

**PARTICIPATION MEASURE
FOR KOREAN CHILDREN WITH DISABILITIES**

**CROSS-CULTURAL ADAPTATION OF THE PARTICIPATION AND
ENVIRONMENT MEASURE FOR CHILDREN AND YOUTH IN THE KOREAN
CULTURAL CONTEXT**

BY

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YOUTH IN THE KOREAN CULTURAL CONTEXT**

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Lay Abstract

The Korean version of the Participation and Environment Measure for Children and Youth (KPEM-CY) was examined for use with Korean children aged 5 to 13 years through two processes. Firstly, the original PEM-CY was cross-culturally translated to Korean based on the different perspectives of various experts working with children with disabilities. Second, the KPEM-CY was tested to determine whether it is a reliable and valid tool to assess the participation of Korean children with disabilities and the environmental supports or barriers to their participation. Through this process, the participation patterns of Korean children with and without disabilities and environmental factors affecting their participation were identified. These results may help occupational therapists plan intervention goals and could provide the basis for future studies of the participation of Korean children with disabilities. The KPEM-CY could also be used in population-level studies to compare children's participation patterns across regions, countries, and cultures.

Abstract

The Participation and Environment Measure for Children and Youth (PEM-CY) is a parent-report measure assessing children's participation and environmental factors across home, school and community. Although the PEM-CY has demonstrated reliability and validity in North America, no studies have yet reported the psychometric properties of a Korean PEM-CY (KPEM-CY). In order to use the PEM-CY in the Korean cultural context, this research developed the KPEM-CY and tested its reliability and validity in the Korean population. Through a unique cross-cultural adaptation guideline, the KPEM-CY was developed. A total of 76% of the participation items and 29% of the environment items were revised to improve their fit with the Korean culture. To examine internal consistency, test-retest reliability, and known group validity of the KPEM-CY, 196 parents of children (80 children with disabilities) aged 5 to 13 years were recruited in the city of Daejeon, South Korea. Internal consistency was found to be moderate to excellent for the summary scores. Test-retest reliability was excellent for participation frequency and extent of involvement across the three settings and moderate to excellent for the home setting. Significant differences were identified in the specific dimensions of children's participation and environmental factors according to factors of a child and their parents (i.e., disability, child's age, and type of school). This thesis provides evidence that the KPEM-CY is a reliable and valid measure for Korean children aged 5 to 13 years. The results of this thesis provide an understanding about Korean children's participation patterns and the impact of environmental factors on their participation. This new knowledge can assist occupational therapists to set intervention goals and to conduct

future studies to improve the participation of Korean children with disabilities. The KPEM-CY also has the potential to be used in population-level studies to compare children's participation patterns across regions, countries and cultures.

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Preface

This thesis is prepared as a sandwich thesis that consists of three individual studies described in separate manuscripts as prepared for peer-reviewed publication.

For all manuscripts, Yunwha Jeong developed the research questions, provided the overall study design, prepared ethic submissions, managed recruitment, performed data collection, analyzed and interpreted the data, and prepared manuscript for submitting to the peer-reviewed journals.

Chapter 2: Development of Korean Version of the Participation and Environment Measure for Children and Youth

Dr. Law reviewed ethics submission, consulted on the cross-cultural adaptation process of a measure to the Korean cultural context, provided assistance with data analysis and interpretation and gave critical review of the manuscript. Dr. Kim consulted on participant recruitment for the cognitive interview in South Korea and the cross-cultural adaptation process. Professor DeMatteo provided editorial assistance with manuscript preparation. Professor Stratford reviewed the manuscript. All co-authors mentioned above approved the final draft.

Chapter 3: Psychometric Evaluation of the Korean Version of the Participation and Environment Measure for Children and Youth in Children with Disabilities

Dr. Law reviewed ethics submission, provided editorial assistance with manuscript preparation, offered assistance with interpretation of the results, gave critical review of the manuscript and approved the final draft. Professor Stratford refined research questions, consulted on the sample size calculation, statistical analysis and the way to display the data and approved the final draft. Professor DeMatteo reviewed the manuscript, provided editorial assistance with manuscript preparation and approved the final draft. Dr. Kim contributed to recruit participants in South Korea.

Chapter 4: Measuring Participation of Children and Environmental Factors at Home, School and in Community: Construct Validation of the Korean PEM-CY

Dr. Law reviewed ethics submission, provided editorial assistance with manuscript preparation, offered assistance with interpretation of the results, gave critical review of the manuscript and approved the final draft. Professor Stratford refined research questions, consulted on the statistical analysis, sample size calculation and the way to display the data and approved the final draft. Dr. Missiuna gave the critical review of the manuscript, provided editorial assistance, consulted on reference that can be applied to support the interpretation of the results and approved the final draft. Professor DeMatteo gave the critical review of the manuscript, provided editorial assistance and approved the final draft. Dr. Kim contributed to recruit participants in South Korea.

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Chapter One: Introduction

The concept of participation was included in the International Classification of Functioning, Disability, and Health (ICF) and its children and youth version (ICF-CY) as a key component of health (World Health Organization [WHO], 2001, 2007). The ICF defines participation as involvement in life situation (WHO, 2001). The participation of children with disabilities decreases in meaningful occupations as compared to typically developing children, due to both personal and environmental factors (e.g., physical functions of a child and household income) (Coster et al., 2011a; Law, Petrenchik, King, & Hurley, 2007). Therefore, it is necessary for health professionals to measure the participation of children with disabilities and factors surrounding them, in order to provide the relevant interventions for their successful participation.

Health professionals, including occupational therapists (OTs), have worked to improve the participation of children with disabilities in meaningful occupations (Noonan, Kopec, Noreau, Singer, & Dvorak, 2009). Due to the strong interest in the participation of children with disabilities, much research has been conducted to identify the participation patterns of children with disabilities (Bedell et al., 2013; Coster et al., 2011b; Longo, Badia & Orgaz, 2013; Ullenhag et al., 2012) and to develop measures to evaluate children's participation across various environments (Coster & Khetani, 2008; King et al., 2007).

Unlike other measures that evaluate the participation of children with disabilities at a particular age range in a specific setting, the Participation and Environment Measure for Children and Youth (PEM-CY) was uniquely designed to measure the participation of

children with and without disabilities comprehensively and the environmental factors affecting their participation at home, school, and in the community at the same time. The PEM-CY is also applicable for use in large-scale studies (Coster et al., 2011a).

The functions and skills of children with disabilities have been primarily considered in Korean OT clinical practice. However, increased interest in the participation of Korean children with disabilities is currently indicated in the literature. The measures that evaluate the participation of children with disabilities in leisure or school activities were translated into Korean (Chang & Ryu, 2010; Kim, 2004) and a particular measure for the participation of Korean school aged children has been in the development process (Yoo et al., 2013). In spite of these participation measurement tools, use of participation measures is still limited in the assessment of the participation of Korean children with disabilities across multiple age groups and various settings.

To evaluate the comprehensive participation patterns of children with disabilities living in Korea, a measure that is suitable for the Korean language and culture is needed. Although generating a new participation measure that fits into the Korean language and culture may be the best way to use it in the Korean cultural context, such development requires not only professional knowledge in measurement but also much time and expense to test the measure in clinical settings (Guillemin, Bombardier, & Beaton, 1993; Patrick & Deyo, 1989). Therefore, it can be more efficient to cross-culturally adapt an existing participation measure, developed in another country or culture, to the Korean cultural context.

This thesis aims to develop the Korean version of the PEM-CY (KPEM-CY) through a standard cross-cultural adaptation process and to test its psychometric properties (i.e., internal consistency, test-retest reliability, and known group validity) in a population of Korean children with and without disabilities.

1.1 Importance of Measuring the Participation of Children with Disabilities

Participation has been described in many different ways; The ICF defined participation as “a person’s involvement in life situations” (WHO, 2001, p.213) and Coster and Khetani (2008) further characterized that life situation consists of organized sequences of activities, which focus on a personal and social goal in a specific setting. Law (2002) regards participation as the context where children master skills, perform activities and form friendship. Coster (1998) also considers it as a child’s ability to organize engagement in activities in the context that is personally satisfying and socially acceptable to the adults who take care of children. Based on these definitions of participation, it is evident that children can acquire new skills and competencies, form relationships with peers and interact in the community by participating in typical activities directed towards a meaningful goal. Participation also aids children to be satisfied with their lives and to improve their physical, emotional and social wellbeing (Law, 2002; Schenker, Coster, & Parush, 2005). Due to the contribution of participation to the quality of children’ lives (Law, 2002), the participation of children with disabilities becomes an ultimate goal of rehabilitation interventions. Thus, it is important to assess participation in order to develop and measure the effectiveness of interventions.

Occupational therapy (OT) is a healthcare profession that enables people across their life span to participate in everyday life through occupation (Townsend & Polatajko, 2013). Occupation includes all of the daily activities that describe the identity of people and are vital to the health and wellbeing of people (CAOT, n.d.). OTs analyze interaction among child’s skills, occupations and environments where occupational performance

occurs, to determine what aspect of a child they need to focus on during their services (Law et al., 1996). With the ultimate goal of OT to improve the participation of a child in meaningful occupations, OTs comprehensively collect data about a child through various assessment methods first and provide specific interventions based on the results of those assessments (Case-Smith & O'Brien, 2015).

The top-down approach has been recommended as a guide for an assessment that supports the development of occupation-based goals for OT intervention (Case-Smith & O'Brien, 2015). This approach gathers data from four levels of assessment: participation in occupations, performance of activities, child factors (body structure & function) and context factors (Case-Smith, 2005). Measuring participation in occupations, as the most global level of assessment, helps to profile the occupations of a child with a disability (Case-Smith & O'Brien, 2015). At this stage, the level of participation in occupations, which are typically available or expected in various environments and social roles, is evaluated (Case-Smith & O'Brien, 2015). Furthermore, environmental factors that support participation or cause potential problems in participation can be measured. The process helps identify the gap between the performance of a child and their expected performance (Case-Smith & O'Brien, 2015). The main feature of this approach is to focus on the extent to which children can engage in occupation that satisfies their needs and societal expectations rather than focus only on their abilities and/or disabilities that affect task performance (Coster, 1998). Likewise, Carey & Long (2012) indicated that data from measuring impairments and activities does not easily determine whether increased functional skills and activities will lead to successful participation (King et al., 2003;

Palisano et al., 2012, Raghavendra, 2013). Therefore, participation in daily occupations and routines should be primarily highlighted in the process of the measurement of children with disabilities, in order to set up the goals of OT intervention.

Measuring the participation of children with disabilities is also very important for large-scale studies (Coster et al., 2011b). Data obtained from measuring the participation of children can compare how the participation patterns of children with disabilities are different. Such studies can also examine factors such as the presence of disabilities, type of disabilities, age, and the environmental factors that influence participation patterns across a range of environments. These data can guide policies to establish the optimal environments where children with and without disabilities can perform meaningful occupations. Furthermore, findings from large studies can be used to design OT services to improve the participation of children with disabilities in a specific setting such as school.

1.2 Relationship between Participation and Environment

Participation is a multi-dimensional concept associated with the environmental factors that affect children's activity performance (McCauley et al., 2013). The ICF has defined environmental factors as the physical, social, and attitudinal environment where people conduct their lives and these factors have a positive or negative impact on the participation of children with disabilities (WHO, 2001). As participation is intimately linked to environment, it is important to investigate what environmental factors act as supports or barriers in a specific setting where children with disabilities perform meaningful activities, in order to thoroughly understand the participation of children with disabilities. For this reason, clinicians, researchers, and policy makers can view an environmental factor as a modifiable factor to promote the participation of children with disabilities in meaningful occupations (Anaby et al., 2013; Anaby et al., 2014; Coster et al., 2011b).

Much research has identified the consistent patterns of children with disabilities and the environmental facilitators and/or barriers to those patterns in a particular setting. In a school setting, children with disabilities were more restricted in participation both in structured and unstructured activities and had more difficulties in interaction with their classmates and engagement in playground and recess activities, in comparison with their peers without disabilities (Egilson & Traustadottir, 2009; Eriksson, Welander, & Granlund, 2007). Research has found that the physical design of school, including such features as stairs and ramps negatively affects the mobility of disabled students and this impact further limits their participation in most school activities (Coster et al., 2013;

Welsh, Jarvis, Hammal, & Colver, 2006). Furthermore, the participation of children with disabilities in activities performed in the community was often more limited than that in a home or school setting (Bedell, Khetani, Cousins, Coster, & Law, 2011; Law et al, 2007). For instance, children with acquired brain injuries struggled particularly with engaging in structured events and social activities with their peers in a community setting (Bedell & Dumas, 2004; Galvin, Froude, & McAleer, 2010). With respect to the environmental factors that influence participation in the community, limited services (e.g., transportation and community programs) and access to information were identified as barriers to children and youth with cerebral palsy (Bedell, & Dumas, 2004; Law et al., 2007; McManus et al., 2006). Unlike those factors, parental involvement (e.g., vigilance and parental support) was regarded as a facilitator to social participation and the formation of friendship (King et al, 2007; McManus et al., 2006).

1.3 Measurement of the Participation of Children with Disabilities and Environment

The types of participation measures vary according to the target population (e.g., preschooler, children and young adults) and context (or domain) (e.g., community and leisure). The measures that are introduced below were designed based on the taxonomy of the ICF and ICF-CY and some domains applied to those measures were identified from qualitative studies.

The Assessment of Preschool Children's Participation (APCP) assesses the participation of a child aged 2 to 5 years in the domains of play, skill development, active physical recreation and social activities (Law, King, Petrenchik, Kertoy, & Anaby, 2012). The Pediatric Activity Card Sort (PACS) measures participation in activities that children aged 3 to 6 years perform in the domains of self-care, community mobility, leisure, social interaction, domestic chores and education (Berg & LaVesser, 2006). Unlike the APCP and PACS assessing the participation of preschoolers in various domains, the Children's Assessment of Participation and Enjoyment (CAPE) evaluates the participation of children aged 6 to 21 years in the recreation and leisure activities that children can perform in the community (King et al., 2007). The Assessment of Life Habits (LIFE-H) assesses the social participation of children with disabilities aged 5 to 13 years (Noreau et al., 2007). The School Function Assessment (SFA) also measures the elementary school student's level of participation in six major school activity settings (e.g., regular versus special education classroom, playground) (Coster, Deeney, Haltiwange, & Haley, 1998). Although the SFA was created prior to the ICF and ICF-CY, this measure includes items and categories that potentially map to the codes of the ICF and ICF-CY (Ogonowski,

Kronk, Rice, & Feldman, 2004). The measures mentioned above are effective to assess the participation patterns of children, but it might be difficult to draw a big picture of the general participation of children and youth with and without disabilities in their routine lives because of several reasons. The instruments: 1) focus on particular populations and/or age ranges (i.e., APCP and PACS), 2) measure participation in a specific setting (i.e., CAPE and SFA), and 3) consider only a subset of areas for participation (i.e., APCP, CAPE, LIFE-H, and SFA). Because of those reasons, these measures may be limited in application to the large-scale studies that are designed to investigate similarities and differences in the participation patterns of children across a wider age range and across various settings.

Childhood participation requires understanding both its objective and subjective aspects (Imms, 2008). Objective participation can be described as society-perceived participation based on a social standard (Isaline, Martijn, Joost, & Caroline, 2011) and subjective participation can be referred to person-perceived participation (Carr & Thompson, 1994) based on person's experience and preference (Noreau, Fougereyrollas, Post, & Asano, 2005). According to these understandings, the objective indicator of a measure includes the frequency of activities (e.g., hours of role functioning), intensity/extent of involvement and difficulty that an individual experiences, with and without assistance, to carry out roles. The subjective indicator of a measure includes satisfaction with the accomplishment of social roles, the importance and value of participation, the sense of belonging, and the desire for change. For example, the APCP is completed by the parent of a child with a disability and scores two objective dimensions:

diversity and intensity (Law et al., 2012). In addition, the CAPE collects more information and this measure quantifies participation by two scales: *diversity* identifying the number of activities (objective) and *intensity* reporting how often a child has participated in activities (objective). Within each of these scales, additional information is collected: *with whom* reporting the breadth of other people with whom an activity is usually done (objective); *where* reporting where an activity usually takes place (objective); and *enjoyment* reporting how much a child enjoys participating in specific activities (subjective) (Hilton, Crouch & Israel, 2008). The objective indicator of participation is useful for comparative purposes, to identify the improvement of rehabilitation intervention and can help clinicians and researchers disentangle the relative influence of factors such as individual's preference for and abilities to participate in particular activities. However, it is not enough to evaluate the quality of children's participation because children may have different overall experiences despite similarities in their frequency of participation. Therefore, assessing the subjective aspect of participation is also important to help better understand the participation patterns of children with disabilities.

In addition to the consideration of two different scales, it is necessary to obtain information about the environments in which children typically participate to analyze the participation patterns of children with disabilities. Because of the need to identify the impact of environmental factors on participation, some environment measures have been developed. For example, the Craig Hospital Inventory of Environmental Factors for Children-Parent version (CHIEF-CP) assesses environmental barriers to the participation

of children, aged 2 to 12 years, in the domains of physical, attitudinal, service, productivity and policy (McCauley et al., 2013). The European Child Environment Questionnaire (ECEQ) also examines environmental facilitators or barriers associated with physical environment, social support, and attitude to the participation of children with cerebral palsy aged 8 to 12 years (Dickinson & Colver, 2011). Although these measures can provide valuable information about environmental factors, it may be difficult to assess the direct impact of environment on the participation of children because the items in these measures are independent of the assessment of participation (Coster et al., 2011b).

All measurement tools mentioned above have been used to assess the participation of children at a certain age range (i.e., APCP and PACS) in a particular setting (i.e., CAPE and SFA) with environmental factors gathered separately from participation (i.e., CHIEF-CP and ECEQ). There remains the need for a measurement tool that gathers both objective and subjective information about participation and environment supports or barriers in various settings and that covers a wider age range of children.

1.4 The Participation and Environmental Measure for Children and Youth (PEM-CY)

The PEM-CY is a new parent-report measure designed for population-level research that assesses the participation of children aged 5 to 17 years and environmental factors across the three settings: home, school, and community (Coster et al., 2011a). It consists of two sections for each setting; 1) a participation section includes the types of activities that children typically perform; 2) an environment section represents the features of environment that typically make it easier or harder for children to participate in activities. It also includes both objective (e.g., participation frequency and the extent of involvement) and subjective indicators to measure participation (e.g., desire for change).

There were three reasons for the initial development of the PEM-CY; there was the need to create a new measurement tool: 1) assessing generic participation patterns and environmental factors concurrently; 2) for children in a broader age range and having various diagnoses (e.g., not only physical disabilities but also cognitive and emotional disorders); and 3) for use in large-scale studies to gather comparative data on children and youth who have different types of disability and are living in different cultures (Coster et al., 2011b). The PEM-CY used the ICF-CY as the framework for creating the items related to typical activities in the three settings. In order to identify the appropriate activities which children and youth generally perform at home, in school, and the community, focus groups, structured interviews with the parents of children with disabilities, and a literature review were conducted (Bedell et al., 2011; Coster et al., 2011b).

After completing the PEM-CY, its psychometric properties were established and several studies were implemented to examine the participation patterns of children and youth. A North American study which was conducted with 576 participants established sufficient reliability and validity of the PEM-CY: internal consistency (0.59 and above), test-retest reliability (0.58 and above), a significant difference between children with and without disabilities on participation and environmental factors, and some significant differences by children's age (Coster et al., 2011a). The cross-sectional validity of the PEM-CY was also established using the CHIEF-CP as a reference standard. There were moderate to strong associations between most PEM-CY environment summary scores and CHIEF-CP total product and magnitude scores (Khetani et al., 2014).

In addition, specific participation patterns and environmental barriers to the participation of children and youth in North America were identified; the participation frequency and the extent of involvement in the school activities were lower for children with disabilities than those without disabilities. Their parents reported that they wanted to change their children's participation in typical school activities and identified environmental features which made their children's participation harder (Coster et al., 2013). Also, children with disabilities had less frequency and lower levels of involvement in community participation versus children without disabilities. The parents of children with disabilities frequently reported that they wanted to change the community participation of their children and they identified reduced environmental support for their children's participation in a community setting relative to the parents of children without disabilities reported (Bedell et al., 2013).

According to the features of the PEM-CY mentioned above, the PEM-CY appears to be the most appropriate measure to assess the participation patterns of children and youth across a wider age range and to simultaneously determine the perceived environmental factors to participation at home, school, and in the community. Therefore, this measure would meet the need for a novel tool for the measurement of children's participation in Korea.

1.5 Trends of Measurement amongst Korean OTs

A series of studies were conducted to examine trends in the use of measurement tools amongst Korean OTs between 2002 and 2011 (Park & Yoo, 2002; Yoo, Jeong, & Jo, 2011; Yoo, Jung, Park, & Choi, 2006). The results from these three studies were very similar. The findings of the latest study indicated that Korean OTs working with children with disabilities most frequently used the Denver Developmental Screening Test (DDST) for development assessment (86.3%), Sensory Profile (SP) for sensory integration assessment (76.3%), Developmental Test of Visual Perception (DTVP) for perceptual assessment (75%), Wee-Functional Independent Measure (Wee FIM) for activities of daily living assessment (61.3%) and Social Maturity Test (SMT) for occupational performance assessment (46.3%) (Yoo et al., 2011). These studies showed that, while Korean OTs mainly used measures assessing the functions and performance of children with disabilities, they rarely focused on evaluating the participation of children with disabilities.

