain wordings were changed and culturally relevant activities added. Similar to our study, the author found that parents relate to activities that have sociocultural meaning to them and that their goals and expectations for their children's participation are influenced by culture, leading to meaningful occupations in the context of their children's environment (Costa, 2014). The author concluded that the process of cultural adaption is important in ensuring a culturally sensitive and responsive practice (Costa, 2014).

Similarities and differences between perspectives of providers and parents

Providers and parents in our study shared some similar perspectives about conceptual, item and semantic equivalence and made similar suggestions to modify the YC-PEM to enhance comprehension. However, providers and parents had differing perspectives of operational equivalence. Operationally, providers commented that the YC-PEM is lengthy, difficult to understand and suggested that parents are unlikely to complete it if they do not understand its importance. In contrast, some parents commented on the length but reported being able to understand items or suggested the use of more explicit examples to improve comprehension. It took about 20 minutes for parents to complete the original version of the YC-PEM (Khetani et al., 2014). In this study, the average duration to complete the YC-PEM together with the cognitive interview was about 60-90 minutes. A systematic review and meta-analysis of studies reporting response burden in relation to questionnaire length suggested that it is the content and not the length of the questionnaire that influences response rates (Rolstad et al., 2011). The more relevant the questions are to the patients, the more motivated they are to respond and time spent on completing the questionnaire may not be perceived as burdensome (Rolstad et al., 2011). Two parents of children without developmental needs did not find the information from the YC-PEM useful to them and thus might have experienced response burden. Comparatively, parents of children with developmental delay find the information from the YC-PEM useful to them and were motivated to complete it despite its length.

This supports the need for this study to improve on the relevance of the items and not focus on the length of the YC-PEM. It is also important for service providers to

educate parents on the need to complete the YC-PEM and for researchers to educate parents on the rationale of completing the YC-PEM in relation to the studies that they conduct. Parents also provided practical suggestions to modify the YC-PEM whereas providers provided comments on its potential utility in the areas of intervention planning and research. Evidently, providers and parents had distinct views and specialized areas of knowledge with regard to assessing the cultural relevance of the YC-PEM. Knalf et al (2007) found that feedback from providers helped assess the conceptual relevance of the measure while parents helped to assess the clarity and relevance of items to them. Our role as researchers is to utilize the input of these different expert sources optimally to successfully adapt the YC-PEM to this cultural context (Knalf et al., 2007). Similar to the findings in Price et al. (2009), this study also found that cognitive interviews are useful in allowing researchers to understand the thought processes of parents and yield evidence for establishing cultural equivalence of a measure, in addition to improving its reliability and validity (Irwin et al., 2009; Knalf et al., 2007).

Need for knowledge translation amongst providers

Our findings suggest that providers may have a more negative view about the utility of the YC-PEM than parents. Lim et al. (2014a) used the Knowledge-To-Action (KTA) Framework to understand the current assessment practice of occupational therapists in Singapore and to introduce the YC-PEM in a form of a research overview. They found that only 4 out of 25 (8%) Singaporean occupational therapists used participation and environment assessments while all used motor and visual-perception skills assessments. Occupational therapists in the study cited the lack of participation and

environment measures as a reason to not using them and all were interested in using the YC-PEM. However, in this study, providers appeared to have a more negative view about the utility of the YC-PEM than parents. One reason is that 7 out of ten of the providers were not occupational therapists and they may not see the need to assess participation and environment of children because their job scopes do not focus on the activities that children participate in. The psychologists, social worker and pediatrician felt that the YC-PEM was useful for occupational therapists that work with children with developmental needs and some of the early childhood educators felt that it is not useful for typically developing children. On the contrary, the YC-PEM could be a potential tool to assist educators in assessing children at risks of developmental delay in terms of their ability to participate like other children, particularly in the childcare/preschool setting.

Since providers play a key role in the uptake of the YC-PEM questionnaire in practice, their feedback can impact the uptake of the instrument in early intervention service delivery and outcomes research. In response, knowledge translation strategies should reach out to service providers beyond healthcare, such as early childhood educators, to increase their understanding of the importance of participation and environment in the development of young children. Knowledge translation strategies include sharing the YC-PEM and its related research through different platforms such as webinar, educational outreach, audit and feedback, interactive continuing education sessions and problem-based learning groups (Law et al., 2001; MacDermid & Graham, 2009). Alternatively, uptake of the YC-PEM in large sample research in Singapore may help to increase attention to this service outcome. For example, translate clinically

relevant knowledge based on the use of the tool (e.g. knowledge about disparities based on use of the tool, utility of the tool in patient care) to important stakeholders such as providers and parents to draw their attention to the importance of measuring participation (Graham et al., 2006). Several studies have used the PEM-CY to generate knowledge about participation and environmental differences between children with and without disabilities in the home, school and community settings (Bedall et al., 2013; Coster et al., 2013; Law et al., 2013) whilst Khetani et al (2014b) studied the utility of the PEM-CY for collaborative planning with parents of children with disabilities.

Limitations

Despite using various sampling methods, our sample had lesser children between 2-4 years old and therefore this age group was under represented. We also did not ensure that the sample was diversified in terms of types of disability so our sample lacked parents of children with physical disabilities. Parents of young children with physical disabilities may have different emphasis in terms of participation and environment. Due to time limitations, we did not sample until the data reaches saturation and assumed that we had sufficient data to culturally adapt the YC-PEM with the pre-determined sample size. More interviews with providers and cognitive interviews with parents could also have been conducted with the YC-PEM (Singapore) to ensure that the adapted version is culturally relevant.

Conclusion

Cultural adaption of instruments should be responsive to the meaning and relevance of the activities to the daily lives of children (WFOT, 2010). Despite using the same language as its original version, the majority of the YC-PEM items needed modification to be relevant to the Singapore culture. This study also informed the importance of establishing cultural equivalence of participation measures through involvement of different expert sources such as healthcare/early childhood providers and parents. Research is underway to examine the reliability and validity of the YC-PEM (Singapore). The YC-PEM (Singapore) has the potential to be used to conduct large-scale studies to build knowledge about patterns and predictors of young children's participation in Singapore as well as environmental supports and barriers to their participation. It also has the potential to determine the effectiveness of early intervention services in achieving full participation and societal inclusion of young children with disabilities in Singapore.

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Table 1: Adapted version of the Applied Cultural Equivalence Framework (Stevelink & Brackel, 2013)

Equivalence Categories	Definition of Equivalence
Conceptual	Relevancy of the underlying concept, domains and focus of the questionnaire to the new culture
Item	Acceptability of the items to the culture that the measure is being adapted in
Semantic	Transfer of meaning across languages
Operational	Suitability of the instructions, format and response options in the culture that the measure is being adapted in
Measurement	Equivalence of the psychometric properties of the adapted version of the participation measure

Table 2: Characteristics of Service Providers (N=10)

Characteristic		n
Professional background	Early Childhood Educator	3
	Occupational Therapist	3
	Psychologist	2
	Social Worker	1
	Pediatrician	1
Setting	Education	4
	Community	2
	Acute Hospital	4
Years of working experience	5-10	3
	>10	7
Parent of a child without disability	Yes	9
	No	1

Table 3: Characteristics of Parents (N=10)

Characteristic		n
Age	20-29	2
	30-39	8
Gender	Female	10
	Male	0
Race	Chinese	8
	Malay	1
	Indian	1
Annual income (SGD)	>90,000	5
	50,000-69,999	3
	30,000-49,999	2
Education level	Primary	1
	Secondary	3
	Polytechnic	1
	University	1
	Post-graduate	4
Main activity	Working full-time	2
	Working part-time and caring for family	7
	Caring for family	1
Child's age	0-2 years	3
	2-4 years	1
	4-6 years	6
Child's gender	Male	6
	Female	4
Child's diagnosis	Autism spectrum disorder	3
	Speech and language delay	2
	No diagnosis	5
Child's education settings*	Kindergarten	5
	Childcare	3
	Early intervention program	5
	No school	2
Child's main caregivers*	Mother	4
	Grandparents	4
	Domestic helpers	5
	Childcare	2

**Some children attend 2 types of education settings and have 2 caregivers*

Table 4: Interview guide for providers and parents

Questions related to:	Providers	Parents
YC-PEM in general	1. Can Singaporean parents understand the instructions of the YC-PEM? If no, how do you suggest we change them? 2. Potential of YC-PEM in measuring participation in Singapore? 3. To what extent do you think YC-PEM is clinically useful? 4. Any other comments or suggestions regarding YC-PEM and its use in Singapore?	1. How do you feel about the instructions? Are you able to understand them easily? If not, how do you suggest we should change it? 2. Do you think the information gathered from the YC-PEM will be useful to you in parenting your child? If so, please describe. If not, why not. 3. Any other comments or suggestions regarding YC-PEM and its use in Singapore?
Activity items	1. Do you think Singaporean parents can understand and relate to this item? If no, how do you suggestion we should change it? 2. Do you think Singaporean parents can relate to the examples given in this item? If no, how do you suggest we should change it? 3. Do you think the response options are appropriate for Singaporean parents? If no, how do you suggest we should change it? 4. Do think YC-PEM has covered a sufficient range of activities that typical Singaporean young children engage in? Are there any other activities that we should consider?	1. How would you interpret this activity? Is it relevant to you? 2. How would you interpret the given examples of the activity and are they relevant to you? 3. Please "paraphrase" the question or give suggestions to change it if you feel that it is not relevant to you. 4. Do you think the response options are relevant to you? If no, how do you suggest we should change it? 5. Do you feel that the YC-PEM has covered a sufficient range of activities that your child typically engages in? Are there any other activities that we should consider?

Environment items	1. Do you think Singaporean parents can understand and relate to this item? If no, how do you suggest we should change it? 2. Do you think Singaporean parents can relate to the examples given in this item? If no, how do you suggest we should change it? 3. Do you think the response options are appropriate for Singaporean parents? If no, how do you suggest we should change it? 4. Do think YC-PEM has covered a sufficient range of environmental supports and barriers associated to the participation of young children? Are there any other environmental factors that we should consider?	1. How would you interpret this item? Is it relevant to you? 2. How would you interpret the given examples of the item and are they relevant to you? 3. Please "paraphrase" the question or give suggestions to change it if you feel that it is not relevant to you. 4. Do you think the response options are relevant to you? If no, how do you suggest we should change it? 5. Do think YC-PEM has covered a sufficient range of environmental supports and barriers associated to the participation of your child? Are there any other environmental factors that we should consider?

Table 5: Example of analysis of an item

Item	Providers' comments	Parents' comments	Equivalence type	Decision
Indoor play and games (e.g. puzzles, workbooks, stuffed animals, cars, blocks, water and sand play, pretend play and dress-up, peek-a-boo, hide-and-seek and board games)	Children in Singapore do not play with sand at home due to physical constraints.	'Workbooks' should not come under indoor play and games, as they are academic-related. Children in Singapore do workbooks but for academic reasons and not as play and games. These workbooks are usually homework from school or enrichment classes that they attend.	Item	Removed 'sand-play' and 'workbooks' Added an additional item 'Structured learning time (e.g. school or enrichment classes homework, workbooks, assessment books)' because it is relevant to Singaporean children but missing from the original YC-PEM

Table 6: Conceptual equivalence

		Comments by:
Service Providers	Occupational therapists	"Clinically useful" "Too brief and vague for clinical usage" "Useful for research" "Useful for early intervention program evaluation" "Large survey may be difficult"
	Non-occupational therapists	"Clinically useful" "Useful for occupational therapists who work with children with developmental delay" "Useful to assess life skills of children" "Useful to gather a picture of family life of the child" "Not useful for typically developing children" "Useful for policy planning" "Useful for early intervention program planning" "Too long and parents may not see the need to complete this"
Parents	Parents of children with developmental need	"Tells me what my child is doing now" "Helps me to reflect on my child's environmental needs" "Helps me to understand my child better and what is happening in his life" "Helps me to reflect if he is doing too much of something or too little of something else" "Provides a bigger picture of what he does" "Helps me to think of what I want more for my son. For example, more community activities" "Gives me a better idea on which area to work more on"
	Parents of children without developmental need	"Not useful as I already know what my child does" "It is just informing what my child does" "Useful as it helps me to know what to improve on and what she is already good in" "Helps me to analyze my child better" "Puts things into perspective for me and has a better picture of what is going on in my child's life"

Table 7: Item equivalence

Item Equivalence	Original item	Modification(s)
Participation items		
Home participation	Cleaning up (e.g. picking up toys, throwing away trash, sweeping floor or wiping table, yard work)	Removed: yard work Added: tidy room
	Taking care of other family members (e.g. sibling, pet)	Added: grandparents
	Laundry and dishes (e.g. load, unload, sort fold or put away)	Added: washing dishes
	Indoor play and games (e.g. puzzles, workbooks, stuffed animals, cars, blocks, water and sand play, pretend play and dress-up, peek-a-boo, hide-and-seek and board games)	Removed: sand play and workbook
Daycare/preschool participation	Field trips and events (e.g. parent night out, going to the library, school concert or fundraiser)	Removed: parent night out, going to the library, fundraiser Added: museums, aquarium, gardens
Community participation	Shopping and errands (e.g. grocery, store, mall, post office, bank, pet store, car wash or auto repair shop)	Removed: auto-repair shop Added: supermarket
	Dining out (e.g. dine-in or take out meals, coffee shop)	Removed: dine-in or take-out meals Added: hawker centre, food court, restaurant
	Classes and lessons (e.g. music, art, language lessons)	Added: reading and mathematics lessons
	Organized physical activities (e.g. soccer, T-ball, gymnastics, dance, martial arts)	Replaced: T-ball with swimming
	Organization, groups, clubs (e.g. boy scouts, brownies/girl guides)	Replaced: Interest groups (e.g. Lego, reading, robotics)
	Community attractions (e.g. libraries and bookstores, museums, movie theater, aquarium, orchards, animal farms, petting zoos)	Replaced: orchards with garden, petting zoos with zoo
	Community events (e.g. festivals, fairs, parades, concerts, theatre, sporting events)	Replaced: theatre with community centre events
	Unstructured physical activities (e.g. playground and parks, beaches, hiking, bikes and scooters, sledding, fishing, ice skating)	Removed: sledding and hiking Added: swimming, beaches
Environment items		
Home environment	The physical layout (e.g. having organized, clean, safe space at home)	Added: no curbs

	The attitudes and actions of babysitters, therapists and other professionals who care for your child at home	Replaced: babysitter with domestic helper
	Policies (e.g. residential and workplace policies, such as family leave or working from home, time-off, hour hours)	Removed: residential policies
	Services in the home (e.g. therapists, babysitters, etc.)	Replaced: babysitters with domestic helpers
Childcare/preschool environment	Programs and services at the organized daycare or preschool (education assistant, special resources, etc.)	Replaced: special resources with learning support educators, school-based therapy
	Supplies (assistive devices, adapted toys, craft supplies, organic food choices, modular furniture, accessible bathrooms, classrooms and playgrounds, access to internet and technology to support learning)	Removed: modular furniture and 'organic' in 'organic' food choices
	Do you (and your family) have enough time to support your child's participation at daycare or preschool (e.g. paying tuition, purchasing supplies, participating in fundraisers)?	Replaced: participating in fundraisers with participating in extra classes or programs, purchasing costumes for school concert
Community environment	Physical layout or amount of space outside and inside the buildings (e.g. distance to stores, presence of sidewalks, availability of ramps or elevators)	Added: availability of nursing rooms
	Your child's relationships with peers	Added: cousins
	The safety of the community (e.g. traffic, crime, violence)	Added: dengue fever and hand mouth foot disease (HMFD)
	Policies (neighborhood, childcare and employer policies)	Replaced: Government, neighborhood, workplace policies, (e.g. flexible work schedule to afford for time to participate in the community)
	Programs and services in the community	Added: (e.g. community center programs and events)
	Information (e.g. about activities, services and programs)	Added: (e.g. brochures, newsletters, websites etc. about community activities, services, programs)

Table 8: Semantic equivalence

Semantic equivalence	Original item	Modifications
Words	Field trips and events	School excursions and events
	Daycare/preschool	Childcare/preschool
	Tuition fees	School fees
	Subway	MRT (Mass Rapid Transit)
	Movie theatre	Cinema
	Educational assistant	Assistant teacher
	Director	Centre supervisor/principal
	Trips/vacations	Trips/tours
Phrases	Please describe up to three strategies that you have tried to help your child participate in this type of activity.	Please describe up to three strategies that you have tried to help your child participate in this type of activity.
	The physical demands of typical activities	The physical skills required to do typical activities
	The cognitive demands of typical activities	The cognitive skills required to do typical activities
	The social demands of typical activities	The social skills required to do typical activities

Chapter Three

Psychometric evaluation of the Singapore Young Children's Participation and Environment Measure (YC-PEM)

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This chapter contains a manuscript entitled: "Psychometric evaluation of the Singapore Young Children's Participation and Environment Measure (YC-PEM)". The proposed journal of this manuscript is Disability and Rehabilitation. This manuscript is currently in an expanded format, and is yet to be submitted to Disability and Rehabilitation.

Abstract

Purpose

The Young Children's Participation and Environment Measure (YC-PEM) is a caregiver questionnaire that was developed in North America and has been culturally adapted for use in Singapore. This paper reports the psychometric properties of the YC-PEM (Singapore).

Method

Participants were caregivers of 151 Singaporean children with (n=83) and without (n=68) developmental needs, between 0 and 7 years. The YC-PEM has 3 Participation scales and 1 Environment scale. Each scale is assessed across 3 settings: home, childcare/preschool, and community. Data were analyzed to obtain estimates of internal consistency, test-retest reliability, and construct validity.

Results

Internal consistency ranged from .59 to .92 for Participation scales and .73 to .79 for the Environment scales. Test-retest reliability ranged from .39 to .89 for Participation scales and .65 to .80 for Environment scale within a 2-3 week period. Moderate to large disability group differences were found in participation and perceived environmental support.

Conclusions

Results indicate that the YC-PEM (Singapore) has potential to be used for population-level studies involving young children with and without developmental needs. It provides information about young children's participation patterns in specific settings,

environmental supports and barriers to participation, and parental strategies to promote participation in home, childcare/preschool and community-based activities.

Introduction

Participation in home, school and community activities is widely recognised as a key indicator of the health and well-being of children [1, 2]. Participation in activities with adequate support from the environment is foundational to optimal child and family outcomes [3, 4]. The development and use of the World Health Organization's International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) has led to increasing emphasis on participation and environment and efforts to develop instruments to measure these important constructs in children [3, 4]. Researchers in North America developed the Young Children's Participation and Environment Measure (YC-PEM) to address the need for instruments that measure both participation and environment of young children [5, 6]. To our knowledge, there are no such measures suitable for use in Singapore. Hence, formative work was undertaken to adapt the YC-PEM culturally for use in Singapore [7, 8]. This study evaluates the psychometric properties of the culturally adapted YC-PEM (Singapore) in young children with and without developmental needs in Singapore.

Background Information

During their early years, children participate in activities with support from their caregivers and with environmental adaptations and supports (e.g. child-size utensils). Caregivers of young children with disabilities often make significant modifications to their daily routines [6, 9] while encountering parenting stress and fewer environmental supports to promote their child's participation [10, 11]. Caregiver strategies and parenting practices are shaped in response to environmental supports and stressors. They are also

shaped by parental beliefs and expectations that can vary across cultural groups [12, 13]. Thus, perceptions about child's participation and environmental supports differ according to parental belief systems. Participation measures that have undergone cultural validation found that the variability in what caregivers do can be challenging to capture without culturally sound instruments due to variability in parental belief systems between cultures [14, 15]. Therefore, there is a need to culturally adapt and validate measures to capture the variability in caregiver perspectives of children's participation.

The prevalence of disability among children younger than seven years in Singapore was estimated at about 3.2% (or about 7,000 children) in 2010 [16]. Little is known about the participation levels of Singaporean children with developmental needs or the factors that influence their participation [17]. A participation measure relevant to this cultural context can further enhance the understanding of the patterns and predictors of young children's participation in Singapore. The Young Children's Participation and Environmental Measure (YC-PEM) is the only measure that simultaneously assesses participation and environment for young children [5]. It was developed because current participation measures for young children were either clinician-administered, individual-level assessments [18, 19, 20] or focus on a narrow age range [21, 22, 23], and do not include an assessment of the environment. Several studies informed the initial decisions of the content and format of the YC-PEM [6, 10, 24]. Results of these studies also affirmed the development of the YC-PEM for research and intervention planning to build comprehensive knowledge about young children's participation.

The Singapore version of the YC-PEM has been culturally adapted through interviews with professionals and cognitive interviews with parents [7]. The current study aims to examine the psychometric properties of the culturally adapted Singapore YC-PEM with young children, aged 0 to 7 years old, with and without developmental needs in Singapore. Although the YC-PEM was originally developed for children aged 0 to 5 years, Singaporean children can access early intervention services from 0 to 7 years [25]. Therefore, the YC-PEM was field-tested with children across a broader age range in this study. The purpose of this study is to establish its (1) internal consistency, (2) test-retest reliability, and (3) construct validity according to whether it can detect disability and age group differences, as well as negative relationship between environmental supportiveness and desire-for-change.

The psychometric properties of the original YC-PEM [5], Participation and Environment Measure for Children and Youth (PEM-CY) [26] and prior research about young children's participation or environmental measures [21, 23, 27] informed the study hypotheses. The study hypotheses are (1) the internal consistency of the YC-PEM is acceptable [alpha coefficient > .7]; (2) the test-retest reliability of the YC-PEM summary score shows fair to good agreement [intraclass coefficient values between .4 - .74]; (3) children with disabilities and younger children participate significantly less often and are less involved in activities than older children and children without disabilities; and (4) there is a negative association between perceived environmental supportiveness and parental desire for change.

Method

Participants. Using a prospective cohort study design, a paper version of the YC-PEM (Singapore) was field-tested with 151 caregivers of young children (83 with and 68 without developmental needs) in Singapore. A convenience sampling approach was used to recruit all the caregivers of young children aged 0 to 7 years. In Singapore, children with developmental concerns are referred to one of three government hospitals in Singapore with a child development unit (Lian et al., 2012). The developmental paediatrician assesses the child and refers them to an Early Intervention Programs for Infants and Children (EIPIC) for long-term early intervention services, run by Voluntary Welfare Organisations (VWO). Due to the VWO's manpower and resource constraints, the children are often placed on a waitlist before enrolment in EIPIC. While waiting, they are provided with interim therapy services at the government hospitals.

For this study, caregivers of children with developmental needs were recruited from a government hospital, KK Women's and Children's Hospital's (KK Hospital) Department of Child Development (DCD) and VWOs with EIPIC located at various geographical regions in Singapore. Caregivers of children without developmental needs were recruited from government-funded and private kindergartens. Caregivers met the following eligibility criteria: (1) they identified themselves as a parent or legal guardian of the child who is the focus of the survey; (2) they were able to read and write English; (3) their child was between 0 and 7 years old at the time of enrolment; and (4) children with developmental needs met the eligibility criteria for enrolment in EIPIC. Children were eligible for EIPIC if they were (1) below 7 years of age; (2) a Singapore citizen or

permanent resident; (3) diagnosed with developmental, intellectual, sensory or physical disabilities or a combination of disabilities; and (4) recommended for EIPIC by a doctor from one of the three government hospitals in Singapore with a child development unit [28].

Measures. Two questionnaires were administered to the participants.

Family Background Questionnaire. Participant demographic information was obtained from items addressing 1) family factors (e.g. employment, education), 2) household factors (e.g. type of housing, income), and 3) child factors (e.g. age, gender, and race). Participants also reported on their child's functional issues in 11 areas (e.g. paying attention, communication) using a 2-point scale (no problem [0] vs problem [1]).

Young Children's Participation and Environment Measure. The YC-PEM is a caregiver-report survey developed in North America for use in large-scale research and service planning [5]. It consists of 29 items, and the measure takes approximately 20-30 minutes to complete. The design of content (i.e., activities, environmental factors), and rating scales were informed by parent input and prior literature [5]. The YC-PEM is similar to the PEM-CY [26] in that participation and environment are assessed together in the same instrument. This measurement approach makes it possible to closely examine perceived environmental impact on home, preschool and community participation. Psychometric evaluation of the YC-PEM in North America revealed internal consistency of .68 to .96 for Participation scales and .92 to .96 for Environment scales for children with and without developmental needs [5]. Test-retest reliability ranged from .31 to .93 for Participation scales and .91 to .94 for Environment scales within a 2-4 week period [5].

Concurrent validity of the YC-PEM environment items was established with the Craig Hospital Inventory of Environmental Factors for Children – Parent Version (CHIEF-CP) [29] and construct validity was demonstrated in that functional performance was significantly associated with increased involvement in activities [5].

The cross-cultural equivalence of the YC-PEM has been established in Singapore [7]. Ten early childhood and healthcare professionals were interviewed to gather their perspectives of the relevance of the YC-PEM in Singapore and to provide suggestions to adapt the YC-PEM to the Singapore context. Cognitive interviews were conducted with 10 parents to understand their interpretation of the items in the YC-PEM and also to provide suggestions to adapt the YC-PEM to the local context. Based on results of the interviews, the original YC-PEM was modified in three areas addressing item, semantic and operational issues [7]. Most of the modifications involved changing examples of activities, and one new activity category (structured learning time) was added to the Singapore version. A response option for the desire change scale was also changed from "be more helpful" to "be more cooperative".

Similar to the original YC-PEM, the Singapore YC-PEM examines participation and environment across three settings: home (14 items), childcare/preschool (3 items) and community (12 items) [7]. **Home** activities fall into one of the following categories: (i) helping with basic care routines, (ii) household chores (iii) interactive and organized play, and (iv) socialising with friends and family. **Childcare/preschool** activities pertain to educational programming in the form of group learning, socializing with friends, and school excursions and events. **Community** activities fall into one of the following

categories: (i) excursions and outings, (ii) classes and groups, (iii) community-sponsored activities, and (iv) recreation. For each activity, the parent is asked to identify how frequently (over the past 4 months) the child has participated (8-point scale: never [0] to once or more each day [7]); how involved the child is while participating (5-point scale: not very involved [1] to very involved [5]); and whether the parent would like to see the child's participation in this type of activity change (no [0] or yes [1]). If change is desired, the parent is asked to specify the type/types of change desired: do more often, do less often, be more interactive, be more cooperative and participate in a broader variety of activities. An open-ended question is also asked regarding strategies that have been tried out by the parent to promote the child's participation in that type of activity.

After completing the participation items for a setting, parents are asked to evaluate the impact of the child's environment on participation in that setting. The parent is asked whether certain features of the environment, for example the physical layout, help or make it harder for the child to participate in activities in that setting (3-point scale: not an issue/usually helps [3] to usually makes harder [1]). The parent is also asked if resources are available and/or adequate, for example programs and services, to support the child's participation in that setting (3-point scale: not needed/usually yes [3] to usually no [1]).

For this study, four YC-PEM setting summary scores were calculated for analyses: (1) *Frequency* was calculated as the average of all ratings within a setting (range = 0-7); (2) *Level of Involvement* was calculated as the average of all ratings within a setting (range = 1-5); (3) *Desire for change* was calculated by summing the number of items scored as 'yes, change desired', divided by the total number of items, and multiplied

by 100 (range = 0-100); and (4) *Environment support* was calculated by summing ratings across all environmental features and resources items and dividing by the maximum possible score, and multiplied by 100 (range = 0-10).

Procedures. SingHealth Institutional Review Board and McMaster University Research Ethics Board approved the study prior to participant recruitment and data collection. Letters of invitation were sent to the person in charge of EIPIC, kindergartens, childcares and infant cares to invite them to participate in the study. Interested centres were given individually packed envelopes containing a participant information sheet, consent form, family background questionnaire and YC-PEM form. Completed forms were collected by the centres or mailed to the project office. Parents who indicated in the consent form that they would like to fill in the YC-PEM again were given another form to complete 2-3 weeks later. All participants were given a $5 SGD shopping voucher upon completion of each YC-PEM form.

Statistical analysis. Data were entered into IBM SPSS 22.0 [30] for analyses. Data were screened for normality via visual inspection (histogram and Q-Q plot). Parametric tests were used when the data were normally distributed and the variance was tested to be equal [31]. Otherwise, non-parametric tests were used. Characteristics of study participants were described using descriptive statistics. For internal consistency of the YC-PEM scales (frequency, level of involvement, desire change, environmental support) for each setting, we used Cronbach's alpha with values of .70 considered acceptable internal consistency [32]. For test-retest reliability of the YC-PEM scales (frequency, level of involvement, desire change, environmental support) for each setting, we used

intraclass coefficients (ICC), two-way mixed effects model (2,1) [33]. ICC values between .40 and .74 are considered to be fair to good agreement and > .75 is considered excellent [32].

To examine whether the YC-PEM can differentiate between groups of children based on disability and age, we examined group differences in YC-PEM summary scores by dividing the sample according to the child's health/developmental status (child has health/developmental issues: yes or no) and child's age (0-3 and 4-6 years), respectively. These age groupings were pursued to ensure sufficient sample sizes for age-wise comparisons. A series of one-way ANOVA analyses was conducted with child age, gender, and annual income to determine potential covariates. Disability status, age and gender were identified as a covariate, in agreement with the literature [21, 22, 26]. Several studies have indicated family income as a potential covariate with mixed conclusions [5, 21, 34]. In this study, one-way ANOVA analyses did not indicate income as a covariate and therefore it was not controlled for in further analyses. We used General Linear Model (GLM) to control for the covariates, while testing for differences for disability groups (2 levels) and age groups (2 levels). Interactions between the covariates were also tested, found to be not significant statistically and were removed from the analyses. Effect sizes for disability and age group comparisons were calculated using Partial Eta square (ηp^2) values where $\eta p^2 = 0.01 - 0.05$ denotes a small effect, $\eta p^2 = 0.06 - 0.13$ is medium, and $\eta p^2 \geq .14$ is large [35].

To examine the relationship between environmental supportiveness and desire for change scores, we used Pearson and Spearman rank correlation (depending on issues of

normality) to determine the strength of association, $r = 0.10 - 0.29$ as weak, $r = 0.30 - 0.49$ as moderate, and $r \geq 0.50$ as strong association [33]. All statistical tests were set to 0.05 level of significance.

Results

Respondent and Child Characteristics. There were 151 children who participated in the study. Most respondents, who are birth parents of the children, were mothers (83.4%) who are employed (64.9%) and with higher than secondary school qualifications (84.2%). Most of the respondents had an annual income range of 70,000 – 129,999. The ethnicities of the respondents are Chinese (73.5%), Malay (9.9%), Indian (7.3%) and others (9.3%). The respondents' children are mostly boys (59.6%) 4 to 6 years old (62.9%) attending Kindergarten, Childcare, EIPIC or a combination (94.7%). They are mostly cared for by their mothers (70.9%) and domestic helper (32.5%). Just under half (45%) do not have any health or developmental issues while 55% reported some type of health or developmental issues. Table 1 illustrates the respondent and child characteristics.

<Insert Table 1 about here>

Internal consistency. As shown in Table 2, most YC-PEM scales are reliable with acceptable alpha estimates greater than 0.70 across all three sections. The alpha coefficient is below threshold for the frequency scale of the childcare/preschool section ($\alpha = 0.59$).

<Insert Table 2 about here>

Test-retest reliability. As summarized in Table 3, reliability estimates for items in the childcare/preschool and community sections were excellent (ICC = 0.80 - 0.89).

Reliability estimates for items in the level of involvement (ICC = 0.43), change desired (ICC = 0.75) and environmental features and resources (ICC = 0.65) scale were moderate for the home section. Lower levels of agreement were found for items in the frequency scale for home section (ICC = 0.39).