Unlike the trend above, an increased interest in measuring the participation of children with disabilities has been identified in the literature. A specific measure that evaluates the participation of elementary school students is currently being developed in Korea (Yoo et al., 2013). In addition, a few participation measures, for example, the SFA and the CAPE measuring participation at school and in the community, have been translated to Korean and have been found to be applicable for Korean children and youth (Kim, 2004; Chang & Ryu, 2010). Although the Korean version of the SFA was completed by Kim in 2004 and has been used in various studies (Bae, 2014; Hong,

Chang, & Kim, 2013; Woo & Chang, 2013), a cross-cultural study was conducted to translate the SFA again into Korean (Shin, 2012). After completing the Korean SFA, the reliability (i.e., test-retest reliability and inter-rater reliability) and validity (i.e., criterion validity and discriminant validity) have been examined (Shin, Park, Lee, & Park, 2014). The CAPE was also translated to Korean and its psychometric properties (i.e., internal consistency and construct validity) were established (Chang & Ryu, 2010). Even though the consistent results of three studies mentioned above show that Korean OTs do not frequently measure the participation of children with disabilities (Park & Yoo, 2002; Yoo et al., 2011; Yoo et al., 2006), there has been a shift toward the measurement of participation of children with disabilities in the Korean OT field.

1.6 Cross-cultural Adaptation of Measures

There are two options to apply a measure to a specific context: 1) development of a new measure and 2) use of an existing measure developed in another country and/or culture (Guillemin et al., 1993). Applying an existing measure is more effective way because developing a new measure is a time-consuming process that needs much effort in conceptualizing the measure and selecting its items (Guillemin et al., 1993). If an existing measure will be used in another country and/or culture, its items and scales should not only be linguistically translated, but also be culturally adapted to maintain equivalence between the original and culturally adapted measurement tool (Guillemin et al., 1993; Herdman, Fox-Rushby, & Badia, 1997). Therefore, the cross-cultural adaptation of a measure is an important process for its use in a new country and a systematic approach needs to be applied for this process. The guidelines for cross-cultural adaptation have been introduced in the literature and there is a general consensus among the processes included in those guidelines: forward translation, backward translation, expert committee review, and pretest (Beaton, Bombardier, Guillemin, & Ferraz, 2000; Guillemin et al., 1993; Oude Voshaar, ten Klooster, Taal, Krishnan, & van de Laar, 2012; Sousa & Rojjanasrirat, 2011). Through these general processes, the content validity of the translated version of a measure can be established (Beaton et al., 2000; Guillemin et al., 1993)

Participation measures are often used in a different culture (Stevellink & van Brackel, 2013). The conceptualization of participation may differ across cultures so that the cross-cultural equivalence testing of a measure is necessary before it is used in a

different cultural context (Stevenson & van Brackel, 2013). For example, Chang and Rue (2010) translated the CAPE to the Korean language through four steps; 1) translation of the CAPE to Korean, 2) pretesting to identify whether the Korean pre-final version is understandable to Korean population, 3) backward translation of the CAPE, and 4) final review to identify whether the translated items are accessible to by Korean experts. As a result of this cross-cultural equivalence testing, there were no items revised according to the Korean culture and the translated version of the CAPE was readily understood by Korean children and youth. After the Korean CAPE established its internal consistency and construct validity, it has been applied to Korean children and youth (Chang & Rue, 2010). Like this example, the PEM-CY needs to be cross-culturally adapted to the Korean cultural context and tested for its utility in Korea because it was developed from the perspectives of North American parents of children. To use the PEM-CY for Korean children and youth, the cross-cultural equivalence testing, including two phases of the translation and adaptation of the PEM-CY, should be conducted with the population of Korean children and youth with and without disabilities.

1.7 Statement of Research Problem

Participation is a key outcome of OT interventions so measuring participation is important. To measure the participation of children with disabilities in Korea, Korean OTs should use an appropriate participation measure that has been translated according to the Korean culture. Even though Korean OTs have Korean versions of the SFA and CAPE, these measures are still limited in evaluating participation patterns across a broader age range and across various settings, with measurement of the environmental factors that facilitate or hinder their participation at the same time. To improve this limitation, a different measurement tool for broadly measuring the participation of children and youth is needed: The Korean version of the Participation and Environment Measure for Children and Youth (KPEM-CY) could be this tool.

The KPEM-CY would help OTs working with children with disabilities to understand the participation patterns of children and youth at home, school, and in the community by gathering both objective and subjective perspectives. With this tool, therapists can both plan for and evaluate the effectiveness of interventions that aim at promoting the participation of children and youth with disabilities. This tool may also be feasible for use in large-scale data collection efforts as the original PEM-CY intends to be used.

Consequently, the overall objective of this thesis was to develop the Korean version of the PEM-CY by translating the original version of the PEM-CY to the Korean language, validating it cross-culturally, and examining its psychometric properties, in

order that it might be used for clinical and research purposes in the Korean cultural context.

1.8 Composition of Dissertation

This dissertation is comprised of three papers (Chapter 2-4) including an interview-based study and two quantitative studies. Data were collected for these research studies in a specific city ‘Daejeon’ in South Korea from May to November 2013. The ethical approval was secured from the Hamilton Integrated Research Ethics Board at McMaster University. Permissions to gather data were obtained from each Korean institution (e.g., rehabilitation hospital, community center, and special education school/kindergarten).

The translation and cultural adaptation study (Chapter 2) describes the process of translation of the PEM-CY to the Korean language using a unique cross-cultural adaptation guideline and provides information about the modifications in the PEM-CY that were needed for the Korean culture. The following specific cross-cultural adaptation guideline was employed: 1) participation item review by Korean experts, 2) translation of the PEM-CY to Korean, 3) backward translation of the Korean version, 4) expert committee review of all translated versions, 5) pre-test using a cognitive interview with Korean parents of children with disabilities, and 6) final review of the modifications. Because of the different language and culture in North America, important considerations arose during the translation process. A critical finding was the difficulty that Korean parents had in distinguishing between the two different main concepts, ‘participation’ and ‘involvement’, that are included in the PEM-CY.

The next two manuscripts (Chapters 3 & 4) examine the psychometric properties of the Korean version of the PEM-CY using two different sets of data. Chapter 3 investigated the internal consistency, test-retest reliability, and known group validity in a

group of children and youth with disabilities. The final manuscript (Chapter 4) examined the known group validity using the whole data set including children and youth both with and without disabilities. Through these two research studies, the reliability and validity of the Korean version of the PEM-CY were established, as was its utility in the Korean cultural context. Furthermore, the participation patterns of Korean children and youth and environmental barriers to their participation were identified at home, school, and in the community, according to the important factors of a child (e.g., the presence of a disability and age) and their parents (e.g., family annual income).

In summary, three research studies in this thesis describe the process of the cross-cultural adaptation of a specific measure PEM-CY, which was developed in North America and examined in the Korean cultural context.

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Chapter Two

Title: Development of Korean Version of the Participation and Environment Measure for Children and Youth

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The contents from Chapter two (i.e., cross-cultural adaptation process and its results) and Chapter three (i.e., results of internal consistency and test-retest reliability) have been combined as a manuscript entitled “Translation and cross-cultural adaptation of the Participation and Environment Measure for Children and Youth in the Korean cultural context”. This manuscript is being submitted to *Disability and Rehabilitation* for review and publication consideration.

2.1 Abstract

Purpose To develop the Korean version of the Participation and Environment Measure for Children and Youth (PEM-CY) by using a cross-cultural adaptation process.

Method The PEM-CY was cross-culturally translated to Korean using a specific translation guideline: pre-review of all participation items by Korean experts, forward and backward translation, expert committee review, pretest of the Korean version by cognitive interview with 10 parents of children with disabilities and, final review for inconsistencies.

Results The interview data demonstrated that the Korean version was understood by the parents of children with disabilities as it was intended. The Korean terms of participation and involvement, the main concepts of the PEM-CY, were the primary issues that caused challenges during the adaptation process. Some issues were encountered because of culturally inappropriate content. In the three settings, 76% of participation items and 29% of environment items were revised to improve their fit with the Korean culture.

Conclusion Results indicated that the Korean version is equivalent to the original version at four levels: semantic, idiomatic, experiential, and conceptual equivalence. Future work is needed to establish the reliability and validity of the Korean version in order to use it with children in Korea.

2.2 Introduction

Since the World Health Organization (WHO) introduced the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) in 2007, the concept of participation, defined as involvement in a life situation, has become a critical consideration to professionals working with children with disabilities in rehabilitation (Noonan, Kopec, Noreau, Singer, & Dvorak, 2009; World Health Organization [WHO], 2007). Professionals have recognized that children with disabilities can form close friendships, develop skills and creativity and achieve physical and mental health by participating in a variety of activities (Law et al., 2013). With the increased interest in improving the participation of children with disabilities in daily activities, many outcome measures assessing participation have been developed and broadly applied for clinical or research purposes (Coster & Khetani, 2008). For instance, the School Function Assessment (SFA) evaluates a student's performance of functional tasks in the academic and social aspects of an elementary school (Coster, Deeney, Haltiwanger, & Haley, 1998) and the Children's Assessment of Participation and Enjoyment (CAPE) examines children's participation and enjoyment outside of school activities (King et al., 2007). Although participation can be assessed with these measures, obtaining the most comprehensive information about children's participation remains difficult (Coster et al., 2011b). Environmental factors can also be assessed together with the concept of participation because participation relates to cultural background in which a child lives and performs activities in local community environment (WHO, 2011). However, most measures were created to include either the dimension of participation or environmental

factors, or nor both. In order to address these limitations, the Participation and Environment Measure for Children and Youth (PEM-CY), which is a new parent-report assessment, was developed to measure the participation of children as well as environment factors, comprehensively. Now that the PEM-CY is ready for use in North America with established reliability and validity (Coster et al., 2011a) and some studies have demonstrated its benefits (Anaby et al., 2014; Bedell et al., 2013; Khetani et al., 2014; Law et al., 2013), an important next step is to introduce it to other countries and cultures.

To date, while occupational therapists (OTs) in South Korea have been interested in promoting the participation of children with disabilities (Chang & Ryu, 2010), there is no measure that can comprehensively assess the participation of children living in Korea (Yoo et al., 2013). According to the literature, which has examined the use of occupational therapy assessment tools, many measurement tools were translated to Korean and have been applied to measure the functions and performance skills of children with disabilities (Yoo, Jeong, & Jo, 2011; Yoo, Jung, Park, & Choi, 2006). In comparison to the number of measures evaluating children's functions and skills, few participation measures (e.g., the SFA and CAPE) have been applicable for Korean children with disabilities after cross-cultural translation. Yoo et al. (2013) has also developed a new participation measure by interviewing with children and their legal guardians about children's activities which are reported for 24 hours 30 minutes. Researchers reviewed the related literature and a report of Statistics Korea, investigating elementary school student's activities. Despite these efforts to apply participation

measures to Korean children with disabilities, there is a clear need for a unique tool to comprehensively measure participation and environmental factors which support or hinder participation. Therefore, the PEM-CY could be an appropriate measurement tool to overcome the current limitations of Korean assessment tools for children and youth with disabilities.

In order for the PEM-CY to be translated and adapted to the Korean culture, a particular guideline for cross-cultural adaptation of the measure is necessary to be followed. It is generally recognized that if the measure is used across cultures, its items and scales should not only be linguistically translated, but also be culturally adapted to maintain the equivalence of the source measure (Guillemin, Bombardier, & Beaton, 1993; Herdman, Fox-Rushby, & Badia, 1997). Due to this reason, the development of the Korean version of the PEM-CY (KPEM-CY) followed a specific guideline that combined processes provided by Participation Environment Project Team (PEP team) (CanChild Centre for Childhood Disability Research, 2014) and suggested by Beaton and her colleagues (Beaton, Bombardier, Guillemin, & Ferraz, 2000). Accordingly, the aim of this study was to translate the PEM-CY to Korean based on a strict and rigorous guideline and to pretest the translated version in a sample of Korean parents of children with disabilities. This is the first study to offer a detailed description of the methodology of the cross-cultural translation of the PEM-CY to the Korean language.

2.3 Material and Methods

2.3.1 Participation and Environment Measure for Children and Youth

The PEM-CY, which was developed in North America, evaluates participation and environmental factors across the three settings: home, school, and community (Coster et al., 2011a). Items for each setting consist of typical activities that children usually perform in the given environments: 10 items of participation and 12 items of environment in the home setting, 5 items of participation and 17 items of environment in the school setting and 10 items of participation and 16 items of environment in the community setting. These items were referenced from the frame of the ICF-CY and identified by focus groups and in-depth interviews with the parents of children with and without disabilities (Bedell, Khetani, Cousins, Coster, & Law, 2011; Coster et al., 2011b). Through this process, the main concepts of the PEM-CY and its components were determined, thus the content validity of the PEM-CY was established (Bedell et al., 2011; Coster et al., 2011b). Parents are asked to respond in the three dimensions of participation patterns: participation frequency (eight options: daily to never), extent of involvement (five point scale: very involved to minimally involved), and desire for change (no or yes with five options for type of change desired) (Coster et al., 2011a). Parents are also asked to score the environmental features that encourage or impede children's participation (four options: not an issue, usually helps, sometimes helps/sometimes makes harder, usually makes harder), as well as comment on perceived supportive resources available such as information, money or supplies (four options: not needed, mostly yes, sometimes yes/sometimes no, usually no) (Coster et al., 2011a).

In terms of the psychometric evaluation of the PEM-CY, a North American study with 576 participants established the reliability and validity of the PEM-CY (Coster et al., 2011a); the PEM-CY has moderate to good internal consistency ($\alpha = 0.59-0.91$) and moderate to good test-retest reliability (ICC = 0.58-0.95). The PEM-CY can also identify a significant difference between typically developing children and children with disabilities by age. Based on these results, the PEM-CY can be used for population-level studies to obtain a better understanding of the participation patterns of children and youth with and without disabilities and the impact of environmental factors on their participation (Coster et al., 2011a).

2.3.2 Adaptation Process

As the number of the multinational research projects has increased, the need to adapt measurement tools for use in other countries and cultures has been highlighted. Even though the measure is developed based on the culture of an English speaking country, researchers and clinicians should consider the immigrant population living in that country when they apply the measure to them, because of a potential systematic bias (Beaton et al., 2000). In order for the measure to be applied in another country, a unique guideline should be followed for cross-cultural adaptation. This study applied two guidelines: a guideline provided by the PEP team and that proposed by Beaton and her colleagues. The first guideline provided by the PEP team includes four processes; 1) obtain approval to proceed, 2) translate the PEM-CY to a target language by a translator who is proficient in English and their own language, 3) back translate to English by another translator who is

also fluent in English and their own language, and 4) send two versions of the PEM-CY to the PEP team in order to identify the equivalence between source and target version.

Beaton et al. (2000) proposed a guideline including main elements revealed in the literature: (1) at least two forward translators translate the measure from the original language to the target language (T1, T2); (2) two translators and a recording observer synthesize the results of the translations (T-12); (3) two translators translate the measure back into the original language (BT1, BT2); (4) an expert committee reviews all the translations and reaches a consensus on any inconsistencies, in order to achieve the equivalence between source and target version; (5) the pre-final version is tested in a small sample through cognitive interviews; and (6) the researcher submits all reports of each process and contacts to the developers of the measure or the committee who keep track of the translated version. By referencing from these two guidelines, this study customized and used the following guideline: (1) Pre-review of the measure by experts who are in target country, (2) forward translation into the target language by a translator, (3) backward translation into the original language by another translator, (4) review of all the translations by expert committee, (5) the test of the pre-final version of the measure through cognitive interviews with a target sample, and (6) final review by expert committee and few participants who already participated in cognitive interview.

Step 1: Pre-review of the Instrument

The first stage in adaptation is the pre-review of the PEM-CY. Four Korean experts including an occupational therapist, psychotherapist and two special educational teachers specialized in cognitive therapy who have been working in a private clinic center with

children with disabilities, aged 3 to 17 years over three years, reviewed the measure. They were given a file including all items and item examples from the participation section in the PEM-CY. Before translating the PEM-CY to the Korean language, Korean professionals reviewed all items and examples for each participation section across the three settings in order to determine them applicable for the Korean culture. After obtaining their feedback, unsuitable items and their examples were changed to more appropriate activities according to the Korean culture through discussions with a PEP team coordinator.

Step 2: Forward Translation

A translator who was both aware of the concepts being examined in the PEM-CY and fluent in English and Korean translated the PEM-CY into Korean. The PEP team coordinator provided the translator with a 12 page-PDF file of paper version of the PEM-CY. The translator could replace the English text in editable text boxes with the translated text in Korean.

Step 3: Backward Translation

The initial translated version of the PEM-CY was translated back into English by another Korean translator, who is a native speaker of English. The translator neither was informed about the concepts explored nor trained in rehabilitation area. The original English items of the PEM-CY could be accessed by the back translator to comment on the forward translation.

Step 4: Expert Committee Review

An expert committee meeting including the developers of the PEM-CY and research coordinator (PEP team) was arranged to consolidate all versions of the PEM-CY and to develop the pre-final version for field testing in a small target sample. All discrepancies between original version and backward translation and issues that might influence the cross-cultural adaptation were reviewed. During this time, the use of the words and the meaning from the text were considered as a priority through discussion with the PEP team coordinator. In addition, the potential cross-cultural issues were discussed with the PEP team through teleconference. This stage was designed to achieve equivalence between original and translated version (Beaton et al., 2000).

Step 5: Test of the Pre-final Version

The aim of this stage was to identify whether the Korean parents of children with disabilities understood the translated instruction and items of the PEM-CY. It was focused on identifying the items and examples that were not familiar in the Korean culture. Through this process, the content validity of the KPEM-CY could be established and thus the conceptual equivalence between English and Korean version was validated. The pretest was conducted by a cognitive interview using a semi-structured questionnaire (Appendix A). Ten parents of children with disabilities, aged 5 to 13 years, in Daejeon city of South Korea, were recruited from three community centers. Participants were divided into 3 groups according to the age of their child: three parents of children aged 5 to 7 years, four parents of children aged 8 to 10 years and three parents of children aged 11 to 13 years. Before the interview, participants were given an envelope including the paper forms of the pre-final version of the KPEM-CY and the consent form (Appendix B)

approved by the ethics board of McMaster University and by local OTs or social workers. They were asked to sign the consent form first and then complete the pre-final version of the PEM-CY. After that, an interviewer met with the parents to informally discuss the pre-final version of the KPEM-CY. Parents were interviewed about their rationale of the translated PEM-CY for 30 to 40 minutes. During the interview, additional short questions were asked of the participants to make sure the interviewer understand what the participants told and obtain more information about their answers (e.g., Please tell me more?). The cognitive interview questions were divided into four sections: survey instructions and three sections according to the settings. The type of interview could be changed according to parents' requests and conducted in a quiet room in person. The parents of children with disabilities aged 8 to 10 years were interviewed as a group, while others participated in the interview individually. Four parents of children aged 8 to 10 years wanted to have the interview together because of the same treatment schedule of their children in the community center.

Step 6: Final Review of the Translated Version

The pre-final version was revised again based on the parents' perspectives obtained from the interviews and discussed with the PEP team. The interviewer produced the written reports that represented all considerations about the assessment, in order to communicate with the PEP team. After completing the modification of the pre-final version, four parents of children aged 8 to 10 years with disabilities who already participated in the previous interview were asked if their opinions were reflected appropriately in the final version.

After the cross-cultural adaptation process was completed, the KPEM-CY was ready for potential future testing in Korea.

2.4 Results

Inconsistencies related to the cross-cultural adaptation were discussed for six steps and summarized according to three components in each step: the instruction of the PEM-CY, questions and scales, and items and item examples. The most important issues in the instruction and questions and scales were associated with the meaning of two main terms ‘participation’ and ‘involvement’. The detailed information about the modifications in those components is presented in table 2.1. In terms of the items and example activities, these were revised or replaced with others based on the Korean culture. In participation and environmental sections across the three settings, 76% of participation items and 29% of environment items were revised. Table 2.2 summarizes the number of items and item examples that were changed and included some examples of the changes. All information about the revised items is shown in detail in table 2.3.

[Insert table 2.1 about here]

[Insert table 2.2 about here]

[Insert table 2.3 about here]

2.4.1 Step 1: Pre-review of the PEM-CY

The first step focused on identifying the items and its examples that are not familiar with the Korean culture. Four Korean experts selected the items and example activities in each setting and suggested alternatives. Most items were not changed significantly but several examples supporting the items were added, removed or modified.

There were four item examples changed in the home participation section. One of the examples supporting item 2 (Indoor plays and games) was modified from ‘playing kitchen’ to ‘playing house’, which has a comprehensive meaning and is more helpful in understanding the item. Another example of item 7 (House chores) was changed from ‘unloading/loading the dishwasher’ to ‘bringing plates/taking plates to the sink’, which is a more common for children in Korean households. ‘Packing lunch’ as an example of item 9 (School preparation) was removed because Korean school provides students with lunch. Item 10 (Homework) had an example ‘daily reading’, which is ambiguous to Korean parents and was in need of clarification. As a result, this example was modified to ‘writing book report’ which Korean students are familiar with as part of their homework. Furthermore, Korean experts took account of item 6 (Socializing using technology) by itself. They thought that ‘technology’ is too comprehensive word in Korean so that the term ‘using technology’ might be difficult to understand without its examples such as telephone and computer. It recommends to be modified to reflect parents’ perspectives through the interview although the experts did not provide alternatives for the specific term.