<Insert Table 3 here>

Construct validity. Table 4 shows significant effects of disability on most YC-PEM scales in all settings after covariates age and gender are entered into the analyses. For *frequency scale*, significant mean disability group differences were found for home ($F = 16.60$, $p < .05$, $\eta p^2 = 0.10$) and community settings ($F = 10.1$, $p < .05$, $\eta p^2 = 0.06$). For *level of involvement* and *change desired scales*, significant disability group differences were found for all 3 settings. For *perceived environmental support scale,* significant differences were found for childcare/preschool ($F = 4.90$, $p < .05$, $\eta p^2 = 0.04$) and community settings ($F = 3.93$, $p < .05$, $\eta p^2 = 0.03$).

<Insert Table 4 here>

Small effects of age were also found in level of involvement ($F = 5.85$, $p < .05$, $\eta_p^2 = 0.04$) and change desired ($F = 4.75$, $p < .05$, $\eta_p^2 = 0.03$) for participation in home activities. Small effects of age were found in the frequency ($F = 7.43$, $p < .05$, $\eta_p^2 = 0.05$), level of involvement ($F = 7.78$, $p < .05$, $\eta_p^2 = 0.05$), and change desired ($F = 7.29$, $p < .05$, $\eta_p^2 = 0.05$) in community activities. There were no significant effects of age on YC-PEM scales in the childcare/preschool setting.

Relationship between the environmental support and desire for change. Significant negative associations were found between parental desire for change and environmental

support scales for childcare/preschool ($r = -0.23$, $p < .05$) and community ($r = -0.20$, $p < .05$) sections but not the home ($r = -0.14$, $p > .05$) section.

Discussion

This study reports the psychometric properties of the culturally adapted YC-PEM (Singapore) with young children, aged 0 to 7 years old, with and without developmental needs in Singapore. Studies have recognized participation as a multi-dimensional and contextualized construct [6, 36, 37]. There are different ways of assessing children's participation in activities and environmental influences to participation across different settings [6, 36]. The findings of this study indicate that the YC-PEM (Singapore) is able to provide consistent and stable estimates for childcare/preschool and community participation along multiple dimensions (i.e., frequency, level of involvement in activities, and parental desire for change) and perceived environmental support. An exception is the childcare/preschool participation frequency that was not in the acceptable internal consistency range. Lower estimates of this scale may be due to parents being unclear of their children's participation frequency at childcare/preschools, and they may have completed the section based on the teachers' input. This is similar to the original YC-PEM validation study [5] and findings from prior studies that validated participation measures for children 2 to 6 years old [21, 23]. To address this limitation, we could consider allowing teachers to complete the childcare/preschool sections in future studies after determining the validity of the items in the childcare/preschool school sections. Previous studies have highlighted the importance of obtaining information from multiple

informants to obtain a fuller and more accurate picture of young children's functioning [38, 39].

Good reliability estimates were obtained for childcare/preschool and community participation along multiple dimensions (i.e., frequency, level of involvement in activities, and parent desire for change) and perceived environmental support over a 2-3 week period. Home participation and environmental support had lower reliability estimates. Our findings differ from prior studies in which higher reliability estimates were found for home participation scales as compared to childcare/preschool and community participation [5, 21, 23]. This difference may be due to two cultural factors. First, our sample indicated that young Singaporean children attend multiple centres such as a combination of kindergarten/childcare and early intervention centres. Early intervention has not been incorporated into the mainstream preschool education and young children with disabilities have to shuttle between childcare/preschool and early intervention centres [25]. This is especially so for young children with mild disabilities, as their parents would like them to receive developmental support from early intervention centres with continual integration with typically developing children in mainstream schools. Consequently, these children may not be spending much time at home and their parents may find it challenging to keep track of their participation at home. Second, the main caregivers for majority of the children in our study include domestic helpers and grandparents. However, it was the parents who completed the YC-PEM and therefore they may be unsure of their child's home participation, resulting in inconsistent completion of the YC-PEM. Parents were chosen to be the respondents of the YC-PEM in

this study because they were more likely to be able to read and write English, as compared to grandparents and domestic helpers, and parents were the respondents of the North American YC-PEM psychometric evaluation study [5]. In the future, if domestic helpers and grandparents are the main caregivers, they should be involved in completing the YC-PEM. Parents should assist them if they are unable to read or write English.

Construct validation of the YC-PEM (Singapore) indicates that it is able to detect differences in frequency, level of involvement and change desired between young children with and without developmental needs across all settings. The extent of effect in the change-desired scores for all settings is large compared to participation frequency and level of involvement scores. This indicates that parents of children with developmental needs desire change in their children's participation more than parents of typically developing children. Parents of children with developmental needs in Singapore may assume that their children are not participating optimally due to their developmental condition. Singapore is a meritocratic society with a competitive education system [40]. With the influence of the larger culture's emphasis on academic achievement, parents of children with developmental needs may fear that their children will fall behind their peers due to their developmental needs and expect more change in their participation. Singaporean parents' perception of optimal participation should be further explored to determine if there is a need to moderate their expectations.

The ability of the YC-PEM (Singapore) to detect differences in perceived environmental support between disability and non-disability groups is weaker in comparison to the psychometric properties of the North America's YC-PEM [5] and

PEM-CY [26]. One reason could be that parents do not see the importance and relevance of environment on participation and did not put in the same effort to complete the environmental items as with the participation items. Given Singapore's emphasis on academic credentials there may be an emphasis on the child's skills and competencies rather than environment [41]. There may be a need to create awareness on how the environment could be utilized to support the participation of children with developmental needs in Singapore. A randomized controlled trial that compared child- versus environment-focused intervention for young children with cerebral palsy found that both types of intervention are equally effective [43]. Depending on the child's needs, environment-focused intervention is a potential alternative that therapists and families could explore in addition to our primary model of child-focused intervention [43].

The YC-PEM (Singapore) did not detect differences in participation and perceived environmental support in all settings between children of different age groups. This is similar to the psychometric properties of the original YC-PEM [5]. However, other studies have found that there are age effects to the participation of children [21, 23, 42]. Similar to the PEM-CY, there is a negative association between parents' desired change and perceived environmental support for the childcare/preschool and community sections [26]. This further validates the relationship between overall satisfaction with participation and perceived supportiveness of the environment. The lack of association between parents' desired change in home participation and perceived environmental support may be due to parents wanting change in their child's participation, but also their feeling that

their home environment is generally supportive because the home environment is within their control.

There are some limitations to this study. First, this study had a convenience sample that is not representative of the general population. The sample consists of more highly educated parents and lacks sufficient representation from minority ethnic groups such as Malays and Indians. Based on the Singapore population statistics, only 66% of Singaporeans have higher than secondary school qualifications and the ethnicities of Singaporeans are Chinese (60%), Malay (15.3%), Indian (11.7%) and others (12.9%) [44]. With a more representative population, the findings of this study could enhance the utility of the YC-PEM (Singapore) for population-based research. Our sample also had fewer children younger than 4 years old, resulting in a need to collapse age groups for analysis. Further construct validation studies for the YC-PEM (Singapore) could include exploring its concurrent validity with similar measures such as the CHIEF-CP [29] and examining its relationship with functional performance level, as studies have found that children's functional performance level is associated with their participation [5, 10]. Performing item level group analysis for each setting could also reveal the validity of its items for each setting [5] and if the YC-PEM could be completed in separate sections based on the setting needs of the child. The utility of the YC-PEM (Singapore) in supporting early intervention and policymaking in this cultural context should also be examined [45, 46].

Conclusion

This study provides initial evidence of the psychometric properties of the YC-PEM (Singapore) that has been adapted culturally, with young children (aged 0 to 7 years old) with and without developmental needs. The YC-PEM (Singapore) is a promising tool to be used by service providers to facilitate participation of their clients and by researchers to implement population-based research that could influence policy makers though providing them a way to consider how environments impact children's participation. To our knowledge, this is the first study in Singapore that explored the differences in participation levels of young children with and without developmental needs. We found that young children with developmental needs in Singapore are participating in fewer activities and are less involved in activities compared to typically developing children. Their parents also desire more change in their participation. This study also lends support to the need for cultural validation of participation measures due to cultural diversity in caregivers' perspectives of children's participation.

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Table 1. Respondent and Child Characteristics

		N= 151
Characteristic	**Response**	**N (%)**
Respondent Type		
	Mother	126 (83.4)
	Father	25 (16.6)
Age (Years)		
	20-29	6 (4.0)
	30-39	105 (69.5)
	40-49	40 (26.5)
Ethnicity*		
	Chinese	111 (73.5)
	Malay	15 (9.9)
	Indian	11 (7.3)
	Others	12 (9.3)
Employed		
	Yes	98 (64.9)
	No	53 (35.1)
Annual Income*		
	<69,999	50 (33.1)
	70,000-129,999	53 (35.1)
	>130,000	42 (27.8)
Respondent Education*		
	None	1 (0.7)
	Primary School	6 (4.0)
	Secondary School	15 (9.9)
	Junior College	3 (2.0)
	Polytechnic	25 (16.6)
	University	69 (45.7)
	Post-graduate	30 (19.9)
Family Type		
	Two-parent	143 (94.7)
	Single-parent	8 (5.3)
Child Gender		
	Male	90 (59.6)
	Female	61 (40.4)
Child Age (Years)		
	0-4	56 (37.1)
	4-6	95 (62.9)
School Type		
	No School	8 (5.3)

	Kindergarten	54 (35.8)
	Childcare	35 (23.1)
	Early Intervention Program for Infant and Children (EIPIC)	20 (13.2)
	Kindergarten & EIPIC	19 (12.6)
	Childcare & EIPIC	15 (9.9)
Caregiver[a]		
	Mother	107 (70.9)
	Domestic Helper	49 (32.5)
	Grandparents	35 (23.2)
	Father	32 (21.2)
	Childcare	24 (15.9)
	Babysitter/Nanny	5 (3.3)
Health/Developmental Issues		
	No	68 (45.0)
	Physical Disability	3 (2.0)
	Hearing Impairment	1 (0.6)
	Speech & Language Delay	15 (9.9)
	Learning Disability	6 (4.0)
	Emotional/Behavioral Difficulty	19 (12.6)
	Developmental/Intellectual Delay	36 (23.8)
	Social Interaction Difficulty	3 (2.0)
Functional Issues		
	Paying attention	93 (61.0)
	Remembering new information	47 (31.2)
	Learning new information or activities	52 (34.5)
	Communicating with others	81 (53.6)
	Reacting to sensations	54 (35.8)
	Moving around	26 (17.2)
	Using his or her hands to do activities	46 (30.5)
	Managing emotions	95 (62.9)
	Controlling behavior or activity level	89 (59.0)
	Seeing	10 (6.7)
	Hearing	12 (7.9)

*Variables in which there is one missing value. Estimates are based on complete cases.
[a] Respondents could select more than one response option.

Table 2. Internal Consistency Reliability of Items in YC-PEM (Singapore) Participation and Environment Scales

YC-PEM Section	Scale	Items	N	Cronbach Alpha Coefficients
Home				
	Frequency	14	148	.78
	Level of Involvement	14	47	.80
	Change Desired	14	150	.92
	Environmental Features and Resources	13	144	.73
Childcare/Preschool				
	Frequency	3	142	.59
	Level of Involvement	3	120	.86
	Change Desired	3	142	.86
	Environmental Features and Resources	16	138	.78
Community				
	Frequency	12	147	.76
	Level of Involvement	12	19	.84
	Change Desired	12	150	.92
	Environmental Features and Resources	17	141	.79

Table 3. Test-Retest Reliability of YC-PEM (Singapore) Participation and Environment Items

YC-PEM Section	Scale	Items	N	ICC	
				ICC	95% CI
Home					
	Frequency	14	33	.39	.06, .64
	Level of Involvement	14	31	.43	.10, .68
	Change Desired	14	31	.75	.54, .87
	Environmental Features and Resources	13	27	.65	.36, .82
Childcare/Preschool					
	Frequency	3	28	.81	.62, .91
	Level of Involvement	3	28	.80	.62, .90
	Change Desired	3	28	.89	.78, .95
	Environmental Features and Resources	16	25	.80	.59, .91
Community					
	Frequency	12	31	.80	.63, .90
	Level of Involvement	12	31	.84	.69, .92
	Change Desired	12	31	.85	.71, .92
	Environmental Features and Resources	17	28	.80	.61, .90

Table 4. Differences in young children's participation and environment according to disability

	Disabilities Mean (SD)			
YC-PEM Scores	Yes	No	*F (p)*	η_p^2
Home				
Frequency	4.80 (.87)	5.44 (.79)	16.6* (.01)	.10
Level of Involvement	3.88 (.61)	4.21 (0.49)	9.84* (.01)	.06
Percent Desire Change	62.2 (30.6)	28.80 (27.8)	34.3* (.01)	.19
Environmental Support	77.2 (7.66)	78.90 (7.80)	1.00 (.32)	.01
Childcare/Preschool				
Frequency	4.66 (1.31)	5.12 (.78)	2.39 (.12)	.02
Level of Involvement	3.64 (1.10)	4.65 (.71)	26.2* (.01)	.16
Percent Desire Change	63.8 (40.8)	8.60 (23.30)	60.6* (.01)	.31
Environmental Support	76.7 (7.00)	79.70 (6.46)	4.90* (.03)	.04
Community				
Frequency	2.59 (.91)	3.23 (.91)	10.1* (.01)	.06
Level of Involvement	3.64 (.96)	4.28 (.80)	10.8* (.01)	.07
Percent Desire Change	51.30 (33.60)	13.9 (20.70)	50.7* (.01)	.26
Environmental Support	73.80 (9.34)	76.30 (8.81)	3.93* (.05)	.03
**p < 0.05*				

Chapter Four

Participation in out-of-home environments for young children with and without developmental needs

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This chapter contains a manuscript entitled: “Participation in out-of-home environments for young children with and without developmental needs”. The proposed journal for this manuscript is Occupation, Participation and Health Journal. This manuscript is currently in an expanded format, and has not been submitted.

Abstract

This study examines caregivers' perceptions of participation patterns and environmental supports and barriers for young children with and without developmental needs within their childcare/preschool and community settings. The Young Children's Participation and Environment Measure (YC-PEM) was completed by 151 parents of Singaporean children (0 to 7 years old) with and without developmental needs. Setting-specific summary and item-level scores of these children were compared using ANCOVA, Mann-Whitney and Pearson Chi-Square tests. Children with developmental needs had significantly lower participation and environment summary scores in both settings as compared to children without developmental needs ($p < 0.05$; $\eta p^2 = 0.03\text{-}0.31$). Group differences were also evident at the item level, particularly when comparing the percentage of parents who desire change in their child's activity participation. Parents of children with developmental needs perceived lack of environmental supports to be more of a challenge than are environmental barriers. Adequate financial support, public awareness, programs and services have been identified as environmental factors that are potentially important to parents of children with developmental needs.

Introduction

Childhood occupations are culturally valued activities and tasks that young children do to occupy themselves, including self-care, leisure and educational activities. Participation in occupations is a means to achieve the positive development of young children (Larson & Verma, 1999; Dunst et al., 2002; Law, 2002) and has been proposed to be an outcome of their health and well-being (UNICEF, 2013; WHO, 2007). While young children typically participate in occupations at home, at childcare or preschool, and in the community, how their time use is allocated across settings can vary across cultures and over time (Larson & Verma, 1999; Dunst et al., 2002). In Singapore, a country that relies on human resources for economic development (Ng, 2011), government policies have been implemented to encourage women to continue to be in the workforce after they have children (Quek et al., 2011). These policies have led to the growth of alternative childcare arrangements such as childcare and preschool facilities (Honig & Lim, 1998). Young Singaporean children thus spend more time in childcare/preschool and the community than in their homes at a young age. This social phenomenon is also common in America where young children are spending more time in daycare than at home due to work commitments of their parents (ChildStats, 2014). In addition, transport networks are increasingly accessible and children are able to travel out of home into the community. In childcare/preschool, children can participate in a variety of activities like group learning and socialization with peers. In the community, examples of participation range from running errands with their parents to playing in the park.

Despite the significant amount of time that young children spend in out-of-home environments, research suggests that young children with developmental needs participate less frequently and in a smaller variety of activities in comparison with children without developmental needs (Leung et al., 2011; LaVesser & Berg, 2011). Among American preschoolers with developmental needs, 39.3% were reported to experience community participation difficulty in at least one activity (Khetani et al., 2013). LaVesser & Berg (2011) found that parents of preschoolers with autism spectrum disorder provided them with opportunities to participate in activities, but the children could not capitalize on these opportunities. Participation difficulties have been associated with several factors, including those related to the child (behavioral and social difficulties), the family (income, parental education levels, informal family support, parents' confidence in managing their child's behavior) and the environment (social support, transportation) (Rosenburg et al., 2012; Khetani et al., 2012; Soref et al., 2011; Leung et al. 2011; LaVesser & Berg, 2011; Khetani et al., 2013). The community environment may pose more barriers to children's participation than the home environment, where parents typically have more control to promote participation in occupation (Rosenburg et al., 2012; Larson, 2000).

There are more studies about the out-of-home participation of children with disabilities aged six years and above than about younger children (Raghavendra, 2013). In part, this is due to a lack of instruments to measure both participation and environments of younger children (Law et al., 2012). There are studies on young children's participation but they are limited in the types of diagnoses (LaVesser & Berg, 2011;

Rosenburg et al., 2012; Soref et al., 2011) and settings (Leung et al., 2011; Khetani et al., 2012; Khetani et al., 2013), and the majority involve children from North America. To our knowledge, this is the first study that focuses on participation and environment of children with developmental needs in both the childcare/preschool and community settings in Singapore. Assessing participation at the same time as environment can increase our understanding of the environmental factors that influence young children's participation in specific settings (Khetani et al., 2013). With this understanding, early intervention providers can consider the full range of factors that might impact participation problems in a specific setting focus (Simeonsson, 1991).

The Young Children's Participation and Environment Measure (YC-PEM) is the first instrument that measures both participation and environment together, in the home, childcare/preschool and community settings (Khetani et al., 2014). The original North American version found disparities in young children's out-of-home participation (Khetani et al., 2014) and the YC-PEM has been recently culturally adapted for use in Singapore (Lim et al., *under review*). This provides an opportunity to explore if these disparities are similar in a new cultural context with some similarities in young children's time use but possibly with different norms for participation. The research questions addressed in this paper were:

1. How is the participation of young children with and without developmental needs similar and different in the childcare/preschool and community setting?

2. What environmental factors support and challenge participation within the childcare/preschool and community for young children with and without developmental needs?

Methods

Recruitment of participants

The YC-PEM (Singapore) (Lim et al., *under review*) was disseminated to 151 caregivers of young children (83 with and 68 without developmental needs) in Singapore using a prospective cross-sectional study design. A convenience sampling approach was used to recruit all the caregivers of young children aged 0 to 7 years. In Singapore, children with developmental concerns are referred to one of three government hospitals in Singapore with a child development unit (Lian et al., 2012). The developmental paediatrician assesses the child and refers them to an Early Intervention Programs for Infants and Children (EIPIC) for long-term early intervention services, run by Voluntary Welfare Organisations (VWO). Due to the VWO's manpower and resource constraints, the children are often placed on a waitlist before enrolment in EIPIC. While waiting, they are provided with interim therapy services at the government hospitals.

For this study, caregivers of children with developmental needs were recruited from a government hospital, KK Women's and Children's Hospital's (KK Hospital) Department of Child Development (DCD) and VWOs with EIPIC located at various geographical regions in Singapore. Caregivers of children without developmental needs were recruited from government-funded and private kindergartens. Caregivers met the following eligibility criteria: (1) they identified themselves as a parent or legal guardian

of the child who is the focus of the survey; (2) they were able to read and write English; (3) their child was between 0 and 7 years old at the time of enrolment; and (4) children with developmental needs met the eligibility criteria for enrolment in EIPIC. Children were eligible for EIPIC if they were (1) below 7 years of age; (2) a Singapore citizen or permanent resident; (3) diagnosed with developmental, intellectual, sensory or physical disabilities or a combination of disabilities; and (4) recommended for EIPIC by a doctor from one of the three government hospitals in Singapore with a child development unit (SG Enable, 2015).

Measures

The YC-PEM (Singapore) is a caregiver-report questionnaire used as the primary measurement tool in this study to examine the participation patterns of young children with and without developmental needs, and the environmental influences on their participation in the childcare/preschool and community settings (Lim et al., 2015). The participants completed paper versions of the YC-PEM (Singapore) (Lim et al., *under review*) and a demographic questionnaire. The demographic questionnaire gathered information about the child and family, such as child's age, main caregivers, developmental issues, and family's socioeconomic status. The YC-PEM (Singapore) includes 29 items that examine participation and environment at home (14 items), at childcare/preschool (3 items) and in the community (12 items). We used data only from the childcare/preschool and community items for this study. *Childcare/preschool* activities pertain to educational programming in the form of group learning, socializing with friends, and school excursions and events. *Community* activities fall into one of the

following categories: (i) excursions and outings, (ii) classes and groups, (iii) community-sponsored activities, and (iv) recreation. For each activity, the parent is asked to identify how frequently (over the past 4 months) the child has participated (8-point scale: never [0] to once or more each day [7]); how involved the child is while participating (5-point scale: not very involved [1] to very involved [5]); and whether the parent would like to see the child's participation in this type of activity change (no or yes). If the parent desires change, the caregiver is asked to specify the type of change desired (do more often, do less often, be more interactive, be more cooperative and/or participate in a broader variety of activities). Caregivers are also asked to describe strategies that they have tried to promote the child's participation in that type of activity.

After completing the participation items for a setting, parents are asked to evaluate the impact of the child's environment on participation in that setting. They are asked whether certain features of the environment, for example the physical layout, help or make it harder for the child to participate in activities in that setting (3-point scale: not an issue/usually helps [3] to usually makes harder [1]). The parents are also asked if resources, for example programs and services, are available and/or adequate to support the child's participation in that setting (3-point scale: not needed/usually yes [3] to usually no [1]).

YC-PEM summary scores were calculated for each setting: (1) *Frequency* was calculated as the average of all ratings within a setting (range = 0-7); (2) *Level of Involvement* was calculated as the average of all ratings within a setting (range = 1-5); (3) *Desire for change* was calculated by summing the number of items scored as 'yes, change

desired', divided by the total number of items, and multiplied by 100 (range = 0-100); and (4) *Environment support* was calculated by summing ratings across all environmental features and resources items and dividing by the maximum possible score, and multiplied by 100 (range = 0-100). The YC-PEM (Singapore) has been shown to be a reliable and valid tool for children with and without developmental needs in Singapore (Lim et al., 2015). Internal consistency ranged from .59 to .92 for participation scales and .73 to .79 for environment scales. Test-retest reliability ranged from .39 to .89 for participation scales and .65 to .80 for environment scales within a 2-3 week period. Moderate to large group differences were found in participation and perceived environmental support between disabled and non-disabled groups, supporting the construct validity of the YC-PEM (Singapore).

Procedures

SingHealth Institutional Review Board and McMaster University Research Ethics Board approved the study prior to participant recruitment and data collection. Letters of invitation were sent to the people in charge of KK Hospital, EIPIC, kindergartens, childcares and infant cares to invite them to participate in the study. Interested centres were informed of the eligibility criteria for the parents to participate in this study. Individually packed envelopes containing a participant information sheet, consent form, family background questionnaire and YC-PEM form were given to the person in charge of the centre who disseminated them to eligible parents in their centre. All participants were given a $5 SGD shopping voucher upon return of each completed YC-PEM form to the project office.

Data analysis

Data were entered into IBM SPSS 22.0 for analyses. Descriptive statistics were used to describe characteristics of study participants. Radar plots are effective in illustrating the interaction among variables related to participation, and were used to explore the relationship between the disability and non-disability groups, and environmental supports/barriers to participation (Manllinson & Hammel, 2010). Data were screened for normality by visual inspection (histogram and Q-Q plot). Parametric tests were used when the data were normally distributed and the variance was tested to be equal. Otherwise, non-parametric tests were used. Analyses of variance (ANOVAs) were used to compare group differences on variables (family income, age and gender) to determine potential covariates based on previous literature (Law et al., 2012; Coster et al., 2011; Khetani et al., 2014; Khetani et al., 2013; King et al., 2007). Age and gender were identified as covariates. For *analysis of summary scores*, analyses of covariance (ANCOVAs) were used to control for age and gender while comparing childcare/preschool and community summary scores of participation frequency, extent of involvement, change desired and environmental support between children with and without developmental needs. Partial eta squares (ηp^2) were used to examine effect size: ηp^2 = 0.01-0.05 denotes a small effect, ηp^2 = 0.06-0.13 is medium, and $\eta p^2 \geq .14$ is large (Kirk, 1995). For *item-level analyses*, (1) ANCOVA (adjusting for age and gender category) and partial eta squares were used to compare mean item-level responses for participation frequency, and (2) Mann-Whitney test was used to compare median item-level scores for participation involvement between children with and without

developmental needs. Pearson chi-square analyses were used to compare the percentage of respondents in each group who responded (1) "never participates" for participation frequency items, (2) "yes" for desired change items, (3) "usually makes harder," and "not an issue/usually helps," to environmental support and barrier items, and (4) "usually, no" and "not needed/usually yes" to availability/adequacy of resources items. To reduce Type I error due to multiple comparisons, Bonferroni adjustments were made to significance levels by dividing .05 by the number of comparison tests conducted for each set of analyses. This resulted in a p-value of < .01 and <.006 for childcare/preschool participation and environment items, respectively, and <.004 and <.007 for community participation and environment items, respectively.

Results

Participants

The YC-PEM was completed by 151 parents of children with (n=83) and without (n=68) developmental needs in Singapore (Table 1). The demographic characteristics of both groups of parents were similar except for employment characteristics and annual income: 91% of parents of typically developing children were working full-time (n = 62) while 59% of parents of children with developmental needs were working full-time (n = 49). Parents of children without developmental needs had higher income levels than parents of children with developmental needs. Among children with developmental needs, 81 (98%) attended EIPIC and/or childcare/preschool while 61 (90%) typically developing children attended childcare/preschool, indicating that majority of the whole sample spent time in out-of-home environments. Among children with developmental

needs, 36 (43%) had developmental/intellectual delay and 19 (23%) had emotional/behavioral difficulty.

Summary scores

The full summary scores of the childcare/preschool and community settings are reported in Lim et al. (2015). In the *childcare/preschool setting*, the highest effect sizes were found in change desired ($\eta p^2 = 0.31$), level of involvement ($\eta p^2 = 0.16$), perceived environmental support summary scores ($\eta p^2 = 0.04$), followed by frequency of participation ($\eta p^2 = 0.02$). In the *community setting*, the highest effect sizes were found in change desired ($\eta p^2 = 0.26$), level of involvement ($\eta p^2 = 0.07$), frequency of participation ($\eta p^2 = 0.06$), followed by perceived environmental support ($\eta p^2 = 0.03$).

Frequency item-level responses

Tables 2 and 3 include results that describe and compare participation at the item level for children with and without developmental needs in the childcare/preschool and community environment. Among children with developmental needs, 15 (18.1%) never participated in school excursions and events while all children without developmental needs did. The mean participation frequency of children with developmental needs in school excursion and events was also significantly lower than typically developing children. Among children with developmental needs 42 (50.6%) never participated in enrichment classes compared to 18 (26.5%) typically developing children.

Involvement item-level responses

Children with developmental needs had significantly lower median involvement scores for group learning, socializing with friends, and school excursions and events

when compared with children without developmental needs. Despite similarities in how often their children participate in community activities, children with developmental needs were less involved in some activities including dining out, community places, religious activities, and social gatherings but not for the rest of the community items.

Change desired item-level responses

Parents of children with developmental needs desired more change in their children's childcare/preschool and community participation in all areas in comparison with parents of children without developmental needs.

Perceived environmental support/barrier item-level responses

Figures 1- 4 illustrate the percentages of parents who perceived the item as an environmental support or barrier to childcare/preschool and community participation. There were no significant differences between groups for most of the childcare/preschool and community environmental support and barrier item scores. Parents perceived the childcare/preschool and community environments as having more supports ("usually helps") than barriers ("usually makes harder"). In the childcare/preschool setting, significantly fewer parents of children with developmental needs perceived their child's relationships with their peers and money as environmental supports. In the community setting, significantly fewer parents of children with developmental needs perceived the social demands of activity, attitude of the public, availability of programs and services and money as an environmental support to community-based participation when compared with parents of children without developmental needs.

Discussion

The findings from this study extend the base of culturally relevant knowledge about participation and environmental supports/barriers among young children within childcare/preschool and community environments. Significant group differences were found on most participation summary scores, illustrating that parents of children with developmental needs generally perceive that their children participated less frequently and were less involved in childcare/preschool and community activities than typically developing children. These findings are consistent with the studies that have made similar comparisons with young children using the North American version of the YC-PEM (Khetani et al., 2014) and school-age children using the Participation and Environment Measure for Children and Youth (PEM-CY) (Bedell et al, 2013; Coster et al., 2013).

Similar to studies of out-of-home participation involving school-age children with and without disabilities (Bedell et al, 2013; Coster et al., 2013), we found fewer differences in participation frequency between children with and without developmental needs in both childcare/preschool and community settings compared to their level of involvement in activities. Since routines and policies may determine frequency of participation (Coster et al., 2013), it is possible that preschoolers with developmental needs can be given similar opportunities with respect to how often they participate in activities but still differ in their level of engagement (LaVesser & Berg, 2011; Khetani et al., 2011). Consequently, findings from this study lend further support to the need for multi-dimensional assessment of children's participation (Coster et al., 2012; Bedell et al., 2011; McConachie et al., 2006; Khetani et al., 2011; Coster & Khetani, 2008).

Frequency might not be the best metric for evaluating participation outcomes, as discrepancies were more evident within the involvement scale. The findings from this study also indicated that participation differences begin in early childhood and persist through school age. It is therefore important to assess children with developmental needs fully at an early age so that strategies can be put in place to improve participation over time.

Parents of children with developmental needs desire change in participation for more activities compared to parents of typically developing children, particularly those activities that involves socialization. Children with developmental needs may have difficulties socializing independently, as they often have poor emotional/behavioral regulation (Baker et al., 2007), which was one of the most reported developmental problems in our sample. One potential way to improve on their socialization in out-of-home environments is to have programs and services that provide support for teachers and parents, to develop an understanding and effective social environment to facilitate socialization with peers, especially in unstructured activities. Parents of children with developmental needs in our study reported lack of programs and services as an environmental need and studies with school-age children have also found that schools and the community lack programs and services specifically designed to meet the social needs of children with disabilities (Coster et al., 2013; Eriksson et al., 2007; Carter et al., 2008; Borell & Hemmingson, 2002; Brewin et al., 2008; Egilson & Traustadottir, 2009). In Singapore, emerging government programs, such as the Developmental Support Program (DSP), that support children with low additional developmental needs in preschools

(Chong et al., 2014) should also focus on their socio-emotional support. Another participation issue raised was that children with developmental needs participated in fewer school excursions/events (Simeonsson et al., 2001; Mancini & Coster 2004; Colver et al., 2006). Parents and teachers may find it difficult to manage the challenging behaviors of children with developmental needs due to the unpredictability of community places (Baker et al., 2002; LaVesser & Berg, 2011; Khetani et al., 2012; Maul & Singer, 2009; Larson, 2000). In Singapore, programs such as the Signposts for Building Better Behaviour program (Yap et al., 2014) have proven effective in increasing parents' self-efficacy in managing their children's behavior and should be made available to more parents. Future research is needed to determine if these programs and services are able to improve participation outcomes.