In the school participation section of the PEM-CY, the changes were made to the examples of three items: item 1 (Classroom activities), item 2 (Field trips and school events) and item 5 (Special roles at school). Unlike North America, each student in Korea is assigned to a specific classroom where students stay for the whole day and a teacher who manages about 30 students for a year. In addition, students do not need to change the classroom for every course. Due to the different system of the school, a number of item

examples were removed and new examples were added. First, doing a presentation, which is a typical example of a classroom activity in Korea, was added. Next, three activities as examples of item 2 were removed because they do not apply to the Korean culture: school fair, spring concert or play, and dances. Instead of these activities, other activities were added to support item 2: school art performance, school festival, school picnic, and school sports day. Almost all students attend these activities and each event is conducted once or twice a year. The last item of the school participation section has 'school lunch helper' as an example, which was modified from 'lunch room supervisor'. All students have lunch with friends and teachers in a designated place of school. Because of this reason, it is not necessary to prepare for lunch every day but students do volunteer as a lunch helper to help with the distribution of meals.

A number of considerations for community participation items and examples were discussed; item 3 (organized physical activities) and item 4 (unstructured physical activities) might be difficult for parents to understand without any explanations although there are several examples supporting these items. It was recommended to provide parents with detailed descriptions for items 3 and 4 in the PEM-CY. For the organized physical activities, an example of 'hockey' was changed to 'soccer' that is a more common activity in Korea. 'Martial arts' another example activity for item 3 was replaced with a Korean traditional martial arts 'Taekwondo'. 'Girl scouts' was added as an alternative to 'Brownies/girl guide' in item 6 (Organizations, groups, clubs, and volunteer or leadership activities). Item 9 (working for pay) was discussed about whether it is appropriate activity for children and youth in Korea. Employing children and youth under

18 years old is restricted by law and requires parental permission. Due to this reason, the experts suggested finding an alternative activity or removing it.

After obtaining the perspectives of Korean experts working with children with disabilities, all mentioned items and item examples were reviewed with the PEP team coordinator to identify whether those changes affected the equivalence of the original version. Almost all items and its examples mentioned above were changed according to the perspectives of Korean experts.

2.4.2 Step 2 to 4: Expert Committee Review after All Translations

During these steps, inconsistencies were identified by comparing the backward translation version to original version and summarized according to the three components. First, in terms of the survey instructions, three words are used: participate (participation), involve (involvement) and engage. When translating these three words into Korean, it was difficult to find the specific Korean words to discriminate the meaning of these words. In order for parents to better understand these terms, ‘participation’ was translated to ‘참여 (Chamyeo)’ and ‘involvement’ was translated to ‘몰입 (Molip)’ that was back translated to ‘level of immersion’. Inconsistency between involvement and level of immersion was examined and it was decided to replace ‘몰입 (Molip)’ with ‘관여 (Kwanyeo)’ which was a more direct translation of ‘involvement’. Even though this word would be less familiar among Korean parents, it is exactly what ‘involvement’ means.

In addition, these two words are also used in the questions and scales of participation sections in each setting. For example, questions A is ‘typically, how often does your child *participate* in 1 or more activities of this type?’ and its scales have 7

options such as daily, few times a week, once a week, few times a month, once a month, few times in last four months, once in last four months and never (skip to question C). By using different Korean words of participation and involvement, it would be easy to distinguish three questions and choose the scales as an answer of each question. In addition, the expert committee recognized the inconsistency between the backward translation and the original version in the meaning of the term ‘few times’. This term could provide parents with an ambiguous numerical value. Because of this reason, ‘two to three times’ was used instead of ‘few times’ in the KPDM-CY.

Finally, Item 3 (organized physical activities) and 4 (unstructured physical activities) were recognized to need additional description for parents: ‘Activities that are done with teachers and coaches who help your child learn the necessary skill’ and ‘Activities that are done for pleasure’, respectively. Item 9 (working for pay) in the community participation section was a significant cross-cultural issue. Korean children and youth cannot work for pay in stores until 18 years of age without parental permission. Although working for pay as a child or youth is an extremely rare situation in Korea, this item was not removed and has become an optional item so that it can be used for Korean immigrants to North America. Korean children who immigrate to English speaking countries might have more opportunities to work for pay and this item can be meant as a typical activity performed in the community setting.

For the items and item examples related to the environment, few items needed to be examined carefully. Item 2 (sensory qualities) was indicated as ‘sensual element’ in the backward translation. The Korean word for ‘sensory’ and ‘sensual’ can be the same

word and the translator for the backward translation who has no medical background translated it literally. However, it was not replaced with another Korean word due to several examples supporting this item.

During the forward translation, the translator translated the PEM-CY less literally to Korean in order to make the sentences less structurally complex so that the KPEM-CY was more understandable to parents. However, it influenced the equivalence of the original version and caused some inconsistencies among forward translation, backward translation and original version. Through the review by the expert committee, these discrepancies were discussed and resolved based on the Korean cultural context.

2.4.3. Step 5: Test of Pre-final Version

Cognitive interview data indicated that most questions of KPEM-CY were understandable for parents but there were still some cross-cultural issues remaining after the previous phases.

In terms of the survey instructions, almost all parents indicated that the concept of the PEM-CY was unfamiliar to them but the instructions provided a good description of participation so that they could understand what participation means. As was mentioned above, it was necessary to clarify the difference in meaning between participation and involvement. Seven parents out of ten had challenges in understanding these two concepts and suggested some ways to resolve this problem. Because of the ambiguity of these two main terms, it was also difficult for parents to understand the scales of each question. Based on the parents' perspectives, this consideration was solved by following the Korean ICF term of participation and changing the Korean word of involvement to a

more familiar word. Consequently, the KPEM-CY has used ‘참여 (Chamyeo)’ for participation, which is the same as suggested by the expert committee, and ‘몰입 (Molip)’ for involvement, which means ‘flow degree’ or ‘commitment level’. The Korean word ‘몰입 (Molip)’ for involvement has been used in Korea for the English term ‘flow’ which is a concept developed by Mihaly Csikszentmihalyi. He defined the flow as “a state of concentration so focused that it amounts to absolute absorption in an activity” (Csikszentmihalyi, 1990, p.1). Because of the similar meaning between flow and involvement in English, using the Korean word ‘몰입 (Molip)’ for involvement in the KPEM-CY is appropriate. In addition, parents endorsed the purpose of the instrument through the interview; the goal of this measure is to help parents know about their children’s participation in daily living and identify the environmental factors that hinder their children’s participation.

After clarifying the use of the Korean terms for participation and involvement, the ambiguity between question A and B and among those scales was resolved. However, seven parents out of ten were confused about the last response option for the question A (Never, skip to question C). Some parents selected the last scale of the question A and then moved to question B and skipped question C. To ensure that parents give a consistent answer to this question, additional clarification was added: Never, do not answer the question B and go directly to question C.

Several items were discussed again among parents even though these were already dealt with during the other phases. When thinking of each activity in the three settings, parents tended to reflect on the daily life of their child. In the home participation section,

specific items were changed according to parents' perspectives; Item 6 (socializing using technology) was modified to 'interacting with others using the media'. As the Korean experts recommended during the pre-review of the PEM-CY, the Korean term of technology in that phrase has an equivocal meaning so that parents had difficulty understanding what this item meant. Due to this reason, item 6 was changed to use the term 'media'. The home environment section had some items that were changed; item 1 (the physical layout or amount of space and furniture in your home) had no example supporting this environmental factor. In order to better understand this item, 'width of hallways and size of bathroom' was added as an example. Items 3, 4, and 5 (the physical/cognitive/social demands of typical activities in the home) were changed because the phrase of 'demands of typical activities' was not understandable to parents. Thus, the items were changed to 'the physical/cognitive/social abilities needed to perform typical activities at home'. These changes were applied to similar items in each setting.

In terms of school setting, participation and environment sections had two items to be changed respectively; item 1 (classroom activities) of the participation section had many examples but parents recommended translating those examples into more familiar Korean terms. Although the translated Korean words were fine to be applied, there were more common words used at school. For example, 'group work' was translated to '그룹 활동 (group hwaldong)' at first, but it was changed again to another Korean term '모듬 활동 (modum hwaldong)', which is generally used by school teachers and parents. Item 3 (school-sponsored teams, clubs and organizations) was changed according to

Korean school system. Activities in school-sponsored teams, clubs, and organizations are conducted with Korean children at school but the number of students doing these activities is very small. Korean schools provide their students with specific services for the discretionary activity during the school and for after-school activities such as arts, sports, and languages. In order to apply to more Korean children, item 3 was changed to 'discretionary activity, organizations, and after-school activity'.

Lastly, the interview data indicated that several activity examples in the community participation section needed to be added and changed to fit with Korean culture. Item 1 (neighborhood outings) added 'indoor playground', which is a common place where the children can play and 'parade' of item 2 (community events) was changed to 'exposition'. Some parents indicated that the examples (attending a play, concert, and etc.) of item 2 were not very distinct from the examples (going to movie) of item 1. For this reason, a few parents wondered if item 2 represented free activities provided by their community. In order to distinguish between item 1 and 2, 'going to the movie' was removed from the item 1.

Aside from these considerations regarding instructions, question and scales, and specific items and examples, another issue related to the way of answering the questions was identified among parents. Parents generally completed the environment section quickly and easily. However, they had more challenges completing the questions in the participation section. For example, some parents answer question A for all items first and then moved to answer question B for all items. In order to help parents to better understand the order of answering the questions A to C, a simple example was added in

the end of the survey instructions; ‘when you answer three questions in the participation section, please refer to the example: after answering the above three questions for ‘computer and video games’ which is one of the activities included in home participation, you will be asked to move on to the next activity, “indoor play and games” and answer the same three questions.’

2.4.4 Step 6: Final Review of the Translated Version

All considerations based on parents’ perspectives were applied to complete the final version of the Korean PEM-CY in order to maintain the equivalence with the original version. After reviewing the interview data with expert committee again, four participants who were already interviewed were asked to identify if their opinions were reflected appropriately in the Korean version. They indicated that the font style and size used in the instrument was not familiar to Korean parents so it would be better to change to another font style that is commonly used at Korean schools, and to make the font bigger. With these suggestions, the KPEM-CY was completed.

2.5 Discussion

In order to use the PEM-CY for Korean children and youth, the cross-cultural adaptation process of the PEM-CY was conducted using the unique guideline. Through this process, various perspectives from different experts including the parents of children with disabilities were reflected in the completion of the KPEM-CY and the content validity of the KPEM-CY was established. The pre-review was conducted to obtain the perspectives of Korean experts in terms of the activities performed among Korean children and youth. They pointed out the terms that seem to be jargons among therapists such as items 3 and 4 in the community participation section. The pre-test of the KPEM-CY was implemented in order to verify the equivalence between the source and final version by using cognitive interview methodology. During the cognitive interview with parents, the interviewer obtained more detailed information about the activities which Korean children and youth typically perform in their environments. It was also learned that there is a specific font style, which is generally used at schools and is more preferred by Korean parents. As can be seen from these results, obtaining the perspectives from various experts through the cross-cultural adaptation process was crucial to use the measure, which is developed in a different culture, for the Korean population.

The modifications in the KPEM-CY can be considered at four levels of equivalence that are necessary to maintain the equivalence between the original and final version of the PEM-CY (Beaton et al, 2000; Morrison et al., 2013). Four levels of equivalence consist of semantic, idiomatic, experiential, and conceptual equivalence: (1) semantic equivalence focuses on linguistic differences between the two versions such as

the meaning of words, vocabulary, and grammar used in the measure (Guillemin et al., 1993). Because of the different grammar and meaning of the words between English and Korean, some changes to words included in the PEM-CY were considered. For example, the term of ‘sensory’ in ‘sensory qualities’ as an environmental item in each setting was translated to Korean word meaning ‘sensual’. In order to maintain the semantic equivalence of the PEM-CY, such items were changed to another word that is more understandable to Korean parents; (2) Idiomatic equivalence relates to the use of colloquialism and idioms (Beaton et al., 2000; Guillemin et al., 1993). Since colloquialism and idioms, which are used in a specific culture, are difficult to be translated based on another culture, it is necessary to find an equivalent expression in another language rather than to translate them literally (Van Widenfelt, Treffers, De Beurs, Siebelink, & Koudijs, 2005). In the PEM-CY, all items represent simple daily living activities and environmental factors for which specific colloquialisms or idioms were not used. Therefore, idiomatic equivalence was not a major concern of this translation; (3) From an experiential point of view, many items and item examples were less relevant or socially acceptable activities in a different culture. For this reason, these were replaced with other activities that are relevant in the Korean culture. Among the items and example activities modified, item 9 (working for pay) in the community participation section was considered carefully. In North America, working in stores to earn money is a typical activity among children while it is extremely rare situation for Korean children; (4) Lastly, conceptual equivalence is associated with the validity of the concept and events experienced by the target population (Guillemin et al., 1993).

Although the item is translated to Korean linguistically, it might not be translated conceptually. For example, the main concept of the PEM-CY is the participation of children and youth. It is quite a new concept of the measurement for the Korean parents of children with disabilities. In spite of providing parents with the instruction of the KPEM-CY, parents still had some difficulties in understanding the main concept of the measure. They pointed out that the Korean terms of participation and involvement cause the difficulties in understanding, even though two English terms were literally translated. Due to this reason, ‘participation’ has been translated to a specific Korean word, which is used in Korean version of the ICF, and ‘involvement’ has been substituted to another Korean word meaning ‘flow degree’ suggested by parents.

There is general consensus that the cross-cultural adaptation process should include forward translation, backward translation, expert committee and pretest (Beaton et al., 2000; Guillemin et al., 1993; Oude Voshaar, ten Klooster, Taal, Krishnan, & van de Laar, 2012; Sousa & Rojjanasirirat, 2011). This study followed the unique guideline to cross-culturally translate the PEM-CY by combining two different guidelines presented by Beaton et al. (2000) and the PEP team: pre-review, forward translation, backward translation, expert committee, pretest, and final review. In the stage of expert committee review, the general guideline indicates that the minimum composition of committee includes a methodologist, health professionals, language professionals, and the translators. This study did not include language professionals because the PEM-CY consists of easy terms and simple sentences but it may be a potential limitation. However, consistent reviews (i.e., pre-review and final review) and pretest were implemented in order to

identify the potential problems between the two different cultures. These stages of review were done by obtaining the perspectives of various professionals working with children with disabilities and those of the parents of children with disabilities. After finishing the pretest, revisions to the measure were reviewed carefully again to identify if the perspectives of parents were adequately reflected in the KPEM-CY. Those three phases, thus, played an important role in the cross-cultural adaptation of the PEM-CY by reducing the potential errors occurred due to the difference between the two cultures.

The completed Korean PEM-CY is able to be used in health services in terms of children and for large-scale studies such as comparing the participation patterns of children across cultures. The results from the KPEM-CY could be used for decision-making among the service providers and policy makers to increase the quality of surroundings around the children, in order to promote their participation in various settings. For the utility of the KPEM-CY in Korea as well as in North America for the immigrant population with the mentioned purpose, the specific research to establish the psychometric properties of the KPEM-CY will be necessary.

2.6 Conclusion

The KPEM-CY was completed using a cross-cultural adaptation process in order to have a measure of the participation patterns of Korean children and environmental factors that affect their participation. This research is the first study to ensure that the translated version of the PEM-CY is equivalent to the original version. All problems caused by the culture differences were verified and revised by experts including the parents of children with disabilities. As a result of this process, all items and questions have been determined to be understood by the parents of children and youth. The Korean version of the PEM-CY is now ready to be tested further for clinical and research purposes in order to assess the participation of children with disabilities and environmental supports or barriers to their participation in various settings.

2.7 References

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Tables

Table 2.1. Adjustments of instruction and questions and its scales during the process of cross-cultural adaptation

Component	Original PEM-CY	Adapted PEM-CY	Reason for adaptation
Instruction	The terms of 'Participation' and 'Involvement' used in the PEM-CY	Translated 'Participation' to 참여 (Chamyeo), the Korean ICF term of 'Participation' Translated 'Involvement' to 몰입 (Molip), Korean word of 'Involvement' meaning 'flow degree' or 'commitment level'	To clarify two different words having almost the same meaning in Korea
	No additional explanation of the way to answer the question A to C in Participation section in the three settings	Added the additional explanation at the end of the instruction: 'when you answer three questions A, B and C of Participation section, please refer to this example: after answering the above three questions for "computer and video games" which is one of the activities included in Home Participation section, you will be asked to move on to the next activity, "indoor play and games" and answer the same three questions.'	To help parents to understand the way to answer the questions effectively
Questions & scales	Question A to C and those scales: used the terms of 'Participation' and 'Involvement'	Followed the way which is applied to the instruction of the PEM-CY	To discriminate the meaning among questions and scales
	Three scales of Question A: Few times a week, Few times a month, and Few times in last four months	Changed those scales to 'Two to three times a week, two to three times a month, and two to three times in last four months'	To resolve the ambiguous numerical value
	Scale of Question A: Never, skip to Question C	Changed it to 'Never, do not answer the question B and go directly to the question C'	To help parent not to be confused to answer the questions

Table 2.2 The number of modification in terms of items and item examples

	The number of items or examples replaced with others (%)	The number of items or examples added others (%)	The number of items or examples removed (%)	Changes in total
Item	15 (41.67)	2 (5.56)	0 (0)	17 (47.22)
Item examples	9 (25)	7 (19.44)	3 (8.33)	19 (52.78)

Table 2.3 Detailed information about the items and item examples modified

Setting & Section	Original item (examples)	Adapted item or example
Home, Participation (10 items)	Item 2: Indoor play and games (e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up)	Item 2: Indoor play and games (e.g., playing with toys, puzzles, or board games, playing house or dress-up)
	Item 3: Arts, crafts, music, and hobbies (e.g., doing arts and crafts, listening to music, playing an instrument, collecting, reading for leisure, cooking for fun)	Item 3: Hobbies (e.g., doing arts and crafts, listening to music, playing an instrument, collecting, reading for leisure, cooking for fun)
	Item 6: Socializing using technology (e.g., telephone, computer)	Item 6: Interacting with others using communication media (e.g., telephone, computer)
	Item 7: Household chores (e.g., unloading/loading the dishwasher, cleaning room or other areas of the house, cooking, taking out the garbage, setting the table, caring for household pet)	Item 7: Household chores (e.g., bringing plates/taking plates to the sink , cleaning room or other areas of the house, cooking, taking out the garbage, setting the table, caring for household pet)
	Item 8: Personal care management (e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup)	Item 8: Self-care management (e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup)
	Item 9: School preparation (e.g., gathering materials, packing school bag, packing lunch, reviewing schedule)	Item 9: School preparation (e.g., gathering materials, packing school bag, reviewing schedule)
	Item 10: Homework (e.g., daily reading, homework assignments, school projects)	Item 10: Homework (e.g., writing book report , homework assignments, school projects)
Home, Environment (12 items)	Item 1: The physical layout or amount of space and furniture in your home	Item 1: The physical layout or amount of space and furniture in your home (e.g., width of hallways and size of bathroom)
	Item 3: The physical demands of typical activities in the home (e.g., strength, endurance, coordination)	Item 3: The physical abilities needed to perform typical activities at home (e.g., strength, endurance, coordination)
	Item 4: The cognitive demands of typical activities in the home (e.g., concentration, attention, problem-solving)	Item 4: The cognitive abilities needed to perform typical activities at home (e.g., concentration, attention, problem-solving)
	Item 5: The social demands of typical activities in the home (e.g., communication, interacting with others)	Item 5: The social abilities needed to perform typical activities at home (e.g., communication, interacting with others)
	Item 8: Are services in your home available and/or adequate to support your child's participation?	Item 8: Are services in your home available and/or adequate to support your child's participation? (e.g., home visiting therapist)
School, Participation (5 items)	Item 1: Classroom activities (e.g., group work, classroom discussions, tests, in-class assignments)	Item 1: Classroom activities (e.g., group work, classroom discussions, tests, in-class assignments, presentation)
	Item 2: Field trips and school events (e.g., going to a museum, the school fair, spring concert or play, dances, fundraisers)	Item 2: Field trips and school events (e.g., going to a museum, school art performance, school festival, school picnic and school sports day)
	Item 3: School-sponsored teams, clubs and organizations (e.g., groups, clubs, teams, student council)	Item 3: Discretionary activity, organizations and after-school activity (e.g., groups, clubs, teams, student council)
	Item 5: Special roles at school (e.g., lunch room supervisor, student mentor)	Item 5: Special roles at school (e.g., school lunch helper , student mentor)
School, Environment (17 items)	Item 4: The physical demands of typical school activities (e.g., strength, endurance, coordination)	Item 4: The physical abilities needed to perform typical activities at school (e.g., strength, endurance, coordination)
	Item 5: The cognitive demands of typical school activities (e.g., concentration, attention, problem-solving)	Item 5: The cognitive abilities needed to perform typical activities at school (e.g., concentration, attention, problem-solving)
	Item 6: The social demands of typical school activities (e.g., communication, interacting with others)	Item 6: The social abilities needed to perform typical activities at school (e.g., communication, interacting with others)
	Item 9: The safety of the school (e.g., supervision, crime, violence)	Item 9: The safety of the school (e.g., supervision, crime, violence, bullying and abuse)

	Item 14: Supplies (e.g., assistive devices or technology, reading materials, sports equipment, crafts supplies)	Item 14: Supplies (e.g., assistive devices or technology, reading materials, sports equipment, learning material)
Community, Participation (10 items)	Item 1: Neighborhood outings (e.g., shopping at the store/mall, going to a movie, eating out at a restaurant, visiting the local library/bookstore)	Item 1: Neighborhood outings (e.g., shopping at the store/mall, eating out at a restaurant, visiting the local library/bookstore, indoor playground)
	Item 2: Community events (e.g., attending a play, concert, sports game, parade)	Item 2: Community events (e.g., attending a play, concert, sports game, exposition)
	Item 3: Organized physical activities (e.g., sports teams or classes such as baseball, hockey, martial arts, dance, horseback riding, swimming, gymnastics)	Item 3: Organized physical activities (e.g., sports teams or classes such as baseball, soccer and Taekwondo dance, horseback riding, swimming, gymnastics)
	* No additional explanation of Item 3 to help better understand	* Added 'Activities that are done with teachers and coaches who help your child learn the necessary skills'
	Item 4: Unstructured physical activities (e.g., nature trail walks, bicycle riding, rollerblading, skateboarding, playing hide-and-seek or chase, playing pick-up games like basketball)	Added 'Activities that are done for pleasure'
	* No additional explanation of Item 4 (Unstructured physical activities) to help better understand	
	Item 5: Classes and lessons (e.g., music, art, languages, computers)	Item 5: Classes and lessons (e.g., music, art, languages, computers, private lessons and academy)
	Item 6: Organizations, groups, clubs, and volunteer or leadership activities (e.g., Boy Scouts, Brownies/Girl Guides, youth groups, public speaking)	Item 6: Organizations, groups, clubs, and volunteer or leadership activities (e.g., Boy Scouts, Girl scout , youth groups, public speaking)
	Item 7: Religious or spiritual gatherings and activities (e.g., attending places of worship, religion classes, groups)	Item 7: Religious activities (e.g., attending places of worship, religion classes, groups)
	Item 9: Working for pay (e.g., babysitting, paper route, working in a store, doing chores or running errands for pay)	Optional Item 10: Working for pay (e.g., babysitting, paper route, working in a store, doing chores or running errands for pay)
Community, Environment (16 items)	Item 3: The physical demands of typical activities (e.g., strength, endurance, coordination)	Item 3: The physical abilities needed to perform typical activities in the community (e.g., strength, endurance, coordination)
	Item 4: The cognitive demands of typical activities (e.g., concentration, attention, problem-solving)	Item 4: The cognitive abilities needed to perform typical activities in the community (e.g., concentration, attention, problem-solving)
	Item 5: The social demands of typical activities (e.g., communication, interacting with others)	Item 5: The social abilities needed to perform typical activities in the community (e.g., communication, interacting with others)

Chapter Three

Title: Psychometric Evaluation of the Korean Version of the PEM-CY in Children with Disabilities

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The contents of Chapter two (i.e., cross-cultural adaptation process and its results) and Chapter three (i.e., internal consistency and test-retest reliability) have been combined as a manuscript entitled “Translation and cross-cultural adaptation of the Participation and Environment Measure for Children and Youth in the Korean cultural context”. This manuscript has been submitted to *Disability and Rehabilitation* for review and publication consideration.