Besides the parents' perceived lack of programs and services, they also perceived public attitude as a lack of environmental support to community-based participation. Parents experience stress and embarrassment when their children with developmental needs exhibit difficult behaviors in the community, because the public often misunderstands and relates the behavior to poor parenting (Chua, 2012). This is especially so in an Asian society where children are expected to demonstrate self-control and compliance at a younger age as compared to their western counterparts (Lim et al., 2013). Additionally, the Asian culture's focus on social identity and value might result in an increased stigma related to disability (Sheridan & Scior, 2013; Mak & Kwok, 2010). Chinese parents of children with developmental needs were also found to internalize the stigma and blame themselves for their child's condition, which is detrimental to their

psychological well-being (Mak & Kwok, 2010). Since research indicates that informal social support is associated with increased community-based participation amongst children with developmental needs (Khetani et al., 2012), strategies could be developed to help families establish support from the public, relatives and friends. Societal attitudes should also be addressed, and this can begin by transforming Singapore into a more inclusive society and to explore the concept of inclusive education (Lim, 2009; Yeo et al., 2011). Being in contact with persons with disabilities was found to be more effective in changing attitudes than only information provision to increase public awareness of the needs of children with developmental needs and their families (Daruwalla & Darcy, 2005).

Despite the emphasis on inclusive education internationally, Singapore has no mandate to integrate children with disabilities into mainstream schools (Yeo et al., 2011). This is likely due to meritocracy being the key principle of governance in Singapore (Tan, 2008). Inevitably, the culture of meritocracy has also influenced the parenting philosophy of Singaporeans and they appear to have high expectations of their children in terms of their functional abilities and academic achievements (Lim et al., 2014). A high percentage of parents of typically developing children in our study reported attention, emotional and self-control difficulties, which may reflect their expectations. On average, children attended enrichment classes a few times a month. In order to keep up with their peers, parents of children with developmental needs enroll their children in early intervention programs, enrichment classes and organized physical activities. Parents have to pay for these costly programs and classes, on top of the regular preschool fees. Not surprisingly,

parents in our study reported money as an environmental factor that is potentially important for childcare/preschool and community-based participation. Additionally, majority of the parents of children with developmental needs in our sample have lower income than children without developmental needs. Due to the higher functional limitations of children with developmental needs, most families may rely on a single-income and one parent, typically the mother, would stay home to care for the child full-time. This childcare arrangement reduces the family's combined income. Law et al. (2012) and Soref et al. (2012) found that the diversity and intensity of participation among young children with physical disabilities were significantly influenced by family income. Service providers should therefore explore financial concerns with parents of children with developmental needs.

Compared to other studies (Bedell et al, 2013; Coster et al., 2013), there were fewer perceived environmental differences between children with and without developmental needs. The few environmental factors that Singaporean parents identified were mainly related to the larger society and policies (e.g. public attitude, financial support, programs and services, etc.) that often require time to change. Moreover, Singaporean parents might be too focused on their child's abilities and competencies that resulted in decreased awareness of the impact of the child's immediate environment on participation. For example, they are not aware that activities could be adapted to the child's cognitive level and to meet their socio-emotional needs. Occupational therapists are well positioned to create this awareness, as their role is to ensure that there is a fit between the child, occupation and environment to achieve successful participation (Law

et al., 1996). Occupational therapists should therefore guide parents to think about the demands of activities and how to intervene on immediate environmental factors to promote participation outcomes. Apart from direct intervention, occupational therapists should also advocate for their clients and intervene through community-building and research (Law et al., 2006), since enabling participation is a multi-method and multi-level approach (Law et al., 1996),

Limitations and future directions

The sample was not randomly selected and may not be representative of the general population. A more diverse sample in terms of children's developmental/health issues and functional abilities should be obtained, as most of the children with developmental needs in our study had more social, emotional and behavioral challenges than physical challenges. The participation profile and environmental needs of young children with physical disabilities impairments may differ from those of children with social, emotional and behavioral difficulties and should be understood as well.

Future directions for research include examining participation in home environments for children with and without developmental needs and if they differ from participation in out-of-home environments. The types of changes that parents of children with developmental needs desire in their children's participation could also be explored by examining the individual item responses to determine whether parents would like more or less frequency of participation, for their child to be more cooperative or interactive, or to participate in a broader variety of activities. Detailed information about the type of changes desired could guide occupational therapists in working on specific types of

activities according to the types of change that the family desires, thus providing family-centered intervention. Future research could also examine the strategies that parents have used to enhance their children's participation, as a previous study reported that parents found it easier to associate participation with environment when they describe the strategies that they have used to enhance their children's participation (Khetani et al., 2011). Understanding the strategies that parents have utilized in our context could provide detailed information about environmental impact on participation. Additionally, parent-reported strategies could offer service providers as well as policy-makers ideas that could facilitate participation of children with developmental needs in their childcare/preschool and community environments.

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Table 1. Respondent and Child Characteristics

		Disability	**No Disability**
Characteristic	**Response**	**N = 83**	**N = 68**
Respondent Type			
	Mother	69 (83)	57 (84)
	Father	14 (17)	11 (16)
Age (Years)			
	20-29	3 (3)	3 (4)
	30-39	57 (69)	48 (71)
	40-49	23 (28)	17 (25)
Ethnicity*			
	Chinese	62 (75)	49 (73)
	Malay	8 (10)	7 (10)
	Indian	6 (7)	5 (7)
	Others	5 (8)	7 (10)
Employed			
	Yes	49 (59)	62 (91)
	No	34 (41)	6 (9)
Annual Income*			
	<69,999	33 (40)	20 (29)
	70,000-129,999	29 (35)	21 (31)
	>130,000	16 (19)	26 (38)
Respondent Education*			
	None	1 (2)	1 (2)
	Primary School	4 (5)	1 (2)
	Secondary School	8 (10)	7 (10)
	Junior College	2 (2)	1 (2)
	Polytechnic	14 (17)	11 (16)
	University	39 (47)	30 (43)
	Post-graduate	13 (17)	17 (25)
Family Type			
	Two-parent	78 (94)	65 (96)
	Single-parent	5 (6)	3 (4)
Child Gender			
	Male	65 (78)	25 (37)
	Female	18 (22)	43 (63)
Child Age (Years)			
		Mean = 4.54 SD = .69	Mean = 4.60 SD = .60
	0-4	33 (40)	23 (34)

	4-6	50 (60)	45 (66)
School Type			
	No School	2 (2)	7 (10)
	Kindergarten	19 (23)	37 (55)
	Childcare	10 (12)	24 (35)
	Early Intervention Program for Infant and Children (EIPIC)	20 (24)	-
	Kindergarten & EIPIC	19 (23)	-
	Childcare & EIPIC	13 (16)	-
Caregiver[a]			
	Mother	61 (73)	46 (68)
	Domestic Helper	29 (35)	20 (29)
	Grandparents	17 (20)	18 (26)
	Father	21 (25)	11 (16)
	Childcare	6 (7)	15 (22)
	Babysitter/Nanny	3 (4)	2 (3)
Health/Developmental Issues			
	No	0 (0)	68 (100)
	Physical Disability	3 (4)	-
	Hearing Impairment	1 (1)	-
	Speech & Language Delay	15 (18)	-
	Learning Disability	6 (7)	-
	Emotional/Behavioral Difficulty	19 (23)	-
	Developmental/Intellectual Delay	36 (43)	-
	Social Interaction Difficulty	3 (4)	-
Functional Issues			
	Paying attention	71 (86)	22 (32)
	Remembering new information	42 (51)	5 (8)
	Learning new information or activities	48 (58)	4 (6)
	Communicating with others	74 (89)	7 (11)
	Reacting to sensations	49 (60)	5 (8)
	Moving around	25 (30)	1 (2)
	Using his or her hands to do activities	42 (79)	4 (6)
	Managing emotions	69 (83)	26 (39)
	Controlling behavior or activity level	67 (81)	22 (33)
	Seeing	9 (11)	1 (2)
	Hearing	12 (15)	0 (0)

NOTE. Values are n (%) or as otherwise indicated.
*Variables in which there is one missing value. Estimates are based on complete cases.
[a] Respondents could select more than one response option.

Table 2: Differences in Childcare/Preschool Participation Items

Items	Never Participate, n (%)*			Frequency, Mean (SD)^			Involvement, Median (IQR)^λ			Desire Change, n (%)*		
	Disability	No disability	P	Disability	No disability	P (η_p^2)	Disability	No disability	P	Disability	No disability	P
1. Group learning	4 (4.80)	1 (1.50)	.250	6.05 (1.65)	6.23 (1.41)	.93 (.001)	3 (2)	5 (0)	.001	50 (62.5)	6 (9.68)	.001
2. Socializing with friends	4 (4.80)	0 (.00)	.670	5.96 (1.82)	6.48 (.92)	.090 (.020)	3 (2)	5 (0)	.001	58 (72.5)	6 (9.68)	.001
3. School excursion and events	15 (18.1)	0 (.00)	.001	1.98 (1.68)	2.65 (1.23)	.001 (.030)	4 (2)	5 (0)	.001	45 (56.3)	4 (6.45)	.001

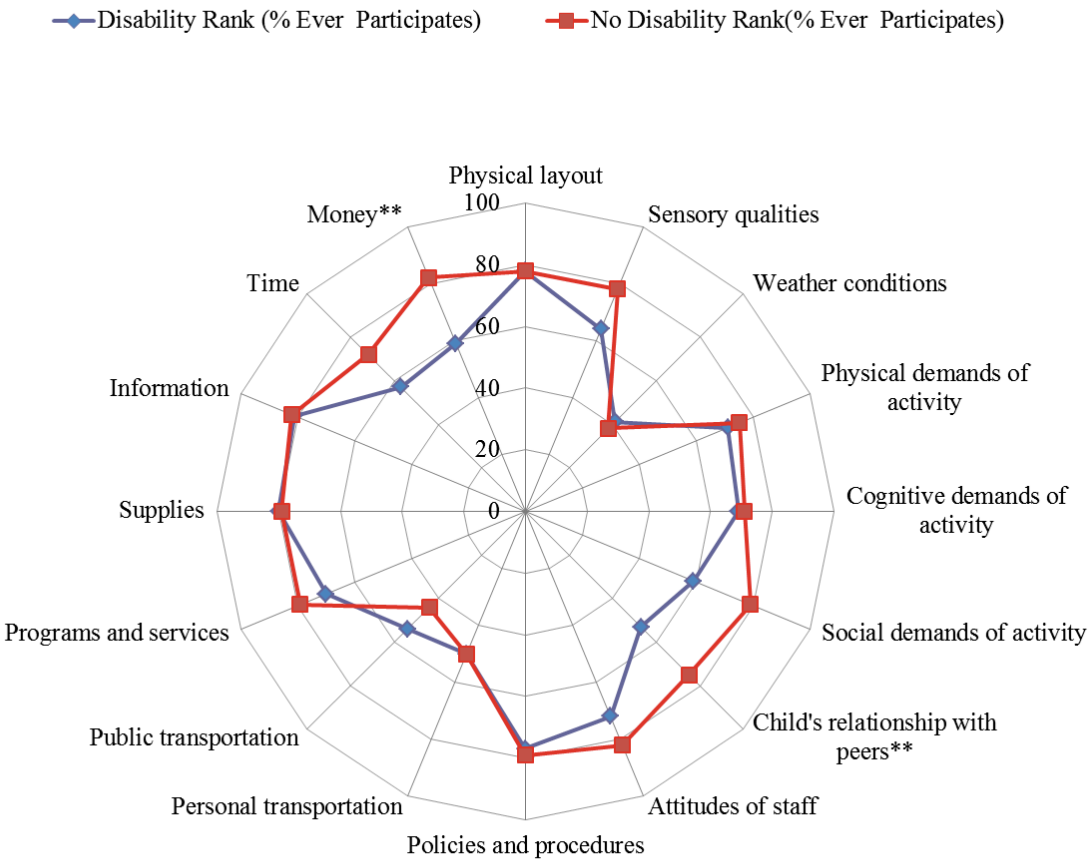
NOTE. *Based on chi-square analyses (Bonferroni adjustment of the significance level was set at P<.01).
^Based on analysis of covariance (ANCOVA) adjusting for child's age and gender (Bonferroni adjustment was set at P<.01).
^λ Based on Mann-Whitney U Test (Bonferroni adjustment was set at P<.01).

Table 3: Differences in Community Participation Item

Items	Never Participate, n (%)*			Frequency, Mean (SD)^			Involvement, Median (IQR)^λ			Desire Change, n (%)*		
	Disability	No disability	P	Disability	No disability	P (η_p^2)	Disability	No disability	P	Disability	No disability	P
1. Shopping	2 (2.40)	0 (0.00)	.198	4.62 (1.59)	5.15 (1.26)	.050 (.020)	3 (2)	5 (2)	.006	38 (45.8)	5 (7.40)	.001
2. Dining out	0 (0.00)	0 (0.00)	NA	4.76 (1.34)	5.16 (.94)	.069 (.023)	4 (2)	5 (2)	.003	7 (10.3)	36 (43.4)	.001
3. Routine appointments	3 (3.60)	2 (2.90)	.818	2.57 (1.14)	2.50 (1.33)	.528 (.003)	3 (2)	5 (2)	.027	36 (43.4)	3 (4.40)	.001
4. Enrichment classes	42 (50.6)	18 (26.5)	.003	2.66 (2.78)	3.93 (2.51)	.160 (0.440)	5 (2)	5 (0)	.026	46 (55.4)	8 (11.9)	.001
5. Organized physical activities	51 (61.4)	27 (39.7)	.008	1.72 (2.40)	3.06 (2.66)	.003 (.050)	5 (2)	5 (0)	.026	49 (59.0)	17 (25.4)	.001
6. Interest groups	65 (78.3)	44 (64.7)	.063	.976 (2.51)	1.63 (2.52)	.083 (.014)	5 (2)	5 (0)	.302	43 (51.8)	13 (19.4)	.001
7. Community places	2 (2.40)	0 (0.00)	.198	2.67 (1.44)	3.54 (1.36)	.006 (.050)	3 (2)	5 (0)	.001	53 (63.9)	11 (16.4)	.001
8. Religious activities	28 (33.7)	19 (27.9)	.444	2.23 (2.17)	2.96 (2.29)	.419 (.004)	3 (2)	5 (2)	.001	39 (47.0)	10 (14.9)	.001
9. Social gatherings	10 (12.0)	3 (4.40)	.096	2.40 (1.57)	2.54 (1.33)	.683 (.001)	3 (2)	5 (2)	.001	52 (62.7)	8 (11.9)	.001
10. Community events	36 (43.4)	17 (25.0)	.019	1.15 (1.30)	1.54 (1.33)	.306 (.007)	3 (2)	5 (2)	.160	46 (55.4)	12 (17.9)	.001
11. Unstructured physical activities	5 (6.00)	1 (1.50)	.154	4.12 (1.86)	5.16 (5.00)	.204 (.011)	5 (1.75)	5 (0)	.031	41 (49.4)	9 (13.2)	.001
12. Overnight trips	22 (26.5)	12 (17.6)	.195	1.16 (1.08)	1.43 (1.21)	.548 (.002)	5 (2)	5 (0.75)	.225	32 (38.6)	10 (14.7)	.001

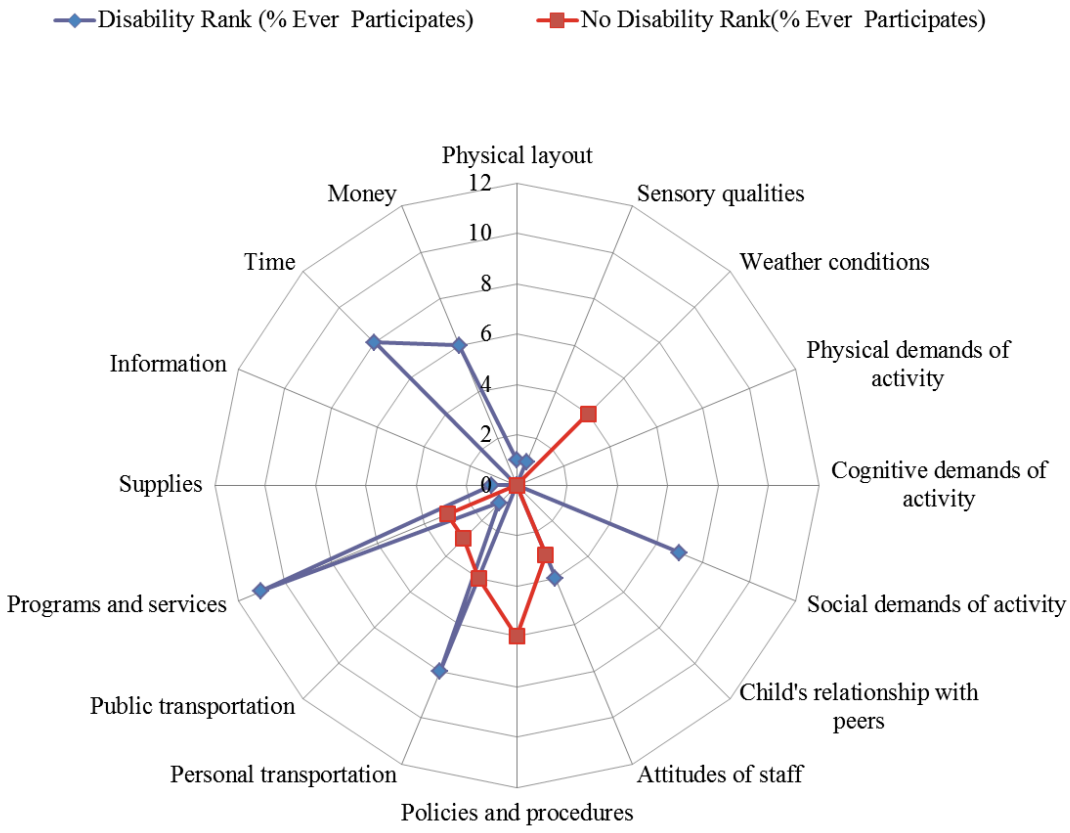
NOTE. *Based on chi-square analyses (Bonferroni adjustment of the significance level was set at P<.004).
^Based on analysis of covariance (ANCOVA) adjusting for child's age and gender (Bonferroni adjustment was set at P<.004).
^λ Based on Mann-Whitney U Test (Bonferroni adjustment was set at P<.004).

Figure 1: Percentage of parents who perceived the item as a support to childcare/preschool-based participation



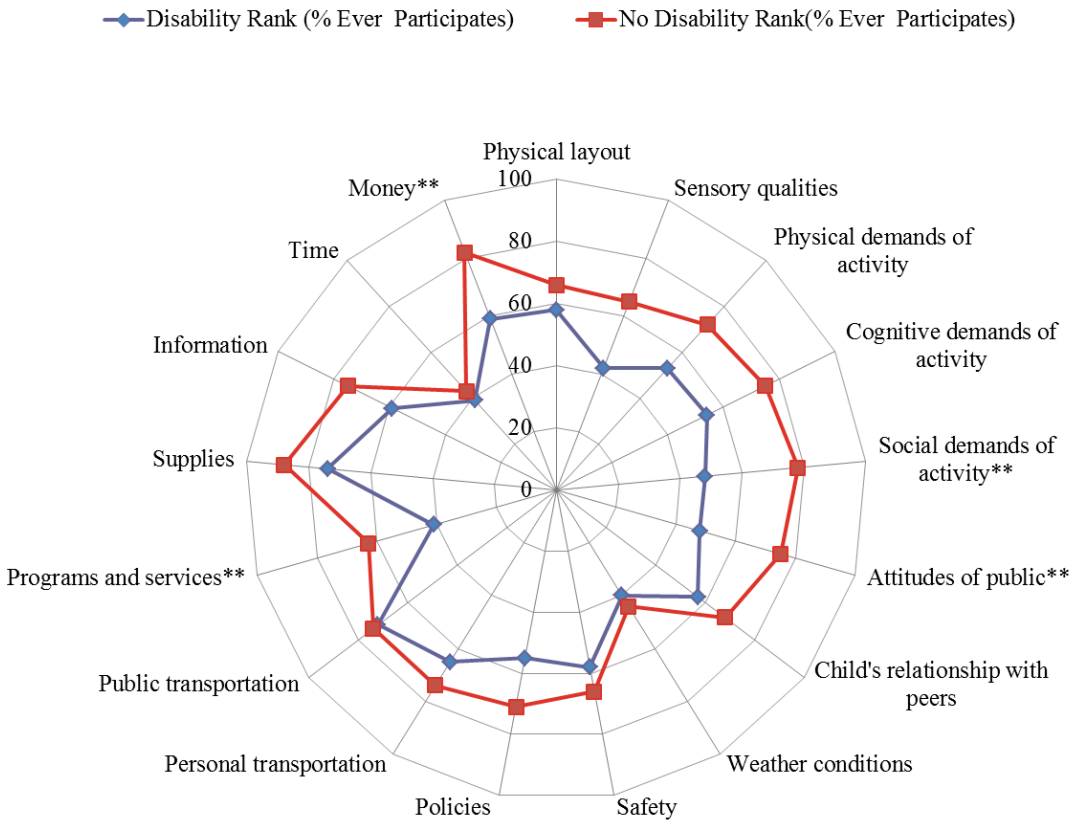
** Based on chi-square analyses (Bonferroni adjustment of the significance level set at P < .006).

Figure 2: Percentage of parents who perceived the item as a barrier to childcare/preschool-based participation



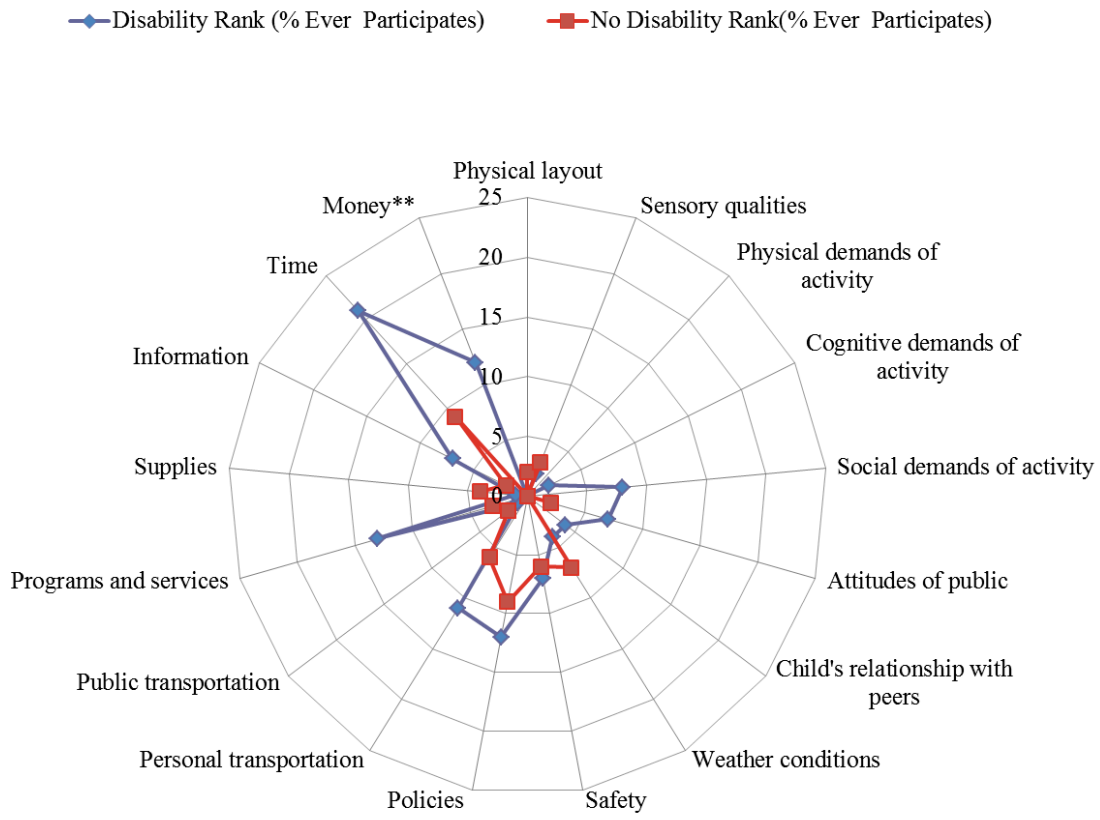
** Based on chi-square analyses (Bonferroni adjustment of the significance level set at P < .006).

Figure 3: Percentage of parents who perceived the item as a support to community-based participation



** Based on chi-square analyses (Bonferroni adjustment of the significance level set at P < .007).

Figure 4: Percentage of parents who perceived the item as a barrier to community-based participation



** Based on chi-square analyses (Bonferroni adjustment of the significance level set at P < .007).

Chapter Five: Discussion

1. Background

The outcome of this dissertation is a culturally relevant and validated participation and environment measure for young children, aged 0 to 7 years old, in Singapore. Participation is important to the development of young children and has been recognized as a key indicator of their health and well-being (UNICEF, 2013; WHO, 2007). Developed in North America, the Young Children's Participation and Environment Measure (YC-PEM) is a caregiver questionnaire about young children's participation in home, childcare/preschool, and community activities and families' perceptions of environmental impact on participation (Khetani et al, 2014a). The purpose of this dissertation was to adapt the YC-PEM to the Singapore culture and evaluate the psychometric properties of the adapted version for use by caregivers of children with and without developmental needs. The performance of the YC-PEM (Singapore) was also examined by using it to describe the participation patterns and environmental supports and barriers for young children with and without developmental needs within their childcare/preschool and community settings.

2. Discussion

2.1. The YC-PEM (Singapore)

This dissertation has established the initial psychometric properties of the culturally adapted YC-PEM with 151 Singaporean children with and without developmental needs (Lim et al., 2015a). The YC-PEM (Singapore) was found to have good to excellent internal consistency, test-retest reliability and has the ability to

discriminate between disability groups at the group summary and item levels for both participation and environment scales. The YC-PEM (Singapore) assesses (1) participation patterns of young children with and without developmental needs in Singapore, in their home, childcare/preschool and community environments, (2) perceived environmental supports and barriers to participation, and (3) activity-specific parent strategies to facilitate participation. The information generated from the YC-PEM may assist service providers and parents in (1) prioritizing areas of participation limitations that require intervention, and (2) identifying environmental factors that are related to participation and could be changed to improve participation outcomes in specific activities. The YC-PEM (Singapore) also addresses the need for large-population outcome measures that are relevant to the local context and grounded within the WHO's ICF framework. The YC-PEM could be used to explore the participation patterns of children with developmental needs at a societal level and to measure the effectiveness of policies, programs, services and projects in improving participation outcomes.

2.2. Cultural adaption of measures

2.2.1. The importance of cultural adaptation of measures

Cross-cultural adaption studies typically include and emphasize language translation (Sousa & Rojjanasrirat, 2010). In this dissertation, cultural adaptation of the YC-PEM did not include language translation because both countries share the same national language and that is English. However, the Applied Cultural Equivalence Framework (Stevelink & Brackel, 2013) guided major item and semantic modifications to the original YC-PEM based on the perspectives of service providers and caregivers on

how the YC-PEM could be made more relevant to the Singapore context (Lim et al., under review). Operational modifications were also made to improve the ease of understanding of the YC-PEM, according to the perspectives of service providers and caregivers in Singapore. These findings indicate that cultural adaptation, without language translation, of the YC-PEM is important because there are cultural differences in the participation and environment items as well as the way people understand words. Cultural adaptation of instruments is also needed within countries, as our world becomes increasingly globalized and high levels of immigration have resulted in multicultural populations. These immigrants may be bilingual and speak the national language of their country of residence, but they also may hold on to the cultural beliefs of their country of origin (Tamis-LeMonda et al., 2007). Having access to culturally relevant instruments facilitates culturally competent assessment practices by ensuring that essential information relevant to the culture is captured (Stevelink & Brackel, 2013).

In the absence of locally developed instruments, many of the instruments that Singaporean healthcare professionals use are developed from Western countries and then conveniently used because they are in the same language (King et al., 2012). Poon & Lim (2012) suggested that child assessment in Singapore is impeded by the lack of availability of locally developed or adapted and normed instruments. Instruments developed in another culture may not be relevant to the Singapore context. Thus, clinicians and researchers may miss essential information because the instruments do not have the items that are reflective of the local culture. For example, the item, ‘structured learning time’, was added to the Singapore YC-PEM because service providers and parents in our study

indicated that it is an important and common activity among young children in Singapore. If the YC-PEM were not culturally adapted, essential information on Singaporean children's participation in structured learning time, an integral part of their daily routine, would not be captured. The YC-PEM would thus be a less accurate reflection of the experience of participation by missing an important dimension of Singaporean children's and families' lives. Hence, Singaporean clinicians and researchers should be cautious when interpreting results of studies using instruments that were developed in other cultures (Lim et al., 2014a), especially for use in policy-making. There should be precautionary measures to ensure that instruments used in policy-making are culturally validated and more should be done to undertake cultural adaptation of existing instruments that were developed in other countries. Having more instruments that are relevant to the Singaporean culture will ensure that children with developmental needs are assessed comprehensively, appropriate referrals for early intervention services are made, and children receive culturally competent care (Lim et al., *under review*).

2.2.2. The cultural adaption process

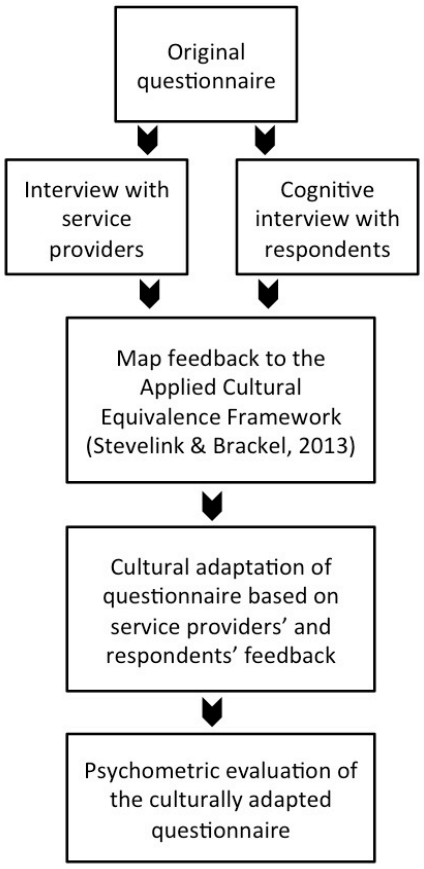
This dissertation used the 'Guidelines of the Process of Cross-Cultural Adaption of Self-Report Measures' developed by Beaton et al. (2000) to culturally adapt the YC-PEM, with the addition of cognitive interviews as suggested by Price et al. (2009). Similar to the findings of Price et al. (2009), cognitive interviews with parents have been found to be useful in cross-cultural adaption of measures. Authors have found that it is important to include multiple stakeholders in the development of measures because they provide distinct views and specialized areas of knowledge with regards to measure

development (Knafl et al., 2007; Coster & Khetani, 2008). This can also apply to cultural adaptation of measures, as the results of the first study suggest that adding cognitive testing to experts' input was useful in strengthening the cultural relevance of the YC-PEM (Lim et al., *under review*). In the current work, cognitive interviews with parents were useful because they are the proposed users of the questionnaire, and they were able to provide perspectives of their understanding of the items. For example, parents indicated that they would like more examples under the environmental items to help them to better understand the item's intent.

Whilst the 'Guidelines of the Process of Cross-Cultural Adaption of Self-Report Measures' (Beaton et al., 2000) guided the process of cultural adaption of the YC-PEM, the Applied Cultural Equivalence Framework (Stevelink & Brackel, 2013) complemented the guidelines by providing the requirements for cultural equivalence. The framework was useful in organizing the data into the various cultural equivalence categories and ensuring that all aspects of cultural equivalence have been considered. To date, the focus of cultural adaption guidelines appears to be on language translation, as it is assumed that the process of language translation naturally leads to cultural adaption of the measure (Guillemin et al., 1993). However, this study demonstrated that it is also important to focus on the cultural relevance of the measure's content (Lim et al., under review). Therefore, there should be guidelines beyond language translation and focus on the requirements and methods to achieve cultural equivalence such as those listed in the Applied Cultural Equivalence Framework (Stevelink & Brackel, 2013). This dissertation proposes a brief guideline for cultural adaptation of questionnaires that enhances existing

guidelines by including (1) cognitive interview with respondents, and (2) mapping the data to cultural equivalence categories (see Figure 1).