3.1 Abstract

Purpose The aim of this study was to examine the psychometric properties of the Korean version of the Participation and Environment Measure for Children and Youth (KPEM-CY) in Korean children with disabilities.

Methods The PEM-CY measures participation frequency, extent of involvement, and desire for change in typical activities that children and youth perform across three settings: home, school, and community. It also evaluates perceived supports or barriers to participation. Eighty parents of children with disabilities aged 5 to 13 years, living in the city of Daejeon, South Korea, received the KPEM-CY through local health care providers and completed it twice, two weeks apart. Cronbach’s alpha and intra-class correlation coefficients were calculated to examine internal consistency and test-retest reliability. T-test for independent samples, one-way ANOVA, and factorial ANOVA were applied to examine construct validity.

Results The KPEM-CY demonstrated moderate to excellent internal consistency (0.67 to 0.92) for all summary scores. Test-retest reliability was excellent (over 0.75) for

frequency and extent of involvement across the three settings and moderate to excellent (0.53-0.95) for all summary scores in the home setting. Child's age, the type of school, and family annual income were the factors that significantly influenced specific dimensions of participation and environment across the three settings.

Conclusion Results support the utility of the KPEM-CY for Korean children with disabilities aged 5 to 13 years in the Korean cultural context.

3.2 Introduction

Participation, which has been increasingly focused on by health professionals working with children with disabilities, is a multi-faceted concept influenced by environmental factors (McCauley et al., 2013). It is difficult to view participation without the consideration of contexts where the participation of children with disabilities occurs (Ziviani, Desha, Feeney, & Boyd, 2010). The influences of physical, social, and attitudinal environments may support or hinder the extent of the participation of children with disabilities in daily activities (Mihaylov, Jarvis, Colver, & Beresford, 2004). Because of this, it is important to not only focus on the capabilities and interests of a child but also environmental supports and challenges, in order to facilitate the participation of children with disabilities (Anaby et al., 2013).

Much research has been conducted to identify the participation patterns of children with disabilities and environmental factors affecting those patterns. Coster and colleagues (2011a) found significant differences in participation and environmental supports between children and youth with and without disabilities. Children with disabilities participated more often in home-based activities rather than community-based activities (Imms, Reilly, Carlin, & Dodd, 2008). In addition, they participated in activities with lower frequency and level of involvement than children without disabilities (Bedell et al., 2013; Bedell, Khetani, Cousins, Coster, & Law, 2013; Coster et al., 2011a; Imms et al., 2008; Majnemer et al., 2008). In terms of environmental impact, the most common facilitator was supports from families and friends to improve social participation and form friendships (Anaby et al., 2013; King et al., 2007; McManus et al., 2006). The barriers that

were frequently raised in literature were negative attitudes, physical accessibility of buildings, services, and inadequate policies (Anaby et al., 2013). Welsh and his colleagues (2006) identified the physical design of schools as restricting the mobility of children with disabilities which further impacted on their participation in various school activities.

As the participation of children with disabilities is considered as a key outcome in rehabilitation, many measurement tools that evaluate participation in a specific setting (e.g., school and community) have been developed for children and youth (Coster & Khetani, 2008; King et al., 2007). Because of the relationship between participation and the environment, it is necessary to focus on both concepts at the same time to better understand the participation of children with disabilities (Coster et al., 2011b). Unlike other measures that assess either participation or environmental factors for children with disabilities, the Participation and Environment Measure for Children and Youth (PEM-CY) was developed to evaluate the participation patterns of children and youth as well as the perceived factors that help or impede their participation (Coster et al., 2011a; Coster et al., 2011b). It is an efficient measure to evaluate both concepts at home, school, and in the community simultaneously and comprehensively.

To apply the PEM-CY to children and youth living in another culture or country, it is important to conduct a cross-cultural adaptation process to establish the reliability and validity of the translation version of the PEM-CY. Korean occupational therapists (OTs) are interested in measuring the participation of children with disabilities (Chang & Ryu, 2010; Yoo et al., 2013), therefore, the PEM-CY has been translated to the Korean

language for children with disabilities aged 5 to 13 years using cross-cultural adaptation guideline (Jeong, Law, Stratford, DeMatteo, & Kim, 2015, submitted 05-Feb-2015 to Disability and Rehabilitation). To improve the fit of the PEM-CY with the Korean culture, this guideline includes the processes of review of the PEM-CY by Korean experts working with children with disabilities and cognitive interviews with Korean parents of children with disabilities. Establishing the psychometric properties of the Korean PEM-CY (KPEM-CY) is a necessary process to examine its utility in Korean clinical and academic settings.

The purpose of this research was to examine the reliability and validity of the KPEM-CY for children and youth with disabilities in the Korean cultural context. The research questions were addressed in two parts: reliability and validity

1. To what extent does the KPEM-CY display internal consistency and test-retest reliability in measuring the participation and environmental factors of children with disabilities?
2. Do the scores on the KPEM-CY show differences in participation patterns and perceived environmental factors of children with disabilities, according to the child's variables (age, gender, the number of siblings, type of school) and parent's demographic characteristics (age, education level, family annual income, time spent with their child)?
 - Hypothesis 1: there are differences in the mean scores of participation (frequency, extent of involvement, and desire for change) when analysed by child and their parent variables.

- Hypothesis 2: there are differences in the mean scores of environment (environmental supports, barriers, helpfulness, resources, and overall environmental supports) when analysed by child and their parent variables.

3.3 Methods

3.3.1 Participants

Parents of children with disabilities were recruited using a convenience sampling method in the city of Daejeon, South Korea in 2013. A primary investigator contacted OTs, social workers, and teachers in special education schools who work with children with disabilities. Through those local health care providers, this study was introduced to the parents of children with disabilities by providing an envelope including a consent form, letter describing the study (Appendix C), demographic questionnaire (Appendix D) and the paper form of the KPEM-CY. Parents were eligible for the study if they met the following inclusion criteria: 1) parent or legal guardian of a child, 2) able to read and write Korean, 3) had a child aged 5 to 13 years with disabilities at a time of enrolment, 4) lived in the city of Daejeon. Eighty participants were recruited from rehabilitation hospitals, community, private centres, and special education schools.

Ethical approval was obtained from the Hamilton Integrated Research Ethics Board at McMaster University (Appendix E). Permission to gather data was also obtained from Korean health care institutes, community centers, and schools (Appendix F).

3.3.2 Measures

The PEM-CY is a unique parent-report survey measure for large-scale studies (Coster et al., 2011a). This tool was designed to assess 1) the participation of children and youth with and without disabilities aged 5 to 17 years in typical activities and 2) perceived environmental supports or barriers to their participation. The PEM-CY includes participation and environment sections in three settings: home, school, and community.

The participation section includes typical activities that children perform in given environments, with activity examples to help respondents understand the items. Respondents score three dimensions of participation: frequency, extent of involvement, and desire for change. The environment section is composed of the factors associated with the physical, cognitive, and social environment. Responders are asked to score factors that encourage or impede children's participation and to report perceived supportive resources available.

A North American study of the PEM-CY established moderate to very good internal consistency (0.59 and above) and test-retest reliability (0.58 and above) (Coster et al., 2011a). The measure detected significant differences in participation patterns and environmental factors between children with and without disabilities (Coster et al., 2011a). In addition, the concurrent validity of the PEM-CY was established against the CHIEF-CP as a criterion measure. There was moderate to strong association between most PEM-CY environment summary scores and CHIEF-CP total product and magnitude scores (Khetani et al., 2014).

The PEM-CY was translated to Korean for children and youth aged 5 to 13 years through a cross-cultural adaptation process. This process used guidelines provided by the Participation and Environment Project (PEP) team in the *CanChild* Center for Childhood Disability Research (Coster et al., 2011a) and Beaton and colleagues (Beaton, Bombardier, Guillemin, & Ferraz, 2000). It has six stages: 1) pre-review of all participation items by Korean experts working with children with disabilities, 2) translation of the PEM-CY to Korean, 3) back translation of the translated PEM-CY to

English, 4) expert committee review of all translated versions to maintain the equivalence of the PEM-CY, 5) cognitive interview with 10 parents of children with disabilities, and 6) final-review of the pre-final version of the KPEM-CY by four parents who participated in the cognitive interviews. Through these stages, 76% of the participation items and 29% of the environment items were revised slightly to improve their fit with the Korean culture (Jeong et al., 2015, submitted 05-Feb-2015 to Disability and Rehabilitation).

3.3.3 Procedures

Field-testing was conducted to establish internal consistency, test-retest reliability, and construct validity of the KPEM-CY for Korean children with disabilities. One hundred and forty form packages were distributed to participants of children with disabilities, aged 5 to 13 years. Participants were asked to complete a retest of the measure after 2 weeks in order to provide the information for the test-retest reliability evaluation. After the participants completed each assessment, they returned all completed forms to the investigator through the local health care providers.

3.3.4 Data Analysis

SPSS statistics 19 data analysis software (IBM Corp., 2010) was used for all analyses. Descriptive analyses were conducted to describe the background characteristics of children with disabilities and their parents or caregivers. Child and parent variables and each summary score of the KPEM-CY were used as an independent and dependent variables, respectively (Table 3.1).

[Insert table 3.1 about here]

Internal consistency was calculated using Cronbach's alpha for items: participation frequency, extent of involvement, desire for change, environmental helpfulness, environmental resources, and overall environmental supports. Test-retest reliability was obtained by comparing KPEM-CY scores completed by the parents of children with disabilities on two occasions, two weeks apart. A randomized block analysis of variance (ANOVA) was applied that identified three sources of variance: participants, occasions, and error. Applying these three sources of variance, the test-retest reliability was quantified by the Type 2,1 intra-class correlation coefficient (ICC) (Shrout & Fleiss, 1979).

To examine construct validity (known group validity), three steps were conducted; 1) t-test for the independent samples (or Mann-Whitney test) and one-way ANOVA (or Kruskal-Wallis test) were applied to determine if there was a significant difference in the participation patterns of children with disabilities and environmental factors according to child and parent variables; 2) If there was a significant difference between or among the groups, Scheffe' post hoc test was employed to identify where differences existed among the groups. 3) With all significant variables, factorial ANOVA with type III sum of squares (unequal cell sizes) was used to examine any interaction effects between or among those variables. If missing cells values or cells having less than 5 participants were identified, the categories of these variables were collapsed to eliminate missing cells and increase each cell size. The Sidak corrected p-value ($p < 0.0064$) was applied to account for multiple comparisons problem instead of a conventional threshold of $p < 0.05$.

Before these statistical analyses were conducted, the basic assumptions of t-test, one-way ANOVA, and factorial ANOVA (i.e., independence, normality and homogeneity of variance from each observation) were checked using two methods: visual inspection (histogram of residual) and formal tests (Shapiro-Wilk test and Levene statistics). In addition, residual, leverage, and cooks' distance were examined to detect outliers that affected the normality of the summary scores of the KPEM-CY.

3.3.5 Sample Size Estimation

Relative reliability sample size was calculated using a formula based on the following assumptions: expected test-retest ICC of 0.80 with a lower 1-sided 95% confidence interval width of 0.1 (i.e., the lower limit will be 0.70) (Stratford & Spadoni, 2003).

According to the parameter estimation sample size calculation, this study needed at least 52 participants in order to determine the test-retest reliability of a new measure in a new population. When considering 20% drop-out, the sample size for the reliability component was calculated to be 65 (Appendix G).

3.4 Results

3.4.1 Participants

Eighty parents participated in this study and seventy of them completed the KPEM-CY twice. Data from the parents who answered at least 80 % of all questions were used for the analysis. Not all participants completed the entire survey; therefore, data from 76 parents of children with disabilities were analysed. Most responders were mothers (93.4%) in their 30s and 40s (both 44.7%). Almost all participants (98.9%) completed at least a high school's diploma. Fifty nine percent of the children with disabilities were males. Children with disabilities were evenly distributed across three age groups: 26 children aged 5 to 7 years (34.2%), 20 children aged 8 to 10 years (26.3%), and 30 children aged 11 to 13 years (39.5%). Thirty eight percent of the families were within the average annual income households (4,000,0000 – 4,999,0000 won) in South Korea. Because parent usually checked more than one diagnosis, it was difficult to identify whether or not a child's diagnosis influenced and what certain diagnosis affected the participation patterns of children and environmental factors. Therefore, diagnosis was not used for the data analysis. More information about the descriptive characteristics of children with disabilities and their parents is provided in Table 3.2.

[Insert table 3.2 about here]

3.4.2 Reliability

Internal consistency coefficients for participation frequency were 0.85 for home, 0.67 for school, and 0.68 for community. The coefficients for the extent of involvement were 0.83 for home, 0.92 for school, and 0.76 for community. In terms of the desire for change, the

internal consistency coefficients were 0.69 for home, 0.74 for school, and 0.76 for community. Cronbach's alphas for the environment scales (environmental helpfulness, environmental resource, and overall environmental supports) were ≥ 0.70 for all settings. Table 3.3 shows Cronbach's alphas for all summary scores across the three settings.

The sample sizes used for each analysis were between 65 and 66 due to missing data. Table 3.4 shows all ICCs and the lower 95% confidence intervals for each summary score. Test-retest reliability estimates of the summary scores for participation frequency and extent of involvement were over 0.75 for all settings, with the highest level for participation frequency. The ICCs of desire for change summary score were lower across the three settings. The estimates of reliability for the environment section (i.e., environmental supports, environmental barriers, environmental helpfulness, environmental resource, and overall environmental supports) ranged from 0.60 to 0.79 except for the summary score for environmental supports in the three settings.

[Insert table 3.3 about here]

[Insert table 3.4 about here]

3.4.3 Validity

Child's age, the type of school that a child goes, and family annual income were the factors that significantly influenced specific summary scores of participation and environment across the three settings.

In the home setting, the type of school showed significant differences in summary scores of participation frequency ($\chi^2(2) = 19.53$, $p < 0.001$) and overall environmental supports ($F(2,69) = 6.18$, $p = 0.003$). All differences were examined between the groups of

children in public and special education schools at $p < 0.0064$, but children in private schools did not significantly differ from those in two other types of school (Table 3.5). Another main effect of family annual income on the extent of involvement was identified, $F(4, 25.29) = 5.52$, $p = 0.002$, however, the Scheffe test could not find differences at a Sidak-adjusted significance level of 0.00064. Child's age was also a significant factor to detect differences in the summary score of environmental helpfulness, $\chi^2(2) = 10.10$, $p = 0.006$. The Mann-Whitney test was applied to identify where the differences existed. Environmental helpfulness was greater for children aged 8 to 10 years ($Mdn = 95$) than for children aged 11 to 13 years ($Mdn = 81$), $U = 144.5$, $p = 0.002$, however, the group aged 5 to 7 years was not significantly different from the other two groups.

No significant effects of any of the parent or child's variables were found in summary scores for children with disabilities in the school setting. However, the type of school was a significant factor to detect differences in the summary score of community participation frequency ($\chi^2(2) = 22.56$, $p < 0.001$) and those differences existed between children in public schools and in special education schools (Table 3.5).

Other factors (i.e., child's gender, the number of siblings, parent's age, the level of education, and time spent with a child) were not significantly different across all summary scores. Even though the planned next step was to test for an interaction effect between and/or among the significant factors on a specific summary score, factorial ANOVA was not applied because there was no instance where two or more factors had a significant effect on a specific summary score of the KPEM-CY.

[Insert table 3.5 about here]

3.5 Discussion

This research represents the first study to examine the reliability and validity of the PEM-CY in the Korean cultural context. The findings of the study indicate that the Korean PEM-CY is a reliable and valid measurement tool to assess the participation of Korean children with disabilities aged 5 to 13 years in typical activities and environmental factors that affect participation.

Internal consistency coefficients for all subscales of the KPEM-CY were moderate to excellent as those were over 0.65. Most items included in a specific subscale are correlated (Tavakol & Dennick, 2011). The coefficients for participation frequency and extent of involvement of the KPEM-CY (0.67-0.92) were higher than those of the original PEM-CY (0.59-0.83), which were established by the North American study (Coster et al., 2011a). However, the coefficients for desire for change (0.69-0.76) were slightly lower than those of the original PEM-CY (above 0.8) (Coster et al., 2011a).

The coefficients of the test-retest reliability were excellent in the summary scores of participation frequency and extent of involvement across the three settings and moderate to excellent for all summary scores in the home setting. Three subscales were lower across the three settings: desire for change, environmental supports, and barriers. The scale of desire for change is a subjective indicator of participation, thus differences between test and retest might be bigger due to the unexpected factors that affect responders (e.g., emotion and increased awareness of participation concept), compared to an objective indicator of participation (e.g., participation frequency). Because the summary scores of the environmental supports and barriers are calculated by counting the

number of environmental items rated as “usually helps/usually makes hard” or “usually yes/usually no”, these scales might be more impacted by changes in the answers of parents between test and retest. Furthermore, the coefficients of the test-retest reliability in the home setting were greater than those at school and in the community. These may explain that parents spent most of the time with their children with disabilities at home and did not have enough information about their participation in school and community activities. In comparison with the test-retest reliability of the original PEM-CY (Coster et al., 2011a), coefficients for participation frequency and extent of involvement of the KPEM-CY were higher and those for all summary scores of the environment section were lower.

Participation of Korean children with disabilities and environmental factors affecting their participation were significantly influenced by the types of school, child's age, and family annual income at home and the types of school in the community. This study has found that children with disabilities who go to public schools participated more frequently in home and community activities than those who go to special education schools. Also, the parents of children with disabilities in public schools reported that there are more resources available at home to support the participation of their children than those reported in special education schools. The curriculum and environment of special education schools (e.g., individualized education program) are designed for children with disabilities while those of public and private schools focus on typically developing children. Furthermore, children in special education schools typically have more severe disabilities/functional limitations in comparison with children in public and private

schools and these may lead to lower participation and more supports necessary to their participation in typical activities.

The family annual income was another factor which influences on the extent of involvement in home activity participation and it seemed that children living with lower annual income than average annual income in Korea are less involved in home activities. However, further research is needed with a large sample size to determine whether those results are statistically significant at a significant level of 0.0064.

Unlike home and community settings, all other child and their parent variables were not related to the participation patterns of children with disabilities and environmental factors in the school setting. The Korean government applies the free and compulsory education system to children and children in this study were educated under the same school board (i.e., Daejeon Metropolitan Office of Education). Therefore, there may be no differences in the participation patterns of children with disabilities and environmental factors according to the child and parent's factors.

By establishing the reliability and validity of the KPEM-CY through this study, the KPEM-CY has been proven as a reliable and valid measure in the Korean population. The KPEM-CY is the first measure to assess the comprehensive participation patterns of Korean children with disabilities and the impact of environmental factors on their participation at home, school, and in the community. Because OTs provide their services to facilitate the participation of children with disabilities (Engel-Yeger, Jarus, & Law, 2007), it is important to have a culturally adapted and psychometrically sound participation measure to assess the effectiveness of OT intervention that is provided to

Korean children with disabilities. The results of this measure can be referred to when setting up goals for OT intervention. Korean OTs can also communicate with the parents of children with disabilities about their children's routines across the three settings using the KPEM-CY. Furthermore, this tool can be applied to population-level studies to profile children's everyday living in a specific city in South Korea and to compare the participation patterns of children in Korea to those of children in other regions, countries or cultures.