Figure 1: Proposed guideline to culturally adapt a questionnaire with a focus on establishing cultural equivalence



This proposed cultural adaptation guideline could be used for instruments that do not require language translation or it could complement existing guidelines and be used after language translation of instruments. The proposed guideline should be used because it focuses on the cultural relevance of the content of the instruments. Other advantages of the guideline are that (1) it includes important stakeholders' input in the cultural adaption process, (2) the analysis of their input is based on an evidence-based framework, and (3)

it provides a systematic process in cultural adaption of instruments. There are limitations to the proposed guideline and they will be discussed in the later sections. More research should be done to verify the process of the proposed guideline.

2.3. Findings around participation

To establish the construct validity and utility of the Singapore YC-PEM, this dissertation compared the participation patterns and environmental supports/barriers between children with and without developmental needs in childcare/preschool and community environments. Through this process, there were new findings about participation patterns of young children in Singapore and differences in participation of children with and without developmental needs.

2.3.1. Participation patterns of young children in Singapore

The out-of-home routine of young children in Singapore appears to revolve around childcare/preschool activities, trips to shopping malls and parks and enrichment classes. Singapore is a modern city-state with many shopping malls and a variety of places to eat out. Shopping and enjoying good food are known to be Singaporeans' favorite pastimes and this has inherently influenced the activity participation of young children in Singapore (Singapore Tourism Board, 2015). Singapore is also known for being a garden city with 300 parks and 4 nature reserves (Singapore Tourism Board, 2015). Young children in Singapore are thus able to engage in unstructured physical activities with such accessible green urban spaces.

Singapore has a competitive education system and many parents send their children to childcare/preschool at an early age and for enrichment classes to keep up with

their peers academically (Tan, 2014). Singaporean children's participation in academic-related activities is substantiated by the addition of 'structured learning time' in the home setting of the Singapore YC-PEM according to the perspectives of Singaporean parents (Lim et al., *under review*). Prior studies found that the incidence of myopia and obesity amongst Singapore children is high and is hypothetically related it to the lack of physical activities and early exposure to academic activities (Dirani et al., 2010; Rose et al., 2008; Schmidt et al., 1998). This study affirmed the hypothesis that Singaporean children start on academic activities such as childcare/preschool and enrichment classes at a very young age.

In comparison, Dunst et al. (2002) reported that the activities in which young children in the US most frequently participated are play, art/entertainment, outdoor, and recreational activities. Differences in participation patterns between young children in Singapore and the US might be due to different parental belief systems. Studies that compared the parenting styles of Asian and Euro-American parents residing in the US found differences even with the effect of acculturation on parental belief systems (Parmar et al., 2004; Parmar et al., 2008). Asian parents spent more time on pre-academic activities that focus on cognitive development while Euro-American parents focus more on allowing their children to express themselves through play; the authors attributed this difference to Asians' cultural beliefs rooted in Confucianism (Parmar et al., 2004; Parmar et al., 2008). Further, the driver of Singapore's economy is human resources, as Singapore lacks natural resources (Ng, 2011). Therefore, Singapore places education as a priority (Ng 2011; Tan 2008), so Singaporean parents may tend to believe that their

children will have a head start in life if they are exposed to academic activities from early in life (Lim et al., 2014).

Consistent with the developmental niche theoretical framework (Harkness & Super, 1992), Singapore's emphasis on education might have influenced the values and beliefs of Singaporean parents about how their children develop, and these beliefs led to opportunities for Singaporean children to participate in academic-related activities (Harkness et al., 2011). Early involvement in academic activities might have facilitated the visual-motor skills of Singaporean children, as they were found to have higher visual-motor scores when compared to American children (Lim et al., 2014). Additionally, the cognitive development of Singaporean students might be enhanced due to early involvement in academic activities, as they consistently show strong performance on international assessments such as the Program for International Student Assessment (PISA) and the Trends in International Mathematics and Science Study (TIMSS) (Lynn & Meisenberg, 2010; Snart, 2011). Evidently, participation might be a mediator between culture and development. Participation might exist within the constructs of the developmental niche framework: customs of care and settings of daily lives. These constructs together with caregiver psychology are mediators between culture and development (Harkness & Super, 1992). More research is required to relate participation to these constructs and to further develop the framework.

The YC-PEM (Singapore) is a useful tool to guide our understanding of participation metrics and what they reflect about the community. Future research could use the YC-PEM (Singapore) to explore the relationship between activity participation

such as academic activities, and health and developmental outcomes of Singaporean children. Research is also required to explore the values and beliefs of Singaporean parents in relationship to their activity participation. The YC-PEM could potentially contribute to further development of the developmental niche framework through measuring participation, and exploring its relationship with parental beliefs and developmental outcomes.

2.3.2. Participation differences: children with and without developmental needs

Children with developmental needs had significantly lower participation summary scores in childcare/preschool and community settings as compared to children without developmental needs. Previous studies in other countries found participation differences between children with and without developmental needs in out-of-home and broad category activities such as community activities, education, social interaction and leisure activities (Khetani et al., 2013; LaVesser & Berg, 2011; Law et al., 2012; Leung et al., 2011; Rosenberg et al., 2012; Soref et al., 2012), which are similar to findings of this dissertation. Parents of children with developmental needs in both Singapore and Western countries report difficulties in out-of-home participation. Previous studies related these difficulties to the management of socio-emotional and behavioural challenges that affect their children's ability to participate in out-of-home activities (LaVesser & Berg, 2011; Khetani et al., 2012; Baker et al., 2002). Parents' ability to manage behaviour as an environmental impact on participation was not identified in this dissertation because the YC-PEM did not include this as an environmental item.

2.4. Findings concerning environmental impact on participation

Environmental impact on participation identified in this study mostly differs in several ways from previous studies (Khetani et al., 2013; LaVesser & Berg, 2011; Law et al., 2012; Leung et al., 2011; Rosenberg et al., 2012; Soref et al., 2012). A similarity in environmental impact on participation is socioeconomic status of the family, while differences are lack of social support and transportation, programs and services, and societal attitude.

2.4.1. Socioeconomic status

Family income has an environmental impact on out-of-home participation amongst children with developmental needs in Singapore (Lim et al., 2015b). Law et al. (2012) and Soref et al. (2012) also found that families' income and socio-economic status influence the participation diversity and intensity of children with developmental needs. In this dissertation, 41% of the parents with children with developmental needs (compared to 9% of parents with typically developing children) rely on a single income so that one parent can be the child's full-time caregiver. Also, money has to be set aside for early intervention expenses. Consequently, these parents may feel that having more money would enable them to support their children's participation optimally, especially if they have more than one child to care for. Future studies should also include number of siblings to explore if this factor has any effect on the family finances and the child's participation.

2.4.2. Social support and transportation

Previous studies that were implemented mainly in America found that the lack of social support and transportation were perceived barriers to participation among children with developmental needs (Khetani et al., 2013; Khetani et al., 2012). In Singapore, these were not identified as barriers to participation. Social support may be perceived to be adequate by caregivers because Singaporean families with young children typically place their children in childcare centres, employ domestic helpers to care for their children, or seek the help of grandparents to care for their children. The Singapore government provides subsidies and incentives if families adopt these alternative childcare arrangements so as to encourage Singaporean women to re-join the workforce after childbirth (Quek et al., 2011). Family support is also more common in collective Asian societies than in individualistic western societies, as the extended family, or even neighbors, are willing to help to care for others' children (Frankenberg et al., 2002). Transportation was also not identified as a barrier to participation and it may be because Singapore is a small island with an effective and cost-efficient public transport network (The Straits Times, 2014).

2.4.3. Programs and services

Another difference in environmental impact on participation between those identified in previous studies (Khetani et al., 2013; Khetani et al., 2012; Soref et al., 2011; Rosenberg et al., 2011) and this dissertation included the lack of programs and services to facilitate the participation of Singaporean children with developmental needs in mainstream childcare/preschool and in the community. Singapore underwent a socio-economic revolution in the 1980s that led to a meritocracy system where students

attended schools based on their perceived aptitudes and abilities (Weng et al., 2015). Schools were separated into two main categories, mainstream and special schools. Despite the benefits of inclusive education and its emphasis internationally, Singapore does not have legislation that mandates inclusion of children with disabilities and the majority of these children receive services outside the mainstream (Yeo et al., 2011). Due to recent leadership changes, legislative reforms and economic development, Singapore is beginning to recognize the importance of being an inclusive society (Lim, 2009). More support has been provided for students with disabilities within the regular education system, but this is limited to primary and secondary schools (Lim et al., 2013a).

Due to limited direct government involvement, less support is provided in the preschool sector (Yeo et al., 2011). Preschool children with developmental needs thus have fewer opportunities to learn alongside their typically developing peers. A Singapore study conducted by Nonis (2006) explored the attitudes of preschool teachers towards inclusive education. Results indicated that 25% were supportive and willing to take on responsibility of teaching students with special needs but 57% rejected this responsibility. The respondents raised concerns such as lack of resources, knowledge and training in helping students with special needs to learn. More efforts are required in developing community-based early intervention programs and services that meet the specific needs of the preschool school sector and to provide equal opportunities for participation among children with developmental needs and their typically developing peers. Programs such as the Developmental Support Program (DSP) (MSF, 2013) are emerging but insufficient in supporting the participation of children with developmental needs, especially those

children with higher needs. Furthermore, wait times for early intervention services are long and access to the clinic is limited (Lian et al., 2007).

2.4.4. Societal attitudes

Along with changes in the education system, there also needs to be a change in the societal attitudes towards people with disabilities in Singapore, as parents from this dissertation reported that public attitude is lacking as an environmental support. Singapore's meritocracy system focused on the high achievers to help develop Singapore's economy (Ng, 2011; Tan, 2008) and may have neglected those who are differently abled to contribute to the economy. This has inherently influenced the attitude of Singaporeans towards people with disabilities. Unlike children with obvious physical disabilities, children with developmental needs have impairments (e.g. problems with social interaction) that are not always noticeable to others, and these may result in the public misinterpreting their actions and behaviours. The public may perceive them as misbehaving or that the parents have not taught them well. This is especially so in Asian societies where children are taught self-control and to be filial at an early age (Lim et al., 2013b). Not surprisingly, parents in our study identified societal attitudes as a barrier to community-based participation. Singaporean parents are in an environment where people are learning to be more receptive of people with disabilities and they also have to manage the public's perception of their children's behaviour. These factors may have deterred Singaporean parents from bringing their children with developmental needs out in the community. More efforts are required to raise awareness of the challenges that these families face.

Congruent with the Person-Environment-Occupation (PEO) Model of occupational performance (Law, 1996), the cultural, political and social environments may have an enabling or constraining effect on occupational performance of children with developmental needs in Singapore. Occupational performance, like participation, is shaped by the transaction between the person, environment and occupation in which the person engages, across time and space (Law et al., 1996; Law et al., 2006). Children with developmental needs in Singapore participate in fewer community activities compared to typically developing children because of environmental influences, such as societal attitudes. The government has recently recognized the importance of an inclusive society and a large amount of funding was allocated to community care efforts and education to change public attitudes (Lim, 2009). With the Singapore society becoming more inclusive over the years, there appears to be increased acceptance of children with developmental needs, evident from the number of emerging programs and services (MSF, 2013; Yap et al., 2014). Children with developmental needs in Singapore now have more participation opportunities compared to children with developmental needs 30 years ago but there is still more that can be done to equalize the opportunities.

To further validate whether intervention at the environmental level is effective in improving participation outcomes, future research could use the YC-PEM (Singapore) to explore the effectiveness of local programs such as the Developmental Support Program (DSP) and the Signposts for Building Better Behavior Program (Yap et al., 2014) that intervene at the environmental level. Longitudinal studies could be done to measure the impact of societal attitudes on community-based participation and whether it evolves over

time with the recent efforts at changing public attitudes of people with disabilities. These studies could validate the assumption of the PEO model that positive changes in the environment across time could lead to a better person-environment-occupation fit that translates to improved occupational performance and participation (Law et al., 1996).

3. Contributions to Occupational Therapy

3.1. The YC-PEM (Singapore)

Internationally, the focus of intervention for children with developmental need has shifted from "fixing a deficit" to promoting functional independence and participation (Law & Darrah, 2014). In keeping with this paradigm shift, measures used in clinical practice should capture information about the child's functional performance and participation success within a family-centred approach (Law & Darrah, 2014). Occupational therapists in Singapore now have a culturally relevant and validated tool to measure the participation and environment of young Singaporean children. The YC-PEM (Singapore) offers occupational therapists a new and innovative measure that they could potentially use in their practice to understand children's participation and environment in a family-centred way. Lim et al. (2014b) used the Knowledge-To-Action (KTA) Framework (Graham et al., 2006) to understand the current assessment practice of occupational therapists in Singapore and to introduce the YC-PEM in the form of a research overview. They found that only 4 out of 25 (8%) Singaporean occupational therapists used participation and environment assessments while all used motor and visual-perception skills (impairment-focused) assessments. Participants in the study cited the lack of participation and environment measures as a reason for not using them and all

were interested in using the YC-PEM. Thus, the YC-PEM (Singapore) could potentially fulfill this assessment practice gap. Moreover, starting the therapeutic relationship with a participation measure informs parents of the role of occupational therapists and the focus on the person-environment-occupation fit to facilitate occupational performance and participation. Occupational therapists may also have an easier time explaining their role in helping the children with an assessment that is reflective of the nature of their profession.

The uptake of the YC-PEM in clinical practice depends on occupational therapists being able to administer it, interpret the results and use the findings to develop an intervention plan in collaboration with families (Khetani et al., 2014b). Occupational therapists in Singapore identified that they may not know how to use the results of the YC-PEM and suggested the development of clear guidelines in interpreting and applying the YC-PEM results to formulate an intervention plan (Lim et al., 2014b). The YC-PEM is similar to the Participation and Environment Measure for Children and Youth (PEM-CY) (Coster et al., 2011) for older children, ages 5-17. The PEM-CY's utility for collaborative care planning with individual families of children and youth with disabilities has been examined and a four-step decisional support algorithm has been identified: (1) the parent rank orders activities in which change is desired, (2) child preferences are included, (3) service provider refines parent and child goals, and (4) activity-specific supports and barriers, and strategies are identified (Khetani et al., 2014c). Given the age of the children, child preferences and goals may be difficult to incorporate if the same decisional support algorithm is used to interpret and apply the YC-PEM

results. More research is required to determine if a similar algorithm could be used to interpret and apply the YC-PEM results.

Knowledge translation strategies, guided by the Knowledge-To-Action (KTA) Framework (Graham et al., 2006) could be utilized to disseminate the YC-PEM (Singapore) effectively to service providers (Lim et al., 2014b). In addition to developing a decision support algorithm, the YC-PEM and its related research could be shared through different platforms such as webinars, educational outreach, audit and feedback, interactive continuing education sessions and problem-based learning groups (Law et al., 2001; MacDermid & Graham, 2009). KT strategies that are interpersonal and multifaceted have been found to be effective (Grimshaw et al., 2001). Lim et al. (2014b) reported that some Singapore occupational therapists in their study felt that parents should be educated about the importance of assessing their child's participation and environment and how they can have an impact on their child's well-being. Therefore, the knowledge translation strategies should also reach out to parents, and other caregivers such as teachers.

3.2. The potential role of occupational therapists

The Singaporean parents in our study identified fewer environmental factors that impact on participation of children with developmental needs as compared to previous studies (Khetani et al., 2013; LaVesser & Berg, 2011; Law et al., 2012; Leung et al., 2011; Rosenberg et al., 2012; Soref et al., 2012). The environmental factors that they identified were mainly related to the larger society and policies (e.g. public attitudes, lack of programs and services), which often require time to change. There appears to be a lack

of awareness of how the immediate environment can impact participation amongst Singaporean parents of children with developmental needs. They may not be aware of how tasks could be adapted to their child's cognitive, socio-emotional or motor functioning, or how their environment could be changed to achieve successful participation. Occupational therapists are well positioned to increase this awareness and to collaborate with parents to improve on their children's home, childcare/preschool and community participation. This is aligned with changes in the field of rehabilitation where functional, activity-focused therapy approaches have developed over the past 15 years and have been shown to be effective in improving the performance of children with disabilities (Law & Darrah, 2014).