This study has indicated that the type of school, which may be a substitute for the severity of a disability/ functional limitation of children, affects participation frequency in typical activities at home and in the community. To clarify this result, it is important to test whether the severity of a disability/ functional limitations of children influences the participation patterns of children with disabilities with the KPEM-CY. Hammal and her colleagues (2004) reported that if children with cerebral palsy have severe impairment (e.g., hearing and visual impairment), they demonstrate decreased participation. Furthermore, this cross-cultural study examined the reliability and validity of the KPEM-CY in children with disabilities aged 5 to 13 years. Because the original PEM-CY targets children with and without disabilities aged 5 to 17 years (Coster et al., 2011a), further cross-cultural study needs to be conducted in children with and without disabilities at a wider age range. This potential study will identify differences in participation patterns and environmental factors between children with and without disabilities across the stages of child's development.

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Tables

Table 3.1 Dependent variables and independent variables

Dependent variables (Summary scores)		Independent variable (Child and parent's variables)	
Participation section	Environmental section	Child variables	Parent variables
1. Participation frequency (average frequency)	4. Environmental supports (counts of supports)	1. Sex	1. Age
2. The extent of involvement (average involvement)	5. Environmental barriers (counts of barriers)	2. Age	2. Level of education
3. Desire for change (% of activities in which change is desired)	6. Environmental helpfulness (1. add all the ratings of environmental helpfulness items, 2. calculate the maximum possible score within a setting, 3. divide the sum of the ratings by the maximum possible score, 4. Multiple by 100)	3. The number of siblings	3. Time spent with their child
	7. Environmental resources (same way to calculate the summary score as 'environmental helpfulness')	4. Types of school	4. Family annual income
	8. Overall environmental support (same way to calculate the summary score as 'environmental helpfulness')		

Table 3.2 Participants' characteristics

Variables	Number of participants (%)
Total <i>n</i>	76
Respondent age	
20-29 years	0 (0)
30-39 years	34 (44.7)
40-49 years	34 (44.7)
50-59 years	7 (9.2)
Over 60 years	1 (1.3)
Respondent education	
Less than high school	1 (1.3)
High school	22 (28.9)
College	19(25)
University	27 (35.5)
Graduate degree	7 (9.2)
Annual household income	
Below 3,000,0000 won	19 (25)
3,000,0000 - 3,999,0000 won	10 (13.2)
4,000,0000 – 4,999,0000 won	29 (38.2)
5,000,0000 – 5,999,0000 won	5 (6.6)
Over 6,000,0000 won	13 (17.1)
Time spent with a child each day	
Below 5 hours	6 (7.9)
5-9 hours	11 (14.5)
10-14 hours	23 (30.3)
15-19 hours	32 (42.1)
Over 20 hours	4 (5.3)
Child sex	
Male	45 (59.2)
Female	31 (40.8)
Child age	
5 – 7 years	26 (34.2)
8 – 10 years	20 (26.3)
11- 13 years	30 (39.5)
Number of siblings	
No	8 (10)
1	36 (47.4)
2	27 (35.5)
Over 3	5 (6.6)
School	
No	4 (5.3)
Yes	72(94.7)

Type of school	
Public school	44 (57.9)
Private school	5 (6.6)
Special education school	23 (30.3)

Table 3.3 Cronbach alpha's for the internal consistency

Section	Summary scores	Home	School	Community
Participation	Frequency	0.85	0.67	0.68
	Involvement	0.83	0.92	0.76
	Desire for change	0.69	0.74	0.76
Environment	All items	0.77	0.86	0.84
	Helpfulness	0.76	0.84	0.85
	Resources	0.71	0.77	0.73

Table 3.4 Type 2,1 intra-class correlation coefficient and the lower 95% confidence interval for test-retest reliability

Section	Summary scores	Home	School	Community
Participation	Participation frequency	0.95 (0.92)	0.82 (0.71)	0.87 (0.80)
	Extent of involvement	0.78 (0.66)	0.85 (0.75)	0.83 (0.74)
	Desire for change	0.61 (0.43)	0.44 (0.23)	0.69 (0.54)
	Supports	0.53 (0.34)	0.40 (0.20)	0.35 (0.24)
	Barriers	0.63 (0.47)	0.60 (0.43)	0.65 (0.50)
Environment	Helpfulness	0.74 (0.61)	0.77 (0.65)	0.73 (0.59)
	Resources	0.68 (0.53)	0.68 (0.52)	0.65 (0.48)
	Overall environmental supports	0.79 (0.68)	0.75 (0.62)	0.73 (0.60)

Table 3.5 Kruskal-Wallis tests/ one-way ANOVA for comparison of median/mean participation frequency and mean overall environmental supports in children with disabilities according to the type of school

	Type of school	N	Mean Rank	P-value
Participation frequency in Home setting	Public	44	43.43	0.000057
	Private	5	48.20	
	Special education	23	20.70	
	Total	72		
Participation frequency in Community setting	Public	44	44.58	0.000013
	Private	5	44.00	
	Special education	23	19.41	
	Total	72		
	Types of school	Mean (SD)	F	P-value
Overall environmental supports in Home setting	Public	82.32 (1.80)	6.18	0.0034
	Private	85 (5.33)		
	Special education	72.10 (2.49)		

Chapter Four

Title: Measuring Participation of Children and Environmental Factors at Home, School, and in Community: Construct Validation of the Korean PEM-CY

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The target journal of this manuscript is OTJR: Occupation, Participation and Health.

4.1 Abstract

This study examined the construct validity of the Korean version of the Participation and Environment Measure for Children and Youth (KPEM-CY) for Korean children with and without disabilities. A total of 184 parents of children aged 5 to 13 years completed the KPEM-CY to measure the participation of their children and environmental factors affecting participation at home, school, and in the community. Construct validity was analyzed by assessing differences in the participation and environment scores for children with and without disabilities across age and gender. Children with disabilities participated in significantly fewer typical activities and were less supported by environmental factors than those without disabilities across all settings. There were several significant interaction effects between the presence of disability and age in specific dimensions of participation and environment. Results support using the KPEM-CY in Korean clinical and research areas to better understand the participation of Korean children and the impact of environmental factors on participation.

4.2 Introduction

Since the International Classification of Functioning, Disability, and Health (ICF) included the new concepts of participation and environmental factors, participation has become increasingly important in describing children's health and wellbeing (World Health Organization [WHO], 2001). By participating in everyday activities, children can improve their skills, competencies, and relationship with their friends, express creativity, and further be satisfied with their lives (Law, 2002). As occupational therapists (OTs) consider participation as an ultimate goal of their interventions, the importance of measuring the participation of children with disabilities has been highlighted (Law, 2002). Participation is a multi-dimensional concept and is often associated with environmental factors that influence the participation of children with disabilities (McCauley et al., 2013). Due to the relationship with environmental factors, it is important to simultaneously consider the impact of environmental factors on the participation of children with disabilities in meaningful activities (Coster et al., 2011b).

Recent literature has identified the participation patterns of children with disabilities and environmental supports and/or barriers to their participation in Europe, Australia, and North America. The participation of children with disabilities has been shown to be restricted in comparison to that of typically developing children (Coster et al., 2013; Law et al., 2006; Law, Petrenchik, King, & Hurley, 2007; Longo, Badia, & Orgaz, 2013). Coster and her colleagues (2013) found that students with disabilities participated less in school-sponsored teams, clubs, and organizations than their friends without disabilities. Longo and her colleagues (2013) identified that children with

cerebral palsy participated in leisure activities outside of school with lower diversity and intensity of participation but higher levels of enjoyment. In terms of environmental factors, family income has been identified as a barrier to the participation of children with physical disabilities in leisure activities (King et al., 2006) because it affected through local sports and leisure facilities (Finch, 2000). Culture was also shown to be a factor affecting participation patterns between Jewish and Druze children living in Israel (Engel-Yeger, Jarus, & Law, 2007). In addition to the impact of environmental factors on participation, personal factors such as age and gender of a child have been addressed in the literature. When a child with a disability enters adolescence, participation patterns change and a decrease in skill-based activities and an increase in social activities are observed (King et al., 2009; Klaas, Kelly, Gorzkowski, Homko, & Vogel, 2010). Also, girls participated more frequently in skill-based and social activities than boys who preferred to perform physical activities (Guevremont, Findlay, & Kohen, 2008; King et al., 2009; Law et al., 2006). As can be seen from these findings, children's participation is affected by environmental and personal factors; it is important for OTs to consider the impact of those factors when measuring the participation of children with disabilities, in order to better understand their participation patterns.

A number of measurement tools have been developed and applied to assess the participation of children with disabilities and/or the environmental factors that support or impede their participation (McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006; Raghavendra, 2013; Ziviani, Desha, Feeney, & Boyd, 2010). The Children's Assessment of Participation and Enjoyment (CAPE) examines participation in a number of leisure

activities and the intensity of the involvement for children aged 6 to 21 years (King et al., 2007). The School Function Assessment (SFA) measures the level of participation in major school activity settings for elementary school students (Coster, Deeney, Haltiwanger & Haley, 1998). The Craig Hospital Inventory of Environmental Factors for Children-Parent version (CHIEF-CP) evaluates environmental barriers to the participation of children, aged 2 to 12 years, in the domains of physical, attitudinal, service, productivity, and policy (McCauley et al., 2013). Despite the ability of these measures to assess participation in a specific setting and also to look at environmental barriers to participation, measuring the comprehensive participation patterns of children across a wider age range and the direct impact of environmental factors across settings at the same time is still limited. To address this limitation, the Participation and Environment Measure for Children and Youth (PEM-CY) was developed to assess the participation of children with and without disabilities comprehensively as well as the perceived environmental factors in home, school, and community settings (Coster et al., 2011a, 2011b).

Although the CAPE and SFA have been shown to be applicable for Korean children with and without disabilities through cross-cultural studies (Chang & Ryu, 2010; Shin, Park, Lee, & Park, 2014), no measure has been available to assess simultaneously the participation patterns of Korean children and environmental factors across various settings. To address this information, the PEM-CY has been cross-culturally translated to Korean for its utility for Korean children (Jeong, Law, Stratford, DeMatteo, & Kim, 2015a, submitted 05-Feb-2015 to Disability and Rehabilitation) and a pilot study has been

conducted to examine the reliability (i.e., internal consistency and test-retest reliability) (Jeong et al., 2015a, submitted 05-Feb-2015 to Disability and Rehabilitation) and validity (i.e., known group validity) in Korean children with disabilities (Jeong, Law, Stratford, DeMatteo, & Kim, 2015b). The purpose of this study was to further examine the construct validity of the Korean version of the PEM-CY (KPEM-CY) in Korean children with and without disabilities. In addition, the participation patterns of Korean children with and without disabilities and environmental factors were investigated to determine the effects of age and gender of a child. The research questions for each of the three environmental categories are as follows:

Are there differences in the participation patterns and environmental factors of children (1) with and without disabilities; (2) of different ages, and (3) of different genders?

The null hypotheses were as follows:

1. There is no difference in participation pattern and environmental factors between the groups of children with and without disabilities.
2. There is no difference in participation pattern and environmental factors across age ranges.
3. There is no difference in participation patterns and environmental factors between the groups of boys and girls.
4. There are no interactions between disability and age, disability and gender, and, age and gender.
5. There is no 3-way interaction among disability, age, and gender.

4.3 Methods

4.3.1 Participants

A convenience sample of the parents of children with disabilities was recruited from community centres, rehabilitation hospitals, and special education schools through local health care providers (e.g., occupational therapists and social workers). To recruit the parents of typically developing children, a snowball sampling method was applied through the parents of children with disabilities and social workers. Participants were eligible if they were the parents or a legal guardian of children with and/or without disabilities aged 5 to 13 years, living in the city of Daejeon, South Korea and were able to read and write Korean. The Hamilton Integrated Research Ethics Board at McMaster University approved this study (Appendix E) and permission for recruitment in Korea was obtained from the rehabilitation hospital, community centers, and special education schools (Appendix F). After the approval of Canadian and Korean institutes was received, parents were sent a package including an information letter about the study, together with a consent form (Appendix C), demographic questionnaire (Appendix D), and paper form of the KPEM-CY. Parents who completed the consent form participated in the study.

4.3.2 Measures

The PEM-CY is a new parent-reported survey measure developed in North America and measures the participation of children with and without disabilities and environmental factors affecting their participation in home, school, and community settings (Coster et al., 2011a). The concept of the PEM-CY initially followed the ICF, but the final content

of the measure was designed based on the results of focus groups and in-depth interviews with the parents of children with and without disabilities (Coster et al., 2011b).

The PEM-CY includes three settings (i.e., home, school, and community) and each setting has two sections (i.e., participation and environment) (Coster et al., 2011a). Participation items are the typical activities that children can perform in a particular setting and each item has examples of activities to help respondents to better understand that item. Three different scales in the participation section are used to measure the various dimensions of participation: frequency, extent of involvement, and desire for change. Environment items are the factors associated with physical, cognitive, and social environment in a specific setting. Respondents are asked to report whether certain factors encourage or impede children's participation and whether perceived supportive resources (e.g., money, information, and supplies) are available.

The PEM-CY has sufficient reliability and validity in the context of North America (Coster et al., 2011a). Both internal consistency and test-retest reliability were moderate to very good. The measure identified significant differences in participation patterns and environmental factors between children with and without disabilities (Coster et al., 2011a). Khetani and her colleagues (2014) found that there was moderate to strong association between most PEM-CY environment summary scores and CHIEF-CP total product and magnitude scores.

In order to be able to use the PEM-CY in the Korean cultural context, the PEM-CY was cross-culturally translated to Korean for children aged 5 to 13 years. Overall, 76% of the participation items and 29% of the environment items were revised to improve

the fit with the Korean culture (Jeong et al., 2015a, submitted 05-Feb-2015 to Disability and Rehabilitation). Using the culturally adapted KPEM-CY, initial field-testing was conducted in Deajeon, South Korea; differences in participation patterns and environmental factors among the groups of children with disabilities were identified based on children's age, type of school, and family annual income (Jeong et al., 2015b).

4.3.3 Procedure

The principal investigator contacted local professionals (e.g., OTs, social workers, and special education teachers) and the parents of children with disabilities, and invited them to participate in data collection. With their assistance, 290 packages including an information letter with the consent form, demographic questionnaire, and the KPEM-CY were distributed to the parents of children with and without disabilities. After parents filled in the consent form, they completed all measures. The packages including the completed forms were returned through the local professionals.

4.3.4 Data Analysis

Statistical analysis was performed using the STATA version 12 (StataCorp, 2011). Descriptive analyses were used to explain the characteristics of children with and without disabilities and their parents.

To examine differences in participation patterns and environmental factors between children with and without disabilities across age and gender, three-way analysis of variance (ANOVA) with a robust error term was applied to test the significance of the main effects (i.e., disability, age, and gender) and interaction effects between and among those three factors. Dependent variables were all summary scores of the KPEM-CY and

independent variables were disability (non-disability and disability groups), age (groups of children aged 5-7, 8-10, and 11-13 years), and gender (males and females). Due to lack of interaction effects between disability and gender and significant gender differences in few summary scores of the PEM-CY (i.e., extent of involvement and desire for change at home and participation frequency in the community), two-way ANOVA with a robust error term was used to identify the main effects of disability and age as well as interaction effects after removing the factor of gender from the analysis. This statistical method using a robust error term was appropriate to compensate for violation of the basic assumptions (normality and homogeneity of variance) of the two-way ANOVA. When the results of the regression analysis were significant, the Sidak multiple comparison test was conducted to find where differences existed (Abdi, 2007). In addition, the cell means specific to the interaction effect between disability and age were examined to interpret the meaning of the interaction. The level of significance was set at 0.05 for all analyses.

4.3.5 Sample Size Estimation

To examine the validity of the KPEM-CY, the sample size was computed with following conditions; effect size 0.75 from the result of the previous North American study (Coster et al., 2011a) with alpha set at 0.05 and p-value 0.20 of Type II error using one-tailed tests. According to this calculation, the sample size for the validity component was 58 with 20% potential drop-out rate (non-disability group). In addition, the sample size for the reliability component (parents of children with disabilities) was added in this study to compare the participation patterns and environmental factors between two groups of children with and without disabilities. In conclusion, at least 123 participants in total were

needed to examine the reliability and validity of the KPEM-CY in Korean children with and without disabilities. The more detailed formulas for these calculations are shown in Appendix H.

4.4 Results

4.4.1 Participants

A total of 196 forms were completed by the parents of children with and without disabilities. Data from the participants who answered at least 80 % of all questions were used for the analysis. Not all participants completed the entire survey; therefore, data from 184 (93.9 %) participants of children with and without disabilities were analysed. Most participants were mothers (86.4%) in their 30s (46.4%) and 40s (45.9%). Almost all participants were highly educated (98.9%) and only two participants had not obtained a high schools' diploma. Slightly more than 50% of children were males; 43% of all children had disabilities and 50% of males had disabilities. Over 40% of children were 11 to 13 years old and approximately 30 % were 5 to 7 or 8 to 10 years old respectively. More information about the background characteristics of children and their parents are provided in Table 4.1.

[Insert table 4.1 about here]

All summary scores of the PEM-CY and the calculation methods for each summary score are shown in Table 4.2.

[Insert table 4.2 about here]

4.4.2 Participation and Environmental Factors of Children across Age Groups

The results of regression analyses with a robust error term to examine the effects of both disability and age are reported in Table 4.3, 4.4, and 4.5 according to each setting. In the home setting, simple analyses of the main effect of disability showed that the mean

summary scores of participation and environment were significantly different between children with and without disabilities except for two summary scores: environmental supports and environmental resources. Unlike the effect of disability, that of age did not identify significant differences among children. However, significant interaction effects between disability and age were found in two mean summary scores of participation and environment: extent of involvement ($F(2,168)=3.64, p=0.0284$) and environmental helpfulness ($F(2,177)=3.52, p=0.0316$). While children without disabilities showed significant increases with age in the mean summary score of the extent of involvement in home activities, children with disabilities showed significant decreases with age. Post hoc tests revealed higher mean summary scores in all age groups of children without disabilities than children with disabilities aged 8 to 10 and 11 to 13 years. In terms of the summary score for environmental helpfulness, children with disabilities showed significant decreases with age but the scores of children without disabilities were similar regardless of age. Post hoc tests showed the differences between typical developing children and children with disabilities aged 5-7 or 11-13 years.

In the school setting, there were significant differences between children with and without disabilities across all mean summary scores of participation and environment. The effect of age identified a significant difference in the mean summary score of environmental supports among the age groups of children ($F(1,177)=7.00, p=0.0012$). However, post hoc analysis using the Sidak multiple comparison test could not identify where this difference existed. This may be because of the small sample size of each group and/or the sensitivity of the tests (e.g., the sensitivity of ANOVA is greater than that of

the Sidak multiple comparison test). There was also a significant interaction effect between disability and age in the same mean summary score ($F(2,177)=5.16, p=0.0066$). Children without disabilities showed significant decreases with age in mean summary scores, but children with disabilities showed significant increases with age. Post hoc tests revealed that significant age group differences existed only in the children who did not have disabilities (between 5 to 7 years and 11 to 13 years).

In the community, simple analyses of main effect of disability showed that the mean summary scores of participation and environment were significantly different between children with and without disabilities except for three summary scores of participation and environment: participation frequency, extent of involvement, and environmental resources. Like the home setting, the main effect of age did not show significant differences in all participation and environment summary scores. However, the significant interaction effects between disability and age were identified in four mean summary scores of extent of involvement ($F(2,166)=3.15, p=0.0454$), environmental barriers ($F(2,177)=3.63, p=0.0285$), environmental helpfulness ($F(2,175)=3.81, p=0.0240$), and overall environmental supports ($F(2,175)=3.40, p=0.0355$). As children age, children with disabilities showed significant decrease in the mean summary scores for extent of involvement, environmental helpfulness, and overall environmental supports but significant increase in the mean summary scores for environmental barriers. Post hoc tests revealed that as children with disabilities become older, greater differences are identified in the given summary in comparison with those of children without disabilities.

[Insert table 4.3 about here]

[Insert table 4.4 about here]

[Insert table 4.5 about here]

4.5 Discussion

The findings of this study showed that participation patterns and environmental impact on participation were significantly different between Korean children with and without disabilities aged 5 to 13 years. In most activities, children with disabilities had lower levels of participation and fewer environmental supports and resources for their participation at home, school, and in the community. The parents of children with disabilities reported a higher level of desire to change their children's participation patterns, meaning that they were less satisfied with their children's participation. They also reported significantly more environmental barriers to the participation of their children than the parents of children without disabilities. Unlike the North American study that identified differences between children with and without disabilities in all summary scores of participation and environment (Coster et al., 2011a), this study did not identify differences between the two groups in a few dimensions of participation and environment in home and community settings. Although the results between the two studies were different, it may be difficult to directly compare them with each other because the ways to calculate the summary scores of the PEM-CY have been revised and additional summary scores were added to the PEM-CY after the North American study (Coster et al., 2014). However, the results of this study are congruent overall with what was found in the previous studies conducted using the participation measures including the PEM-CY (Bedell et al., 2013; Coster et al., 2011a; Coster et al., 2013; Hilton, Crouch, & Israel, 2008; Law et al., 2006; Law et al., 2007; Longo et al., 2013; Michelsen et al., 2009). A European study found that children with cerebral palsy participated less

frequently in many areas of everyday life (e.g., housework, riding a bicycle or wheelchair for fun, and sports) than typically developing children (Michelsen et al., 2009). In addition, these children were involved in less diverse leisure activities (Longo et al., 2013). This pattern was also identified among children with high-functioning autism spectrum disorders in out-of-school activities (Hilton et al., 2008).