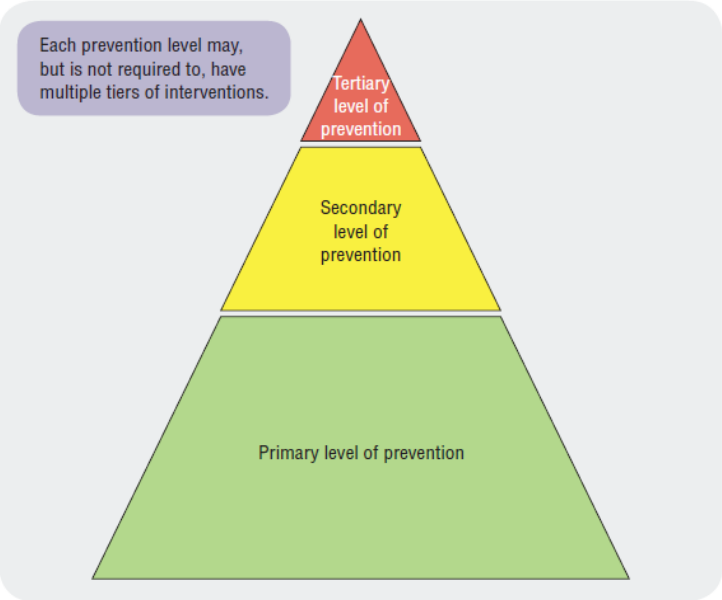
Two approaches, context-focused therapy and occupational performance coaching, could be considered, both of which guide occupational therapists in facilitating parents to think about the demands of the activities/environment and how to intervene on immediate environmental factors to promote participation outcomes. Context therapy involves changing the task and environmental factors to achieve parent-identified functional goals (Darrah et al., 2011). A randomized controlled trial conducted with 128 young children with cerebral palsy found that context-focused therapy approaches were as effective as child-focused therapy approaches and should be considered as a viable treatment strategy (Law et al., 2011). Context-therapy is a potential intervention, as the environment is considered more amenable to change than the person (Law et al., 2011). However, if it is logistically difficult to conduct therapy in the natural environment of the child such as at home or at preschools, Occupational Performance Coaching (OPC)

(Graham et al., 2009) could also be considered. OPC utilizes collaborative problem-solving within a coaching relationship to guide parents to recognize and apply social and physical environmental changes that support more successful participation outcomes for themselves and their children (Graham et al., 2009). Law et al. (2015) found that using a coaching approach collaboratively with youths with physical disabilities and their families was effective in identifying and implementing strategies to remove environmental barriers to leisure participation. Contemporary practice perspectives that influenced the development of context therapy and OPC (Darrah et al., 2011; Graham et al., 2009) are similar to those of YC-PEM. Therefore, both could be potential intervention approaches for Singaporean occupational therapists to adopt so as to address the participation and environment issues that the YC-PEM has indicated.

To address the lack of programs and services for children with developmental needs in Singapore, occupational therapists should also be working beyond the acute hospitals and within the community to develop programs and services that support the participation of children with developing needs. An example is the involvement of occupational therapists working within the Response to Intervention (RtI) Framework (Cahill, 2009). Adopted by the U.S Department of Education, the RtI guides implementation of special education programs in schools (National Center on Response to Intervention, 2010) (see Figure 2). The RtI benefits students with various learning needs by providing a system for delivering responsive instructional interventions that integrate academic instruction with positive behavioural support (American Occupational Therapy Association [AOTA], 2008). The RtI consists of three prevention foci: primary,

secondary and tertiary level. Primary prevention is high quality core instruction that meets the need of most students; secondary prevention involves evidence-based intervention(s) of moderate intensity that addresses the learning or behavioral challenges of most at-risk students; and tertiary prevention is intensive intervention that includes referrals to special education for individualized education plans (National Center on Response to Intervention, 2010).

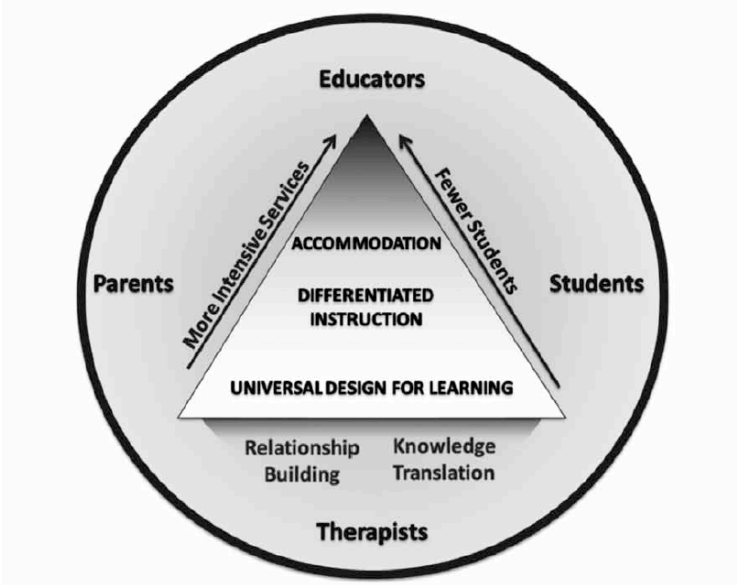
Figure 2: Response to Intervention (RtI) Framework (National Center on Response to Intervention, 2010)



Occupational therapists have been increasingly involved in preschools within the context of RtI in the areas of handwriting, self-regulation and self-management (Cahill, 2009; Frolek et al., 2008; Henry et al., 2009; Kiss 2007). There appears to be great potential for occupational therapists to contribute to RtI in improving the participation of children within preschools because of their knowledge and skills in changing the

environment to enable children of various learning needs to participate in preschool activities. A school-based occupational therapy service delivery model, Partnering for Change (P4C), emphasizes the partnership of the therapist with teachers and parents to change the life and daily environment of a child with developmental coordination disorder (Missiuna et al., 2012) (see Figure 3). P4C focuses on building the capacities of teachers and parents through collaboration and coaching in context with the goal of successful participation without referring them all for individualized, specialized intervention (Missiuna et al., 2012). The concepts of this model are similar to RtI except for its key features that emphasize building relationships and knowledge translation that occurs during the partnership between therapists and teachers in context (Missiuna et al., 2012). The occupational therapists that implemented P4C found that it was effective in building relationships within the community and providing services that are impactful (Campbell et al., 2012).

Figure 3: Partnering for Change Model (Missiuna et al., 2012)



As Singapore progresses towards inclusivity, RtI could be a potential framework to guide implementation of inclusive education and P4C could be a potential model to guide the delivery of occupational therapy services within the community. Developed locally in recent years, the Developmental Support Program (DSP) is a community-based early intervention program that provides learning support and therapy interventions to at-risk children with mild developmental needs in their childcare/preschool (MSF, 2013). The program is led by Learning Support Educators (LSEd) who are senior preschool teachers supported by allied health professionals such as occupational therapists, so that some of the knowledge in supporting children with developmental needs can be applied to help them participate in their preschools (Chong et al., 2014; MSF, 2013). The DSP could be a form of secondary prevention within the RtI framework and occupational therapists could be involved in the RtI framework by providing support to preschool

teachers to facilitate the participation of children with developmental needs within the preschools. The YC-PEM (Singapore) is a tool with the potential to measure the efficacy of programs such as the DSP and service frameworks such as the RtI and P4C in improving the participation outcomes of children with developmental needs.

3.3. Challenges faced by parents of children with developmental needs

The environmental factors (e.g. financial support, programs and services, and societal attitudes) that have been identified to be important by parents of children with developmental needs suggested that bringing up a child with developmental needs in Singapore could be emotionally and financially demanding. With the society's emphasis on education, parents of children with developmental needs may be constantly worried about their children not catching up because that may affect their academic performance at school. They may also be concerned about their children falling through the cracks of the competitive education system and not being given the opportunity to develop in their own way. To address these concerns, they seek programs and services to help bridge the developmental gaps, but these programs and services are often not integrated, and parents have to choose between mainstream and early intervention centres at voluntary welfare organizations. Almost 40% of the parents of children with developmental needs in this study chose both, as they may like their children to have the opportunity to experience mainstream education. Parents thus have to ferry their children between childcare/preschools, early intervention centres or clinic-based therapy and at the same time implement the home program shared by the therapists from various disciplines/centres, in addition to their school homework. Their children are also

receiving different modes of instructions from the different centres, which can be confusing especially for children with developmental needs who often have difficulties with adaptation.

The dissertation also reported that 41% of the parents of children with developmental needs rely on a single income so that there is a caregiver available to care for the child full-time. Families have to pay for therapy, childcare/preschool and early intervention centre fees. They may have limited resources for participation in community activities that incur costs such as enrichment classes and dining out. Another deterrent from community-based participation is public attitudes towards children with developmental needs.

Healthcare and early childhood professionals working with families with children with developmental needs should understand the stressors that these families face in their everyday lives so as to support the child and family's well-being during intervention. Rehabilitation interventions that embrace family-centred services were found to be more effective in promoting participation (Law & Darrah, 2014). Family-centred service acknowledges that families are different and special, and that children function best within a supportive family and community (Rosenbaum et al., 1998). Healthcare providers are seen as collaborators with the family, promoting the family's capacity to make decisions about their needs and preferences (Nijhuis et al., 2007). Tang et al. (2011) found that early intervention providers in Singapore do not perceive themselves as family-centred despite their strong beliefs and attitudes about family-centred service. This might be because they lack the tools and knowledge to provide family-centred service.

The YC-PEM (Singapore) is a tool that potentially could be utilized by service providers to bridge the gap between beliefs and practice, as this study found it to be useful in understanding the family life and environmental needs of children with developmental needs. However, even with a tool that is grounded in the lives of families, it might be difficult for service providers to work in the natural contexts of these families because clinic-based interventions are more cost effective. Therefore, coaching approaches such as the Occupational Performance Coaching (OPC) (Graham et al., 2009) could be utilized in the clinic to empower caregivers with the knowledge and skills to facilitate participation of children with developmental needs within their natural contexts.

4. Study Limitations

The cultural adaption process of the YC-PEM (Singapore) could be better implemented with the addition of the cognitive interviews. For example, the interviews with service providers and cognitive interviews with respondents were conducted with the original version of the YC-PEM (Lim et al., under review). The limitations of this approach were that similar comments were repeated in both groups and the YC-PEM was only assessed and modified once. The process might be better if cognitive interviews with respondents were conducted first with the original version of the questionnaire, followed by cultural adaption of the questionnaire, then interviews with service providers with the adapted version of the questionnaire. The questionnaire could then be further adapted based on the providers' input, resulting in two rounds of cultural adaption. This approach could be more efficient in reducing overlapping comments from both groups and effective

in ensuring that the content of the adapted version is valid with two rounds of assessment and modification.

Another limitation of the study was that the principal investigator, who is also the developer of the YC-PEM (Singapore), conducted the interviews and therefore the principal investigator might unintentionally influence the participants' perspectives. Further, member checking and self-reflexivity were not implemented to strengthen the trustworthiness and rigor of the cultural adaptation process. Participants could have checked parts of the interview transcript. Self-reflexivity is a process that researchers use to establish trustworthiness through acknowledging their experiences that may influence data collection and/or analysis that can potentially impact on findings (Creswell, 2013). Due to my own background as a Singaporean and pediatric occupational therapist, my experiences might have influenced interpretations of the findings and self-reflexivity could strengthen the trustworthiness of the findings.

Another limitation of this study is the convenience sample that is not representative of the general population. The sample consists of more highly educated parents and lacks sufficient representation from minority ethnic groups such as Malays and Indians. Based on the Singapore population statistics, only 66% of Singaporeans have higher than secondary school qualifications and the ethnicities of Singaporeans are Chinese (60%), Malay (15.3%), Indian (11.7%) and others (12.9%) (Singapore Statistics, 2014). The study could have recruited more participants or adopted a stratified sampling approach to ensure that the study population was representative of caregivers of all educational backgrounds and ethic groups (Lim et al., 2014). Our sample also had fewer

children younger than 4 years old, resulting in a need to collapse age groups for analysis and thus reducing the likelihood of detecting age group differences in participation because the groups have been reduced to two. The respondents were mostly mothers (83.4%). Fathers might have differing perspectives of their children's participation and environment as compared to mothers.

5. Future directions

This dissertation highlighted the need for a gold standard cultural adaption guideline that extends beyond language translation, is evidence-driven and has clear procedures and requirements to achieve cultural equivalence. It would be useful in addressing worldwide prevalence of many diverse cultures within the same language group by guiding the development of measures that facilitate culturally competent assessment practice. A brief guideline has been proposed in this dissertation but more research is required to validate the usefulness of the guideline.

Internationally, more studies could use the YC-PEM to assess participation in specific activities. Current studies of participation of young children with and without developmental needs focus on broad category activities (Khetani et al., 2013; LaVesser & Berg, 2011; Law et al., 2012; Leung et al., 2011; Rosenberg et al., 2012; Soref et al., 2012). Studies that assess specific activities in various settings should be conducted to compare the participation patterns between children with and without development needs across cultures. Locally, the responsiveness of the YC-PEM (Singapore) in measuring clinical change should be assessed to ensure that it works well for therapists and families. The YC-PEM (Singapore) could be used to determine the effects of intervention (e.g.

Developmental Support Program) on participation outcomes. The YC-PEM (Singapore) could be used in longitudinal studies to explore the effect of changes in environment (e.g. change in societal attitudes) on participation, changes in policy (e.g. more inclusion) and the effects of participation (e.g. more academic activities) on developmental outcomes.

To further understand Singaporean parents' perspectives of participation and environment as well as their parenting values ands beliefs, qualitative interviews could be conducted and the results could direct interventions to increase the awareness of participation and environment amongst Singaporean parents. For example, besides focusing on the parents' academic-related participation goals for their children (e.g. group learning), occupational therapists could advocate for leisure goals of both children and their parents (LaVesser & Berg, 2011). Leisure and play activities aid in self-expression, are important in facilitating feelings of competence, and can be an opportunity for parent-child bonding (Matuska & Christiansen, 2008; Ginsburg, 2007). Qualitative interviews could also be conducted with parents of children with developmental needs to complement the YC-PEM (Singapore) findings through gaining a deeper understanding of their daily stressors in caring for their child with developmental needs and the specific types of assistance they require.

6. Conclusion

Occupational therapists have long acknowledged the influence of culture on occupations and the need to provide culturally competent care (Bonder et al., 2004). Using an assessment tool that is adapted to the cultural context of the client, like the YC-PEM, is a way of initiating culturally competent care. After adapting its content culturally

to the Singapore context, the YC-PEM was found to be a reliable and valid tool to measure participation and environment of young children with and without developmental needs in Singapore. In Singapore, occupational therapists have assumed that the assessments that they have adopted from other countries could be used in Singapore because they are in the same language. The findings from this dissertation challenged this preconception and found that cultural differences between assessments tools exist even if they are in the same language. Thus, it is important to adapt participation measures culturally before they are used in a new culture, even when language translation is not required. This dissertation also found ways to adapt assessment tools to enhance their cultural relevance and the same knowledge can be applied to many countries in our increasingly multicultural world.

Through the cultural adaptation process, the participation patterns and environmental supports and barriers to participation of young children with and without developmental needs in Singapore were explored, highlighting the challenges that Singaporean parents of children with developmental needs face. The Singapore (YC-PEM) is a promising and innovative measure that occupational therapists in Singapore could use in their practice to initiate participation focused interventions. Researchers could also use the YC-PEM to implement population-based research that could influence policy makers by providing them a way to consider how our environments impact children's participation and their development.

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