The age of a child is one of the determinants of participation patterns (Law et al., 2004; Simpkins, Ripke, Huston, & Eccles, 2005). Although the participation patterns of younger (i.e., 6-10 years) and older (i.e., 11-15 years) children were found to be different according to the type of activity, overall frequency of participation in community activities declined as children grew older (Colón, Rodríguez, Ito & Reed, 2008; King et al., 2009). However, this study found that the age of a child did not significantly affect the participation patterns of Korean children aged 5 to 13 years. The reason for lack of differences in participation patterns across the three settings may be because of the narrow age range, which did not include children older than 13 years in this study. Because children increase their developmental capacities and expand their proximal environments as they age (Bronfenbrenner & Morris, 2006), their participation patterns become significantly changed.

While there were no differences in participation patterns and environmental factors among the three age groups of children in the home and community settings, significant differences were identified in the number of environmental supports available in the school settings. The number of environmental supports at school increased as children age. This finding may be explained by the fact that, as children advance into

higher grades, the school environment is changed from kindergarten (children aged 5 to 7 years) to elementary school (children in lower grade aged 8 to 10 years and children in higher grade aged 11 to 13 years) so the number of subjects which a student takes increases. As children age, a growing number of environmental supports (e.g., additional expense for education and after-school programs) are needed for their successful participation in school activities, regardless of the presence of disability.

According to the interaction effects between disability and age of a child, significant differences in participation patterns and environmental factors were found among the groups of children. In comparison with home and school settings, the interaction effects affected more dimensions of participation and environmental factors (e.g., extent of involvement, environmental barriers, environmental helpfulness, and overall environmental supports) in the community setting among the groups of children. Korean children with disabilities became less involved in community activities, were less supported by environmental factors in the community and their participation was impacted by more environmental barriers as they age. This finding may be explained by the fact that there is a lack of services and resources to help children with disabilities successfully participate in community activities and/or that their parents do not have enough information about the services and resources for which their children with disabilities may be eligible at different ages. A similar phenomenon was also confirmed at home. This study found that the participation patterns of children at home and in the community were significantly different due to both disability and age but did not find this in the school setting. Unlike home and community settings in Korea, children can

participate in school activities in comparatively similar environments. Environmental factors at Korean schools supporting the student's participation may be similar not only because the Korean government provides basic supplies to the elementary schools in a free education system but also all children in this study were under the same school board of Daejeon. This may explain why the school participation patterns of children and environmental factors may not have differed according to either disability or age. Another reason can be that the parents of children provided mostly exact responses about the participation of their children in home and community settings based on their experience while they did not have as much information about their children's school participation so that they answered based on their assumptions.

The results of this study helped to establish further the validity of the KPEM-CY for Korean children with and without disabilities aged 5 to 13 years. The KPEM-CY is now able to be used in clinical and research areas for Korean children and youth. Various stakeholders can apply the KPEM-CY, which has been culturally and psychometrically adapted to the Korean cultural context, and its results can be used for different purposes. Firstly, the parents of a child with a disability can be provided with the typical activity profile of their child in a specific setting and, through the profile, they can identify what activities with which their child is struggling. Parents can then attempt to balance the activities in a child's daily routine by discussing the issues related to the participation of their child in particular activities with health care providers. Next, Korean OTs can obtain comprehensive information about the participation of their clients in typical activities across the three settings and can determine environmental barriers to their participation

through use of the KPEM-CY. This information will help therapists better understand their clients in each particular environment and may facilitate goal-setting in order to improve the participation of clients at home, school, and in the community (e.g., modify environmental barriers to support their participation). Furthermore, the findings of this study can be evidence to start other studies that are associated with the participation patterns of children with specific disabilities and environmental factors in different regions of South Korea. Because the PEM-CY was designed for population-level studies, the KPEM-CY should also be able to be applied in population-level studies to examine similarities and differences in participation and environment across the groups of children and youth with the different types of a disability and living in different regions in Korea. The results of those studies can be compared with the participation patterns and environmental factors of children and youth in other cultures and/or countries.

4.6 Study Limitations and Future Directions

The results of this study were obtained from a small sample collected in a specific city and were not randomly selected; therefore, they may not be representative of the entire Korean population. In addition, the KPEM-CY was developed for children with and without disabilities aged 5 to 13 years, which is different from the original version of the PEM-CY targeting children aged 5 to 17 years. Future studies are needed to determine whether the KPEM-CY is a valid measure for children aged from 14 to 17 years, for children and youth with more diverse disabilities, and for those living in other regions in South Korea.

Much research has identified the participation patterns of children according to the type of activity in community settings (e.g., leisure) compared to other settings such as school (Bult et al., 2010; Longo et al., 2013; Ullenhag, 2012). These studies were typically conducted in North America and Europe. Therefore, future studies are necessary to determine how the participation patterns of children and youth in Asia and the environmental factors relevant to their participation may be similar or different in activities at home, school, and in the community.

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Tables

Table 4.1 Participant's characteristics

Variables	Number of participants (%)
Total <i>n</i>	184
Respondent age	
20-29 years	0 (0)
30-39 years	85 (46.4)
40-49 years	84 (45.9)
50-59 years	13 (7.1)
Over 60 years	1 (0.6)
Relationship with a child	
Father	24 (13)
Mother	159 (86.4)
Grandparents	1 (0.6)
Guardian	0 (0)
Respondent education	
Less than high school	2 (1.1)
High school	59 (32.2)
College	34 (18.6)
University	64 (35)
Graduate degree	24 (13.1)
Annual household income	
Below 3,000,0000 won	61(33.3)
3,000,0000 - 3,999,0000 won	21(11.5)
4,000,0000 – 4,999,0000 won	48 (26.3)
5,000,0000 – 5,999,0000 won	18 (9.8)
Over 6,000,0000 won	35 (19.1)
Child sex	
Male	94 (51.4)
Female	89 (48.6)
Child age	
5 – 7 years	53 (28.96)
8 – 10 years	55 (30.05)
11- 13 years	75 (40.98)
Child group	
Non disability	104 (56.52)
Disability	80 (43.48)

Table 4.2. Participation and Environment Measure for Children and Youth (PEM-CY)

scoring

Section	Summary scores	Calculation
Participation	Participation frequency	Item frequency, rated on a 7-point scale, divided by total number of activities
	Extent of involvement	Item frequency, rated on a 5-point scale, divided by total number of activities
	Desire for change	Percentage of activities in which change is desired
Environment	Environmental supports	Count the number of environmental items within the setting rated as “usually helps” or “usually, yes”
	Environmental barriers	Count the number of environmental items within the setting rated as “usually makes harder” or “usually no”
	Environmental helpfulness	Percentage of helpful environmental factors supporting participation (1. Add all the ratings of environmental helpfulness items, 2. Calculate the maximum possible score within a setting, 3. Divide the sum of the ratings by the maximum possible score, 4. Multiple by 100)
	Environmental resources	Percentage of environmental resources available supporting participation (1. Add all the ratings of environmental resource items, 2. Calculate the maximum possible score within a setting, 3. Divide the sum of the ratings by the maximum possible score, 4. Multiple by 100)
	Overall environmental supports	Percentage of all environmental supports to participation (1. Add all the ratings of environmental helpfulness and resource items, 2. Calculate the maximum possible score within a setting, 3. Divide the sum of the ratings by the maximum possible score, 4. Multiple by 100)

Table 4.3 Interaction effects between disability and age on each PEM-CY scale in home setting

Setting	Summary scores	Non-disability group			Disability group			F (p)
		5-7	8-10	11-13	5-7	8-10	11-13	
Home participation	Frequency	5.96 (0.60)	5.88 (0.42)	5.95 (0.61)	4.63 (1.63)	4.97 (1.76)	4.39 (1.67)	0.75 (0.47)
	Involvement	3.61 (0.51)	3.66 (0.58)	3.69 (0.48)	3.24 (0.72)	2.78 (0.80)	2.65 (0.94)	3.64* (0.03)
	Desire for change	66.96 (29.14)	67.08 (30.18)	74.29 (26.24)	87.16 (14.60)	87.14 (20.21)	92.67 (13.37)	0.03 (0.97)
Home environment	Supports	4.22 (2.30)	4.37 (2.26)	3.33 (2.30)	3.90 (2.06)	3.60 (2.28)	3.23 (2.56)	0.30 (0.74)
	Barriers	0.87 (1.22)	0.57 (1.22)	0.82 (1.39)	1.97 (1.69)	1.65 (1.76)	2.67 (2.52)	0.80 (0.45)
	Helpfulness	92.55 (10.14)	94.97 (8.87)	93.44 (9.15)	82.70 (13.26)	90.71 (10.87)	77.78 (15.28)	3.52* (0.03)
	Resources	81.45 (10.63)	84.38 (16.95)	79.70 (18.20)	78.89 (17.78)	74.33 (18.00)	71.33 (18.12)	0.82 (0.44)
	Overall supports	87.92 (8.52)	90.55 (10.68)	87.72 (11.35)	81.11 (10.48)	83.89 (10.88)	75.10 (14.45)	1.21 (0.30)

Note. Values are mean and SD, * $p \leq 0.05$

Table 4.4 Interaction effects between disability and age on each PEM-CY scale in school setting

Setting	Summary scores	Non-disability group			Disability group			F (p)
		5-7	8-10	11-13	5-7	8-10	11-13	
School participation	Frequency	4.86 (1.39)	5.10 (0.91)	5.14 (1.03)	2.99 (1.68)	3.68 (1.67)	4.23 (1.23)	1.65 (0.19)
	Involvement	4.01 (0.68)	4.21 (0.57)	4.07 (0.70)	2.76 (1.22)	2.36 (0.99)	2.21 (1.06)	1.61 (0.20)
	Desire for change	64.55 (41.37)	63.13 (38.72)	62.86 (38.90)	95.56 (8.47)	90.00 (27.91)	94.67 (11.67)	0.10 (0.91)
School environment	Supports	7.65 (3.56)	5.77 (3.00)	4.29 (3.37)	5.30 (3.06)	5.95 (3.50)	5.83 (3.02)	5.16* (0.01)
	Barriers	0.43 (0.79)	0.51 (1.01)	0.53 (0.99)	2.40 (2.85)	2.10 (2.34)	3.77 (3.84)	1.66 (0.19)
	Helpfulness	90.41 (9.12)	93.76 (9.15)	93.10 (9.44)	80.25 (16.37)	84.44 (11.37)	77.41 (16.05)	1.12 (0.33)
	Resources	89.20 (8.40)	88.10 (11.62)	85.99 (11.08)	81.94 (15.55)	79.79 (13.13)	76.67 (17.60)	0.08 (0.92)
	Overall supports	89.84 (7.45)	91.09 (9.04)	89.75 (8.20)	81.05 (13.66)	82.25 (9.60)	77.06 (15.10)	0.55 (0.58)

Note. Values are mean and SD, * $p \leq 0.05$

Table 4.5 Interaction effects between disability and age on each PEM-CY scale in community setting

Setting	Summary scores	Non-disability group			Disability group			F (p)
		5-7	8-10	11-13	5-7	8-10	11-13	
Community participation	Frequency	4.83 (3.56)	4.14 (0.89)	4.59 (2.94)	3.26 (3.62)	4.19 (3.76)	4.74 (4.81)	0.92 (0.40)
	Involvement	3.82 (0.64)	3.97 (0.65)	3.87 (0.73)	3.52 (0.99)	2.90 (1.06)	2.88 (0.94)	3.15* (0.04)
	Desire for change	70.43 (30.37)	65.00 (32.53)	68.29 (31.62)	87.04 (16.60)	85.50 (22.12)	87.00 (15.79)	0.07 (0.93)
Community environment	Supports	6.13 (2.82)	4.97 (3.17)	4.29 (2.94)	4.43 (3.09)	4.30 (2.54)	3.77 (2.45)	0.68 (0.51)
	Barriers	1.26 (1.76)	0.97 (1.67)	0.78 (1.28)	2.93 (2.56)	3.15 (3.07)	5.03 (4.00)	3.63* (0.03)
	Helpfulness	88.73 (9.57)	93.23 (10.38)	94.28 (8.62)	78.97 (14.50)	77.04 (17.85)	66.91 (18.66)	3.81* (0.02)
	Resources	78.05 (16.24)	83.40 (16.63)	83.87 (13.08)	76.19 (16.24)	75.48 (14.52)	70.00 (15.17)	2.16 (0.12)
	Overall supports	84.06 (10.78)	88.93 (11.16)	89.73 (8.87)	77.75 (11.93)	76.35 (12.63)	68.26 (15.05)	3.40* (0.04)

Note. Values are mean and SD, * $p \leq 0.05$

Chapter Five: Discussion

Occupational therapists (OTs) apply top-down approaches to assess and measure outcomes for clients (Case-Smith & O'Brien, 2015). OTs working with children with disabilities primarily identify what children want and need to be able to do (Case-Smith & O'Brien, 2015). There are various reasons why pediatric OTs comprehensively assess children with disabilities (Case-Smith, 2005). OTs assess children in order to identify if they are eligible for ongoing OT services. They also assess children to inform intervention planning, to improve children's participation, and to reevaluate the effectiveness of interventions provided to children. In addition, testing can be conducted to assess the intervention's outcomes and efficacy. In order to achieve these goals, it is necessary for OTs to select appropriate tools that have sufficient reliability and validity, and to consider whether those tools have been validated in a particular context (Beaton, Bombardier, Guillemin, & Ferraz, 2000).

After the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) was revised to become the International Classification of Functioning, Disability, and Health (ICF) including new elements (i.e., participation and environmental factors), the ICF has encouraged great consideration in participation and environmental factors that affect participation (WHO, 2001). As the focus of rehabilitation shifted from a deficit-focused perspective to an enablement perspective toward people with disabilities, people with disabilities are understood by the extent of their participation in meaningful occupations within personally important contexts, rather than by their deficits resulting from their disabilities (Goldstein, Cohn, & Coster, 2004). Because of this shift, the

ultimate goal of rehabilitation has become the successful participation of children with disabilities in meaningful activities performed in natural environments.

Participation is an indicator of a child's development, health, and wellbeing (World Health Organization [WHO], 2001). Successful participation is regarded as a key outcome of OT intervention for children with disabilities (Graham, Rodger, & Ziviani, 2009). The Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006) highlights the role of environment in child development, and proposes that a child's development is shaped by both a child's biology and by various environments around a child over time (Bronfenbrenner & Morris, 2006). In addition, the ICF points out how factors within the physical, social, and attitudinal environments can have both positive and negative effects on the participation of children with disabilities (WHO, 2001). Therefore, it is important to consider the impact of environmental factors on the participation of children with disabilities when OTs deliver services to them in order to improve their participation. For intervention planning and examination of outcomes, OTs need to assess the participation of children with disabilities, as well as environmental supports or barriers to participation, using a well-developed tool.

Several measures assessing the participation of children and youth across different age ranges and contexts have been developed in North American and European countries. Unlike in Western countries, few measurement tools assessing participation in a specific setting such as school exist in the Korean OT society (Chang & Rue, 2010; Shin, Park, Lee, & Park, 2014). These tools were developed in North America and translated into Korean through a cross-cultural adaptation process. Given the few tools applicable to

Korean children with disabilities, there is still the need for a measure that can evaluate the broader patterns of participation of children with disabilities in a wider age range, as well as the environmental factors that support or hinder their participation across various contexts.

The Participation and Environment Measure for Children and Youth (PEM-CY) can be used to comprehensively assess the participation of children and youth with and without disabilities, and environmental factors, concurrently at home, at school, and in the community (Coster et al., 2011). In order to meet the need identified in Korean OT practice, the PEM-CY needs to be useable for Korean children with disabilities. Therefore, the objectives of this thesis were to develop the Korean version of the PEM-CY (KPEM-CY) and to test its psychometric properties in the context of Korean children with and without disabilities.

Through a series of three studies, this thesis has resulted in the development of the Korean version of the PEM-CY and determined its utility in the context of Korean children with and without disabilities, aged 5 to 13 years. In addition, information about the participation patterns of Korean children and the environmental factors affecting their participation has been provided. The interview-based study (Chapter 2) detailed a cross-cultural adaptation of the PEM-CY in the Korean culture using rigorous guidelines and provided detailed information about each stage of the cross-cultural adaptation process. In Chapter 3, the prospective cohort study examined the reliability (i.e., internal consistency and test-retest reliability) and validity (i.e., construct validity) of the KPEM-CY with a sample of children with disabilities. The final study (Chapter 4) examined the further

validation of the KPEM-CY with the entire sample of children with and without disabilities, and reported the patterns of Korean children's participation and environmental supports or barriers across disability, age, and gender groups. A summary of the findings for each chapter is below.

5.1 A Summary of Findings for Each Chapter

5.1.1 Chapter 2: Cross-Cultural Adaptation of the PEM-CY to the Korean Cultural Context

In order to cross-culturally translate the PEM-CY to the Korean language, a specific process was applied by combining two different guidelines suggested by the Participation Environment Project team (PEP team) and Beaton and her colleagues (Beaton et al., 2000; CanChild Centre for Childhood Disability Research, 2014). This process consisted of pre-review of participation items by Korean experts, forward and backward translation, expert committee review, cognitive interviews with Korean parents of children with disabilities (pre-testing), and final review of the Korean version by selected Korean parents of children with disabilities. This unique process allowed this study to obtain different perspectives from various professionals working with children with disabilities and children's parents on the utility of the PEM-CY for Korean children with disabilities. These procedures helped to improve the fit of the PEM-CY into the Korean culture.

A total of 76% of participation items and 29% of environment items were revised to maintain the equivalence between the original and Korean PEM-CY. Most changes in the KPEM-CY were made based on semantic and experiential equivalence. Linguistic differences between the two versions were mainly identified in the instructions, question, and scales (e.g., Never, skip to question C). The experiential equivalence was maintained by revising many items and item examples that were not relevant to the Korean culture (e.g., working for pay). The most important issue that was addressed dealt with conceptual equivalence. It was difficult to determine relevant Korean terms representing

the main terms of the PEM-CY: participation and involvement. Even though those English terms could be linguistically translated to Korean, the Korean terms were not conceptually understood by the Korean parents of children with disabilities. Through consistent reviews by various experts, the most appropriate Korean terms for participation and involvement were identified and used.

5.1.2 Chapter 3: Examination of Reliability and Validity of the KPEM-CY

This was the first study to examine the reliability and validity of the KPEM-CY in the context of Korean children with disabilities. The results of this study indicated that the Cronbach's alpha values of all summary scores of the KPEM-CY were over 0.65, meaning that most items in each subscale of the KPEM-CY correlate. Test-retest reliability coefficients were excellent in the summary scores of participation frequency and the extent of involvement across the three settings, and moderate to excellent for all summary scores in the home setting. Based on these findings, the ICCs in the summary scores of the KPEM-CY might be affected by two factors: the features of summary scores (e.g., average frequency and counts of supports) and amount of information about children's participation in each setting that their parents had.

This study revealed that a child's age, type of school, and annual household income are significant factors affecting participation patterns and/or environmental factors in particular settings. These findings support the construct validity of the KPEM-CY. The results of this study showed that children with disabilities who attend public schools more frequently participate in home and community activities, and have more resources available at home to support their participation in comparison to those attending

special education schools. Based on these results, it can be expected that children who go to public schools have a higher ability to do typical activities at home and in the community compared to children who go to special education schools. Furthermore, while previous studies found significant age differences in the participation of children with disabilities in leisure activities (Hilton, Crouch, & Israel, 2008; Jarus, Anaby, Bart, Engel-Yeger, & Law, 2010; Law et al., 2006) those differences were not identified across the three settings in this study. Because children's participation changes significantly when they enter adolescence (King et al., 2009; Klaas, Kelly, Gorzkowski, Homko, & Vogel, 2010), it may be important to consider the participation patterns of Korean children aged over 13 years and compare their participation patterns to those of younger age groups, in order to detect significant age differences.

5.1.3 Chapter 4: Further Validation of the KPEM-CY

By examining the differences in participation patterns and environmental factors between children with and without disabilities across age or gender, further construct validity of the KPEM-CY was established. Like a North American study using the PEM-CY (Coster et al., 2011), the results of this study demonstrate that children with disabilities had lower levels of participation and fewer supports and resources for their participation across all settings. Unlike in previous studies (Colón, Rodríguez, Ito, & Reed, 2008; Coster et al., 2011; King et al., 2009), age group differences were not significant, due to the narrow age range of children recruited in this thesis. Significant gender group differences in a few dimensions of participation and no significant interaction effects between disability and gender were identified.

Significant interaction effects between disability and age were identified in some of the dimensions of participation and environment. Similar participation patterns and environmental factors (according to the interaction effects between disability and age) were found in both home and community settings, but not in the school setting.

Environmental factors at Korean schools may be similar because the Korean government provides the same basic supplies to elementary schools through the free education system and all children recruited in this study were under the same educational board of Daejeon. Therefore, it can be expected that children participate in school activities in comparatively similar environments, so their participation patterns and environmental factors at school may not be affected in different ways by those interaction effects.

5.2 Contributions of the Thesis to Rehabilitation

Three studies in this thesis have resulted in some key contributions to theory, practice, and research associated with participation measurement for children with disabilities in three primary areas: (i) utilizing a rigorous guideline for the cross-cultural adaptation of a measure; (ii) applying the KPEM-CY for different purposes; and (iii) increasing interest in the participation of children with disabilities.

5.2.1 Utilizing a Rigorous Guideline for Cross-cultural Adaptation of a Measure

Most measures used by Korean OTs were developed in Western countries (Park, & Yoo, 2002; Yoo, Jung, Park, & Choi, 2006; Yoo et al., 2013) because developing and testing a new measure requires professional knowledge and much time and expense (Guillemin, Bombardier, & Beaton, 1993; Patrick & Deyo, 1989). Using a specific measure, which was developed in Western countries, in Korea is an extreme case of the attention that should be paid during the cross-cultural adaptation process due to differences in language and culture between the countries (Beaton et al., 2000; Guillemin et al., 1993). In addition, conceptualizing participation may be different across cultures (Stevenson & van Brakel, 2013). Therefore, the cross-cultural adaptation process allowing a strict process has been highlighted in this thesis in order to use the PEM-CY for Korean children with and without disabilities.

If the PEM-CY was used in the Korean cultural context without cross-cultural adaptation, significant issues may arise. First and most importantly, due to the abstract concept of participation and difficulty in explaining it with a simple sentence, Korean parents may struggle with understanding the main concept of the PEM-CY. The method

of completing the PEM-CY is different from other tools that Korean parents of children with disabilities have used, requiring more time to complete the PEM-CY, and yielding a low response rate. In addition, many items that are not relevant and socially acceptable in Korea may be scored by Korean parents so that the results of the PEM-CY may not represent the participation of 'Korean children'. In effect, these phenomena were identified during the cross-cultural adaptation process in this thesis and the PEM-CY was consistently revised with the consideration of such issues. By completing the cross-cultural adaptation process in this thesis, potential problems with the use of the PEM-CY amongst Korean parents may have been prevented, increasing the likelihood that the scores are interpreted correctly. Furthermore, this procedure allows the results of this thesis to be compared to those of other studies using the PEM-CY in other countries and cultures.

A particular guideline for the translation of the PEM-CY into Korean was created by combining two different processes that the PEP team and Beaton and her colleagues suggested (Beaton et al., 2000; CanChild Centre for Childhood Disability Research, 2014). This rigorous guideline was used to consider the perspectives of various professionals on the application of the PEM-CY to the Korean culture and reconcile those perspectives to create the KPEM-CY in this thesis. Consistent reviews by Korean experts working with children with disabilities, including their parents, helped to identify the specific issues which could occur when using the PEM-CY for Korean children, and to inform revision of the PEM-CY. If the Korean experts' recommended revisions to the PEM-CY were entirely followed, there may have been difficulty in maintaining

equivalence between the original and Korean versions of the PEM-CY. In order to prevent this problem, ongoing communication with the developers of the PEM-CY occurred to reduce the discrepancies between the two versions.

The cross-cultural adaptation process promoted equivalence between the two versions in four areas (i.e., semantic, idiomatic, experiential, and conceptual equivalence), establishing the face and content validity of the KPEM-CY. This thesis described this process in detail. By providing detailed information about the process of cross-cultural adaptation, the importance of using a rigorous guideline to direct the process is made evident. Health care providers and researchers who plan to use the existing measure developed in other countries will be aware of this importance and would be encouraged to select the relevant measures that are cross-culturally adapted to their language and/or culture through the guideline that was used in this thesis.

5.2.2 Applying the Korean PEM-CY for Different Purposes

By examining the psychometric properties of a measure in a particular context, one can determine whether that measure is relevant to the target population. By establishing the psychometric properties of the KPEM-CY in this thesis, the KPEM-CY was shown to be a reliable and valid measure. The KPEM-CY could be used for various purposes in the fields of clinical practice and research as follows.

The KPEM-CY could serve as a communication tool among the professionals working with children with disabilities to share extensive information about the participation of children with disabilities. Current best practice for children with disabilities encourages a collaborative approach with multiple disciplines involved

(Adolfsson, 2013) so that communication with key stakeholders plays an important role in delivering services to children with disabilities. As children age, the person who they can interact and the context where they can perform meaningful activities is changing and become diverse (Ahtola et al., 2011). It is therefore crucial to measure the participation of children with disabilities in various contexts in order to better understand about them (e.g., specific activities that they struggle with and barriers to their participation in a specific setting). However, it may be impossible for OTs to check the participation of children with disabilities in other environments (e.g., school) compared to those in clinical settings and home due to their heavy caseloads. Consequently, the KPEM-CY could be effectively used for communication between OTs and other professionals, in order to examine the different aspects of participation of children with disabilities (i.e., frequency, involvement, and parent's desire to change) without direct observation in their personally important environments. Another purpose that OTs use the KPEM-CY in clinical settings can be to find the specific areas of support or barriers that could be enhanced or addressed to facilitate the participation of children with disabilities. Based on the comprehensive and detailed information generated by the KPEM-CY, OTs can define the intervention goal and establish the action plan in partnership with the parents of children with disabilities. OT interventions can focus on participation limitation in a particular activity (e.g., classroom activities with peers) with consideration of environmental barriers (e.g., teacher's insufficient knowledge about a specific disability and peer's negative attitudes toward a child with a disability). OTs can also help to modify the environmental barriers and provide supports (e.g., a customized educational session for teachers and peers) to

facilitate the participation of children with disabilities in a specific activity by collaborating with other stakeholders (e.g., teachers and parents). After such interventions, the KPEM-CY can be used over time to determine whether environmental factors support children's participation, how their participation patterns have changed, and the parents are satisfied with their children's participation after the intervention.

The PEM-CY was designed for use in population-level studies (Coster et al., 2011). The population-level studies consider the political power of the study results and researchers who conduct those studies focus on the relationship between people with special needs and society based on the systematic and structured point of view (McColl, 2005). Therefore, the results of the population-level studies are expected to promote changes at the system level (McColl, 2005). Like the PEM-CY, the KPEM-CY can be administered in large-scale studies to provide information about the general participation patterns of children with disabilities, and environmental barriers to their participation in the three settings. This information can be compared across regions, cultures, and countries. Policy makers would be interested in learning about the similarities and differences in participation patterns and the impact of environmental factors upon participation because those information would contribute to improve the participation of children with disabilities in various settings. Such findings could be used as evidence to justify the creation of policies that facilitate the participation of children with disabilities.

5.2.3 Increasing Interest of the Participation of Children with Disabilities

This thesis not only established the validity of the KPEM-CY, but also identified the different participation patterns of Korean children and environmental factors that support

or hinder their participation across child and parent's factors (e.g., a child's age, gender, family annual income). Similarities and differences in participation patterns and environmental factors between North American/European children and Korean children were briefly addressed in this thesis. Like children with disabilities living in Western countries, Korean children with disabilities participated less frequently, were less involved, and had fewer resources to support their participation in typical activities across the three settings compared to typically developing children. This thesis did not find age group differences in specific dimensions of participation and environment; the results generally differ from those of the previous studies conducted in Western countries (Colón et al., 2008; Coster et al., 2011; King et al., 2009).

The similarities and differences that were identified by comparing the results of this thesis to those of other studies can support further research in Korea and other Asian countries. In order to determine whether different participation patterns and environments identified in this thesis are consistent in the context of children with particular disabilities and in other regions of South Korea, additional studies are needed. It is also necessary to examine if these differences in the participation of Korean children compared to those in Western countries are identified in other Asian countries. If Korean children demonstrate similar participation patterns as children in other Asian countries, it may be necessary to conduct a population-level study, in order to investigate the effect of culture upon participation, and compare the participation patterns of children in between Asian and Western cultures. These findings would enable a comparison of the resources that support and hinder the participation of children with disabilities within Western and Asian

countries. These potential studies would enable supportive environments where children with disabilities can engage in their meaningful activities and could further lead to enhanced participation of children with disabilities in Asian countries.

In comparison with studies conducted in North America and Europe, there is a lack of evidence associated with the participation of children with disabilities and the environment in Asian countries, including South Korea. OT services in South Korea are provided according to the traditional medical-based approach that focuses on improving physical and mental impairments, rather than on the social participation level of health (An, 2014; Yoo, Lee, Kim, Cha, & Park, 2012). However, as the national paradigm underlying OT has changed from the medical model to the social-ecological model, Korea has attempted to reflect this paradigm in policies related to rehabilitation for children with disabilities, resulting in dramatic changes (Yoo et al., 2012). Therefore, the development of the KPEM-CY and the findings of this thesis about the participation patterns of Korean children with disabilities and environmental factors could contribute to this paradigm shift in Korean OTs' focus, from children's impairments and functions to their participation.

5.3 Limitations

There are three main limitations in this thesis. The generic guideline for the cross-cultural adaptation requires the inclusion of a minimum set of professionals (e.g., methodologists, developers/health professionals, language professionals, translators) in a process of expert committee review (Beaton et al., 2000). The perspectives of those professionals are important to achieve cross-cultural equivalence between the original and target version (Beaton et al., 2000). However, language professionals were not involved in the expert committee for the adaptation of the PEM-CY to the Korean culture. Because of significant language differences between Korean and English, their perspectives would have been helpful in selecting the most relevant Korean terms for a specific English term and completing the KPEM-CY with consideration of the current Korean spelling system. Although the opinions of language professionals were not obtained (which may have been a potential limitation in this thesis), it is expected that consistent reviews by various experts and cognitive interviews with Korean parents can compensate for this limitation.

Next, this thesis did not collect data about the functional limitations of children with disabilities, which was identified as a significant factor influencing their participation in various settings (King et al., 2006; King et al., 2009; Law et al., 2004; Palisano et al., 2011). Absence of this data may influence the results of the thesis. In Chapter 3, the type of school was determined as a significant factor in the frequency of participation among public school students in home and community activities. It is expected that public school students have higher functional ability to take part in general activities compared to students in special education schools. Based on this assumption,

children's functional ability can be a covariate, which may influence the summary scores of participation and environment in the KPEM-CY. Therefore, it is necessary to collect additional data related to children's functional limitations to determine the effect upon the participation patterns of Korean children with disabilities and environmental factors, and how it is associated with the factors of a child and their parents that were applied in this study.

The last limitation in this thesis may be the generalizability of the study results to the entire population of Korean children with and without disabilities. Data were collected in a specific city of Daejeon in South Korea through a convenience and snowball sampling methods. Although the sampling methods were cost effective and helpful to readily recruit the participants who were difficult to reach, they may have lead to sampling biases because the participants were not randomly selected in the city of Daejeon and may have shared similar traits and characteristics. In addition, a small sample size in this thesis may have also limit the generalization of the results to the Korean children with and without disabilities.

5.4 Future Directions

The thesis adds to the understanding of measuring the participation of children with disabilities using a tool that has been cross-culturally adapted for use by Korean OTs. In order to improve the utility of the KPEM-CY in the clinical and research fields in Korea, some future studies need to be considered.

The original PEM-CY targets children and youth with and without disabilities aged 5 to 17 years in North America (Coster et al., 2011), however the KPEM-CY was revised for children with and without disabilities aged 5 to 13 years due to difficulty with recruitment. In order to use the KPEM-CY for Korean children in a broader age range, additional cross-cultural study should be conducted in the context of children and youth with and without disabilities aged 14 to 17 years. Furthermore, as a previous study found moderate to strong associations between the PEM-CY environment summary scores and Craig Hospital Inventory of Environmental Factors for Children-Parent Version (CHIEF-CP) total product and magnitude scores (Khetani et al., 2014), a future study could be conducted to examine the concurrent validity of the KPEM-CY against another participation and environment measures (e.g., Korean version of the Children's Assessment of Participation and Enjoyment) which was already cross-culturally adapted to the Korean culture and has sufficient reliability and validity. A specific research question can be posed in this future study: is there any relationship between the summary score of participation frequency in the KPEM-CY community section and the summary score of participation intensity of the Korean CAPE?

As much research has presented the participation patterns of children with disabilities at an item level (i.e., activity level) (Bedell et al., 2013; Bult et al., 2010; Coster et al., 2013; Law et al., 2013; Longo, Badia, & Orgaz, 2013; Ullenhag et al., 2012), subsequent studies can be designed and implemented to identify in which activities and settings Korean children with disabilities less frequently participate, and are less involved, in comparison with typically developing children. In addition, these studies will help to identify specific environmental barriers to the participation of Korean children with disabilities in particular settings. More meaningful information will be available for intervention planning and for comparison across countries and cultures. One of the research questions in these studies can be “how is participation similar and different between children with and without disabilities in the school setting, and what environmental factors are supports and barriers to the school participation of children with disabilities?”

One final research direction to be explored in the future is the feasibility of using the KPEM-CY in the Korean OT clinical setting. A specific knowledge translation study addressed that Korean OTs did not use participation measures in clinical settings, and one of the reasons for this phenomenon was a lack of relevant participation measures that can be practically applied in clinical settings (Jeong, Law, DeMatteo, Stratford, & Kim, 2015, submitted 10-Mar-2015 to Occupational Therapy in Health Care). The same phenomenon was identified in several other studies about trends in the evaluation tools used by Korean OTs (Park & Yoo, 2002; Yoo, Jeong, & Jo, 2011; Yoo et al., 2006). Yoo and her colleagues (2006) also presented that Korean OTs prefer a simple measure that can be

used in a short time (Yoo et al., 2006). Furthermore, the results of the KPEM-CY only reflect the perspectives of parents about their children's participation, and those may be different from the children's perspectives. Because of these reasons, it would be important to investigate the feasibility of using the KPEM-CY and the barriers to using it in clinical settings. According to the results of this investigation, the development of the short form and/or child-report version of the KPEM-CY could be considered to increase the use of the KPEM-CY amongst Korean OTs.

5.5 Conclusion

This thesis has led to the development of the KPEM-CY and clarification of its utility for Korean children with and without disabilities through two main procedures. The interview-based study increased awareness of the importance of cross-cultural adaptation using a rigorous guideline for the utility of measures developed in other countries for Korean children. Through two prospective cohort studies, the KPEM-CY was proven as a reliable and valid measure to be used in the Korean cultural context. Those studies also offered extensive knowledge about the participation patterns and environmental factors impacting participation at home, school, and in the community according to the child and parent's factors. Such information justified the OTs' clinical practice, future research, and decision-making among health care providers and policy makers.

Future studies will compensate for the limitations evident in this thesis. The construct of the KPEM-CY will be further examined through different types of validity, and the use of the KPEM-CY for children with and without disabilities in a wider age range will be assessed using a large sample in the future. In addition, knowledge about the participation patterns of Korean children and environmental factors at an item level will be provided and the short form of the KPEM-CY could be considered to increase the use of the KPEM-CY in clinical settings by Korean OTs. By conducting these future studies, the KPEM-CY could be applied broadly and efficiently to improve the participation of children with disabilities in South Korea at different levels (i.e., practice, research, and policy).

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Appendix A: Semi-structured cognitive interview questionnaire

Cognitive Interview Questionnaire

Yunwha Jeong
(School of Rehabilitation Science– McMaster University)

Date of interview:

The name of participant:

The age of participant's child:

Information about these interview questions: This interview gives you an idea what I would like to identify in the Korean version of the Participation and Environment Measure for Children and Youth (PEM-CY). Interviews will be one-to-one and will be semi-structured. You can answer the question Yes or No. After that you can explain why you choose that answer. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking such as: (“So, you are saying that ...?”), to get more information (“Please tell me more?”), or to learn what you think or feel about something (“Why do you think that is...?”).

1) Survey instructions

1. Were the instructions provided to you clear? ☐ Yes ☐ No
If no, please describe what was unclear.
2. Did the definition of participation make sense to you? ☐ Yes ☐ No
If no, please explain
3. Did the explanation of each scale make sense to you? ☐ Yes ☐ No
If no, please explain.
4. What do you think is the purpose of the survey?

2) Section1: Home Setting

2-1) Home Participation

1. Do you think that these types of activities are defined clearly? ☐ Yes ☐ No
If no, please explain.
 - a. Were any of the words or phrases used to describe these types of activities

confusing? If so, which ones?

- b. Can you think of words or phrases that could be used instead?
2. Were you able to find an answer for each of the three questions? ☐ Yes ☐ No
If no, please explain.
3. According to the Korean culture, is there any type of activity that you think is important but missing (as it relates to your child's participation at home)?
☐ Yes ☐ No
If yes, please describe.
4. Do you think all items are applied into the Korean culture context? ☐ Yes ☐ No
If no, which items and why?

2-2) Home Environment

1. Are each of the items defined clearly? ☐ Yes ☐ No
If no, please explain
2. Were you able to find an answer for each of the questions? ☐ Yes ☐ No
If no, please explain.
3. According to the Korean culture, is there something that impacts your child's participation at home but is missing from this section? ☐ Yes ☐ No
4. Do you think all items are applied into the Korean culture context? ☐ Yes ☐ No
If no, which items and why?

3) Section2: School Setting

3-1) School Participation

1. Do you think that these types of activities are defined clearly? ☐ Yes ☐ No
If no, please explain.
- a. Were any of the words or phrases used to describe these types of activities confusing? If so, which ones?
- b. Can you think of words or phrases that could be used instead?

2. Were you able to find an answer for each of the three questions? ☐ Yes ☐ No
If no, please explain.

3. According to the Korean culture, is there any type of activity that you think is important but missing (as it relates to your child's participation at school)?
☐ Yes ☐ No
If yes, please describe.

4. Do you think all items are applied into the Korean culture context? ☐ Yes ☐ No
If no, which items and why?

3-2) School Environment

1. Are each of the items defined clearly? ☐ Yes ☐ No
If no, please explain

2. Were you able to find an answer for each of the questions? ☐ Yes ☐ No
If no, please explain.

3. According to the Korean culture is there something that impacts your child's participation in school but is missing from this section? ☐ Yes ☐ No

4. Do you think all items are applied into the Korean culture context? ☐ Yes ☐ No
If no, which items and why?

4) Section3: Community Setting

4-1) Community Participation

1. Do you think that these types of activities are defined clearly? ☐ Yes ☐ No
If no, please explain.

a. Were any of the words or phrases used to describe these types of activities confusing? If so, which ones?

b. Can you think of words or phrases that could be used instead?

2. Were you able to find an answer for each of the three questions? ☐ Yes ☐ No
If no, please explain.

3. According to the Korean culture, is there any type of activity that you think is

important but missing (as it relates to your child's participation in community)?

☐ Yes ☐ No

If yes, please describe.

4. Do you think all items are applied into the Korean culture context? ☐ Yes ☐ No

If no, which items and why?

4-2) Community Environment

1. Are each of the items defined clearly? ☐ Yes ☐ No

If no, please explain

2. Were you able to find an answer for each of the questions? ☐ Yes ☐ No

If no, please explain.

3. According to the Korean culture, Is there something that impacts your child's participation in community but is missing from this section? ☐ Yes ☐ No

4. Do you think all items are applied into the Korean culture context?

☐ Yes ☐ No

If no, which items and why?

Appendix B: Informed consent form for cognitive interview participants

A Study of the psychometric properties of the Participation and Environment Measure for Children and Youth (PEM-CY) in Korean culture context



Principal Investigator: Yunwha Jeong
School of Rehabilitation Science
McMaster University
Hamilton, Ontario, Canada
(289)684-9324 / 010-9384-0818
E-mail: jeongy3@mcmaster.ca

Co-Investigator(s):

1. Professor Paul Stratford
School of Rehabilitation Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext.22523
Email: stratfor@mcmaster.ca

Faculty Supervisor:

Dr. Mary Law
School of Rehabilitation Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext.27837
Email: lawm@mcmaster.ca

2. Professor Carol Dematteo
School of Rehabilitation Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext.27805
Email: dematteo@mcmaster.ca

3. Dr. Hwan Kim
Department of Occupational Therapy
Daegu University
Daegu, Gyeongbuk, Korea
(011-82-53) 850-4392
Email: hwan.kim@daegu.ac.kr

Research Sponsor

You are being invited to take part in a research project about children's participation in daily activities. This form explains the part of this study which we are asking you to take part in, the cognitive interview

Purpose of the Cognitive Interview

In working with children, occupational therapists often assess a child's participation in daily activities and how the environment helps or does not help their participation. The Participation and Environment Measure for Children and Youth (PEM-CY) is an assessment of participation developed in North America. We now want to test the use of this assessment in Korea.

The goal of the cognitive interview is to identify parents' perspectives on the Korean version of the PEM-CY. The original version of the PEM-CY is translated to Korean. The cognitive interview with the parents of children with disabilities is needed to see if items and examples need to be changed for the Korean version of the PEM-CY. After completing the measure, it will be applied in a larger Korean study in order to examine the reliability and validity of the Korean version of the PEM-CY.

Procedures of the cognitive interview

Firstly, you will be given an envelope including a consent form and the paper form of the Korean version of the Participation and Environment Measure for Children and Youth (PEM-CY) by mail or e-mail a week, before you do the interview with the researcher. Secondly, you will have an interview with the researcher. The interview will be for about 30 minutes.

We will ask you questions about the Korean version of the PEM-CY, such as 'did the definition of the participation make sense to you?' and 'do you think all items are applied into the Korean culture context?'. At your convenience, the time, place, and method of the interview can be changed.

Potential Risks and Benefits

There are no known direct benefits to you for participating in this study. In addition, there are no known risks. You will receive a 10\$ gift card for your participation.

Confidentiality

All information about you or your child is confidential. Neither of you will be identified in any reports or publications, nor will information that could identify you be disclosed. All information you provide will be stored in locked cabinet or on the password protected computer on a safe network. These files will be destroyed in 10 years after the study is over.

Participation and Withdrawal

Your participation is completely voluntary. You may refuse to participate or may withdraw from the study at any time with no penalty. If you withdraw from the cognitive interview, you may ask us to destroy any of the information we have already gathered about your perspectives on the Korean version of the Participation and Environment Measure for Children and Youth.

Information about the Study

I expect to have this study completed by approximately in May 2014. If you would like a brief summary of the results, please let me know how you would like it sent to you.

...Yes, I would like to receive a summary of the study's results.
Please send them to this email address

Or to this mailing address:

... No, I do not want to receive a summary of the study's results.

Questions about the Study

If you have any questions about the study or your participation in the cognitive interview, either now or at any time in the future, please feel free to contact me. Yunwha Jeong, the Principal Investigator, can be reached at 010-9384-0818 or jeongy3@mcmaster.ca.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). If you have any questions about your rights as a research participant, please call the Office of the Chair, HIREB at 905.521.2100 x 42013

CONSENT

Do you consent to participate in the cognitive interview of the research?

☐ Yes ☐ No

- I have read the information presented in the information letter about the cognitive interview of this study being conducted by Yunwha Jeong of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in the cognitive interview of this study, I may withdraw from the study at any time.
- I have been given a copy of this form.
- I agree to participate in the cognitive interview of the study.

Signature: _____

Name of Participant (Printed) _____

Appendix C: Informed consent form for field-testing participants

*A Study of the psychometric properties of the Participation
and Environment Measure for Children and Youth (PEM-
CY) in Korean culture context*



Principal Investigator: Yunwha Jeong
School of Rehabilitation Science
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Hamilton, Ontario, Canada
(289)684-9324 / 010-9384-0818
E-mail: jeongy3@mcmaster.ca

Co-Investigator(s):

1. Professor Paul Stratford
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(905) 525-9140 ext.22523
Email: stratfor@mcmaster.ca

Faculty Supervisor:

Dr. Mary Law
School of Rehabilitation Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext.27837
Email: lawm@mcmaster.ca

2. Professor Carol Dematteo
School of Rehabilitation Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext.27805
Email: dematteo@mcmaster.ca

3. Dr. Hwan Kim
Department of Occupational Therapy
Daegu University
Daegu, Gyeongbuk, Korea
(011-82-53) 850-4392
Email: hwan.kim@daegu.ac.kr

Research Sponsor

You are being invited to take part in a research project about children's participation.
This form explains what the study is about.

Purpose of the Study

In working with children, occupational therapists often assess a child's participation in

everyday activities and how the environment helps or does not help their participation. The Participation and Environment Measure for Children and Youth (PEM-CY) is an assessment of participation developed in North America.

The goal of this study is to examine the reliability and validity of the Korean version of the PEM-CY in the Korean population. When I apply the Korean version of the PEM-CY to Korean population, I want to know if the assessment is consistent across time and if it measures participation in a valid way. In addition, I want to identify the patterns of participation of children with and without disabilities and the different types of environmental factors around children without disabilities and to see if they are different across child and parents' variables (gender, age, education level, family income and etc.).

Procedures involved in the Research

Firstly, you will be given an envelope including a consent form, demographic questionnaire, the paper form of the Korean version of the Participation and Environment Measure for Children and Youth (PEM-CY), and letter for parents from your child's teacher or therapist. Secondly, you will be asked to complete the paper form of the Korean version of the PEM-CY. You will be able to complete it within 30 minutes. Third, after 2 weeks, you will be asked to complete the same paper form again. When you complete the forms every time, you can give them to your child's teacher or therapist.

We will also ask you to complete a brief (5 minutes or less) Family Background Questionnaire that asks questions about things like your age and the number of children in your family. This information will help us describe who the participants in this research study were. But, the information you provide will not be reported in a way that will identify your family or your child. It will be reported as a summary for the results of all participants.

Potential Risks and Benefits

There are no known direct benefits to you for participating in this study. In addition, there are no known risks or costs to you.

Confidentiality

All information about you or your child is confidential. Neither of you will be identified in any reports or publications, nor will information that could identify you be disclosed. All information you provide will be stored in locked cabinet or on the password protected computer on a safe network. These files will be destroyed in 10 years after the study is over.

Participation and Withdrawal

Your participation is completely voluntary. You may refuse to participate or may withdraw from the study at any time with no penalty. If you withdraw from the study, you may ask us to destroy any of the information we have already gathered about your family or your child.

Information about the Study

I expect to have this study completed by approximately in May 2014. If you would like to have a brief summary of the results, please let me know how you would like it sent to you.

...Yes, I would like to receive a summary of the study's results.
Please send them to this email address

Or to this mailing address:

... No, I do not want to receive a summary of the study's results.

Questions about the Study

If you have any questions about the study or your participation in it, either now or at any time in the future, please feel free to contact me. Yunwha Jeong, the Principal Investigator, can be reached at 010-9384-0818 or jeongy3@mcmaster.ca.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). If you have any questions about your rights as a research participant, please call the Office of the Chair, HIREB at 905.521.2100 x 42013

CONSENT

Do you consent to participate in this research? ☐ Yes ☐ No

- I have read the information presented in the information letter about a study being conducted by Yunwha Jeong of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time.
- I have been given a copy of this form.
- I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____

Appendix D: Demographics questionnaire

Family Background Questionnaire

(Psychometric Properties of the Participation and Environment Measure for Children and Youth in the Korean cultural context)

Date:

Name of participant:

The date of birth of the child:

INSTRUCTIONS: Please fill in this form to provide background information.

1) Information of parent

1. How old are you?

☐ 20 – 29 years

☐ 30 – 39 years

☐ 40 – 49 years

☐ 50 – 59 years

☐ Over 60 years

2. What is your gender?

☐ Female

☐ Male

3. What is your role for your child?

☐ Mother

☐ Father

☐ Guardian

☐ Grandparents

4. How much times do you typically spend with your child per day?

☐ Below 5 hours

☐ 5 – 9 hours

☐ 10 – 14 hours

☐ 15 – 19 hours

☐ Over 20 hours

5. What is the highest level of education that you have completed?

☐ Less than high school

☐ High school

☐ College

☐ University

☐ Graduate degree

6. What is your annual household income?

- ☐ Below 9,999 ☐ 10,000 – 19,999 ☐ 20,000 – 29,999
☐ 30,000 – 39,999 ☐ Over 40,000

2) Information about your child

1. How old is your child?

- ☐ 5 – 7 years ☐ 8 – 10 years ☐ 11 – 13 years

2. What is your child's gender?

- ☐ Female ☐ Male

3. Does your child have a disability? ☐ Yes ☐ No

If yes, what kind of diagnosis does your child have?

- ☐ Developmental delay ☐ Intellectual delay ☐ Hearing impairment
☐ Speech/language impairment ☐ Vision impairment ☐ Emotional impairment
☐ Orthopedic impairment ☐ Autism spectrum disorder ☐ Attention-deficit disorder
☐ Traumatic brain injury ☐ Learning disability ☐ Cerebral palsy
☐ Other

4. How many siblings does your child have?

- ☐ No siblings ☐ 1 ☐ 2 ☐ Over 3

5. Does your child go to a school (or preschool)? ☐ Yes ☐ No

If yes, which school (or preschool) does your child go?

- ☐ Public school ☐ Private school ☐ Special education school

Please return this brief information with other forms. Thanks.

Appendix E: Certificate from ethics approval



HIREB: Student Research Committee

Final Approval

Date:	May 21, 2013
REB Number:	13-319-S
Title of Study:	Psychometric Properties of the Participation and Environment Measure for Children and Youth in Korean Cultural Context.
Student PI:	Yunwha Jeong
LPI:	M. Law
Version date:	Document:
Apr 25 2013	Application
Apr 25 2013	Protocol
May 10 2013	Consents (3 consents in Korean)
May 10 2013	Advertisement (therapist/participant in Korean)
Apr 15 2013	Telephone Script (therapist/participant)
Apr 15 2013	Interview Guide
Apr 15 2013	Questionnaire(PEM-CY)/Demographics
May 10 2013	Recruitment Letters (4 recruitment letters in Korean)
Apr 15 2013	Study Budget

Dear Yunwha:

We have completed our review of your study and are pleased to issue our final approval. You may now begin your study.

All recruitment and consent material must bear an REB stamp. You may pick up the stamped forms from our office.

Any changes to this study must be submitted with an Amendment Request form before they can be implemented.

This approval is effective for 12 months from the date of this letter. Upon completion of your study, please submit a **Study Completion form**.

If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an **Annual Review form** with your request.

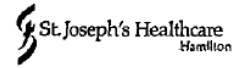
The Study Completion form and the Annual Review form can be found on our website: <http://fhs.mcmaster.ca/healthresearch/reb/forms.html> and should be sent to Tina Arnosti at arnoschr@HHSC.CA.

Please cite your REB number in any correspondence.

Good luck with your research,

Kristina Trim, PhD, RSW
Chair, HHS/FHS Student Research Committee
Health Research Services, HSC 1B7, McMaster University

The HHS/FHS SRC complies with the guidelines set by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans and with ICH Good Clinical Practice.



**Hamilton Integrated Research Ethics Board
RENEWAL FORM**

Review of an Active Study (to be completed by HIREB Chair only)

REB Project #: 13-319-S

Principal Investigator: Dr. Mary Law

Project Title: Psychometric Properties of the Participation and Environment Measure for Children and Youth in Korea Cultural Context

☒ **Approved for Continuation**

☐ **Approved conditional on changes noted in "Conditions" section below**

Type of Approval:

☒ **Full Research Ethics Board**

☐ **Research Ethics Board Executive**

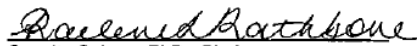
REB Approval Period: Approval period covers May 21st 2014 to May 21st 2015

☐ **New Enrolment Suspended**

☐ **Suspended pending further review**

Conditions:

The Hamilton Integrated Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; for studies conducted at St. Joseph's Hospital, HIREB complies with the health ethics guide of the Catholic Alliance of Canada.


Suzette Salama PhD., Chair
Raelene Rathbone, MB BS, MD, PhD, Chair

5/7/2014
Date of REB Meeting

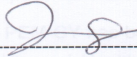
All Correspondence should be addressed to the HIREB Chair(s) and forwarded to:
HIREB Coordinator
293 Wellington St. N, Suite 102, Hamilton ON L8L 6E7
Tel. 905-521-2100 Ext. 42013 Fax: 905-577-8378

Appendix F: Letters of support from Korean Institutions

Recipient: School of Rehabilitation Science, McMaster University

Title: Cooperation in the thesis research

1. We wish you tremendous success in everything you do.
- 2 Youth Academy of Songkang Social Welfare Center has cooperated in recruiting a sample of parents of children in Korea for a thesis research of YunwhaJeong who belong to the Rehabilitation Science Graduate Program at McMaster University as below.
 - A. Content: Recruiting a sample of parents of children and youth in Korea
 - B. Method: Distributing the PEM-CY and bringing it back by social workers
 - C. Recruiting period: 2012. 09. 23 ~ 2013. 09. 27
 - D. Recruiting place: Youth Academy of Songkang Social Welfare Center
 - E. Participant: Parents of children and youth aged 5 to 13 years


Jin-Kyeong Jang

Social worker, Youth Academy of SongKang Social Welfare Center



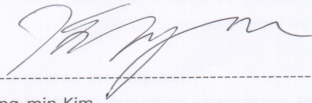
Appendix I . A thesis research proposal related to a new instrument (the PEM-CY)

Recipient: School of Rehabilitation Science, McMaster University

Title: Cooperation in the thesis research

1. We wish you tremendous success in everything you do.
2. Occupational therapy department of Daejeon Convalescent Hospital has cooperated in recruiting a sample of parents of children in Korea for a thesis research of Yunwha Jeong who belong to the Rehabilitation Science Graduate Program at McMaster University as below.

- A. Content: recruiting a sample of parents of children with disabilities in Korea
- B. Method: Distributing the PEM-CY and bringing it back at 2 week intervals by occupational therapists
- C. Recruiting period: 2012. 07. 31 ~ 2013. 09. 06
- D. Recruiting place: Pediatric occupational therapy department of Daejeon Convalescent Hospital
- E. Participant: parents of children with and without disabilities aged 5 to 13 years



Young-min Kim,
Director, Pediatric occupational therapy department

Appendix I . A thesis research proposal related to a new instrument (the PEM-CY)

Recipient: School of Rehabilitation Science, McMaster University

Title:Cooperation in the thesis research

1. We wish you tremendous success in everything you do.
2. Dream-love Kindergarten of Daejeon Christian Social Welfare Center has cooperated in recruiting a sample of parents of children in Korea for a thesis research of YunwhaJeong who belong to the Rehabilitation Science Graduate Program at McMaster University as below.
 - A. Content: Recruiting a sample of parents of children with disabilities in Korea
 - B. Method: Distributing the PEM-CY and bringing it back at 2 week intervals by occupational therapists
 - C. Recruiting period: 2012. 09. 09 ~ 2013. 09. 27
 - D. Recruiting place: Dream-love Kindergarten of Daejeon Christian Social Welfare Center
 - E. Participant: Parents of children with disabilities aged 5 to 13 years

Min-Hui Kim,

Director, Dream-love Kindergarten



Appendix I . A thesis research proposal related to a new instrument (the PEM-CY)

Recipient: School of Rehabilitation Science, McMaster University

Title: Cooperation in the thesis research

1. We wish you tremendous success in everything you do.
2. Susia Choir of Daejeon Metropolitan Society Rehabilitation of Persons with disabilities has cooperated in recruiting a sample of parents of children in Korea for a thesis research of YunwhaJeong who belong to the Rehabilitation Science Graduate Program at McMaster University as below.

- A. Content: Recruiting a sample of parents of children with disabilities in Korea
- B. Method: Introducing parents of children with disabilities aged 5 to 13 years to principal investigator and providing a place to distribute and withdraw the forms
- C. Recruiting period: 2012. 08. 30 ~ 2013. 09. 27
- D. Recruiting place: Daejeon Metropolitan Society Rehabilitation of Persons with disabilities, Susia Choir
- E. Participant: Parents of children with and without disabilities aged 5 to 13 years

1. Participation and Environment Measure for Children and Youth (PEM-CY):

- The PEM-CY has been developed based on the International Classification Functioning, Disability and Health (ICF) by the professors in North America. It is a parent-reported checklist which is intended for parents of children with and without disabilities aged 5 to 13

Daejeon Metropolitan Society Rehabilitation of Persons with disabilities



Each section is also separated into two parts: Participation and Environment. Participation part assesses the frequency of participation, the extent of involvement, and the desire for change in various activities which can be occurred in each environment. In addition, Environment part determines how various environmental factors influence children's participation.

- Occupational therapists can comprehensively understand children using the PEM-CY which measures participation of children and the PEM-CY can help them to navigate the

Appendix I . A thesis research proposal related to a new instrument (the PEM-CY)

21/10 2013 11:13 0425386174 A #3351 F.001 / 001

Recipient: School of Rehabilitation Science, McMaster University

Title: Cooperation in the thesis research

1. We wish you tremendous success in everything you do.

2. Daejeon Wonmyeong School has cooperated in recruiting a sample of parents of children in Korea for a thesis research of Yunwha Jeong who belong to the Rehabilitation Science Graduate Program at McMaster University as below.

A. Content: Recruiting a sample of parents of children with disabilities in Korea

B. Method: Distributing the school newsletter to parents of children with disabilities in order to inform the research and help to contact to them

C. Recruiting period: 2012. 08. 26 ~ 2013. 09. 30

D. Recruiting place: Daejeon Wonmyeong School

E. Participant: parents of children with disabilities aged 5 to 13 years

This study will identify the participation patterns of Korean children with and without disabilities in activities of daily living and assess the relationship between environmental factors and children's participation.

1. Participation and Environment Measure for Children and Youth (PEM-CY)

The PEM-CY is based on the International Classification of Functioning, Disability and Health (ICF) and is a parent-reported measure for parents of children with and without disabilities aged 5 to 13 years. It is a parent-reported measure for parents of children with and without disabilities aged 5 to 13 years. It is a parent-reported measure for parents of children with and without disabilities aged 5 to 13 years.

Han-Ho No,

Principal, Daejeon Wonmyeong School

Appendix I . A thesis research proposal related to a new instrument (the PEM-CY)

Recipient: School of Rehabilitation Science, McMaster University

Title:Cooperation in the thesis research

1. We wish you tremendous success in everything you do.
2. The Children Development's Research Institute of Daejeon Health Sciences College has cooperated in recruiting a sample of parents of children in Korea for a thesis research of Yunwha Jeong who belong to the Rehabilitation Science Graduate Program at McMaster University as below.

A. Content: Recruiting a sample of parents of children with disabilities in Korea

B. Method: Distributing the PEM-CY and bringing it back at 2 week intervals by occupational therapists

C. Recruiting period: 2012. 09. 25 ~ 2013. 10. 18

D. Recruiting place: The Children Development's Research Institute of Daejeon Health Sciences College

E. Participant: Parents of children with disabilities aged 5 to 13 years

Ji-Hun Park, 

Director, The Children Development's Research Institute

Appendix I . A thesis research proposal related to a new instrument (the PEM-CY)

Recipient: School of Rehabilitation Science, McMaster University

Title: Cooperation in the thesis research

1. We wish you tremendous success in everything you do.
2. Hadam Children's Education Center of Daejeon Christian Social Welfare Center has cooperated in recruiting a sample of parents of children in Korea for a thesis research of Yunwha Jeong who belong to the Rehabilitation Science Graduate Program at McMaster University as below.

- A. Content: Recruiting a sample of parents of children and youth in Korea
- B. Method: Distributing the PEM-CY and bringing it back by social workers
- C. Recruiting period: 2012. 09. 30 ~ 2013. 10. 11
- D. Recruiting place: Hadam Children's Education Center of Daejeon Christian Social Welfare Center
- E. Participant: Parents of children and youth aged 5 to 13 years

3. Participation and Environment Measure for Children and Youth (PEM-CY):

- The PEM-CY has been developed based on the International Classification Functioning, Disability and Health (ICF) by the professors in North America. It is a parent-reported measure of children with and without disabilities aged 5 to 13.

Hyun-Mi Kang, Social worker

Director, Hadam Children's Education Center

Appendix I . A thesis research proposal related to a new instrument (the PEM-CY)

Appendix G: Sample size calculation (Chapter Three)

Reliability component: A parameter estimation sample size calculation

This study expects to obtain a test-retest reliability of 0.80 and desire a lower 1-sided 95% confidence interval. Each participant will assess twice.

K = the number of parallel assessment
 Za = the tabled z-value
 Z_{Expected} = z-value associated with the reliability
 $Z_{\text{Rlowerlimit}}$ = lower confidence limit for the desired confidence internal width

$$n = \frac{0.5 k Z_a^2}{(Z_{\text{Expected}} - Z_{\text{Rlowerlimit}})^2 (k+1)} + 2$$

$$Z_{\text{Expected}} = .5 \text{ natural log } \frac{1+(k-1)R_{\text{Expected}}}{1-R_{\text{Expected}}} = .5 \text{ natural log } \frac{1+(2-1)0.80}{1-0.80} = 1.10$$

$$Z_{\text{Rlowerlimit}} = .5 \text{ natural log } \frac{1+(k-1)R_{\text{lowerlimit}}}{1-R_{\text{lowerlimit}}} = .5 \text{ natural log } \frac{1+(2-1)0.70}{1-0.70} = 0.88$$

$$n = \frac{0.5 \times 2 \times (1.65)^2}{(1.10 - 0.88)^2} + 2 = 52.07$$

With 20% drop-off, the sample size for the test-retest reliability will be **65** (parents of children with disabilities).

Appendix H: Sample size calculation (Chapter Four)

1. Reliability component: A parameter estimation sample size calculation

This study expects to obtain a test-retest reliability of 0.80 and desire a lower 1-sided 95% confidence interval. Each participant will assess twice.

K = the number of parallel assessment

Z_a = the tabled z-value

Z_{Expected} = z-value associated with the reliability

$Z_{\text{Rlowerlimit}}$ = lower confidence limit for the desired confidence internal width

$$n = \frac{0.5 k Z_a^2}{(Z_{\text{Expected}} - Z_{\text{Rlowerlimit}})^2 (k+1)} + 2$$

$$Z_{\text{Expected}} = .5 \text{ natural log } \frac{1+(k-1)R_{\text{Expected}}}{1-R_{\text{Expected}}} = .5 \text{ natural log } \frac{1+(2-1)0.80}{1-0.80} = 1.10$$

$$Z_{\text{Rlowerlimit}} = .5 \text{ natural log } \frac{1+(k-1)R_{\text{lowerlimit}}}{1-R_{\text{lowerlimit}}} = .5 \text{ natural log } \frac{1+(2-1)0.70}{1-0.70} = 0.88$$

$$n = \frac{0.5 \times 2 \times (1.65)^2}{(1.10 - 0.88)^2} + 2 = 52.07$$

With 20% drop-off, the sample size for the test-retest reliability will be **65** (parents of children with disabilities).

2. Validity component: The participants will be grouped by several variables related to parent and child. The sample size for the validity will be computed by following conditions; this study expects to obtain above 0.75 effect size with one-sided 95% confidence interval. The sample size will be established by using the statistical calculator.

Anticipated effect size (Cohen's d):

Desired statistical power level:

Probability level:

Minimum total sample size (one-tailed hypothesis): **46**

Minimum sample size per group (one-tailed hypothesis): **23**

Minimum total sample size (two-tailed hypothesis): **60**

Minimum sample size per group (two-tailed hypothesis): **30**

In terms of this calculation, this study will need at least 46 participants, however this sample size should become larger because of the drop-off participants. With 20% drop-

off, the sample size for the validity will be 58 (parents of children without disabilities). This sample size doesn't need to be grouped by two groups according to the presence of disabilities because the sample for the reliability component will be separately recruited.

3. In conclusion, the required sample size for this study will be 123 parents of children with and without disabilities.