Face Validity, Internal Consistency And Applicability Of The Participation And Environment Measure: Child And Youth (German Translation) In Switzerland: A Mixed Methods Pilot Study

by

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Dedication Page

This project is dedicated to my two children, my partner and all the families with whom I worked in Switzerland. Thank you for your support, patience and encouragement.

I hope this project will contribute to a broader awareness of the daily participation challenges that children with disabilities encounter, and pave the way for greater access and involvement.

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Abstract

The Participation and Environment Measure: Child and Youth is a parents' self-report, descriptive measure of childhood participation, with established validity and reliability in large-scale participation research (Anaby et al., 2014; Bedell et al., 2013; Law et al., 2013), clinical rehabilitation settings (Coster et al., 2011) and collaborative care planning (Khetani, 2015). A mixed method, explanatory sequential design with an emergent approach was applied to pragmatically evaluate the face validity, internal consistency, and applicability of the German version of the measure, for use in Switzerland. Nineteen German-speaking parents of children receiving Occupational Therapy treatment field-tested and evaluated the measure. Five parents participated in retrospective cognitive interviews exploring emerging issue related to the content and cultural applicability of the measure in German-speaking Switzerland. Results showed some support for face validity, reliability (internal consistency) and applicability of the measure. Further revision; simplification and cultural adaptation of the measure is recommended.

List Of Abbreviations and Symbols Used

a	Cronbach's Alpha
GPEM-CY	Participation and Environment Measure: Child and Youth (German version)
ICF	International Classification of Functioning: Disability and Health
OT	Occupational Therapy
UN	United Nations
PEM-CY	Participation and Environment Measure: Child and Youth (Original English version)
Stiftung RGZ	Stiftung Regional Group Zürich (Non-Profit Organization)
WHO	World Health Organization
WFOT	World Federation of Occupational Therapists
X	Missing Items

Glossary

Applicability	"Suitability for being applied" (Merriam –Webster, 2017), determined by factors of respondent burden (invasiveness, administration time, respondent acceptability), and format capability (clarity of instructions, cultural relevance of items, language used (Auger, Demers & Swaine, 2005)
Face validity	a form of content validity based on the subjective view of questionnaire respondents/ or other key stakeholders in terms of accuracy, acceptance/likeability and relevance (Thomas, Hathaway & Arheart, 1992)
Internal Consistency	An indicator of test reliability of the internal structure of an instrument. "The extent to which all items in the instrument measure the same construct", evaluated by use of correlation coefficients such as Cronbach's alpha (Depoy & Gitlin, 2011, p. 203)
Participation	"a child's involvement in important everyday activities at home, in school, and in the community. … This includes both how often a child does activities and how involved he or she is when doing these activities" (Coster et al, 2010, p.2).
Involvement	the engagement, initiative and interest a child displays while participating "in an activity, using whatever supports, assistance, adaptations or methods he or she routinely uses or has available". (Coster et al., 2010, p.2)
Environment	the physical layout, sensory qualities, cognitive and social demands, and psychological network in the individuals' school, home, community (Coster et al., 2010)

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My Family

Thank you.

Chapter 1 Introduction

1.1 Introduction

Participation, defined as 'involvement in a life situation' (WHO, 2002, p.10), is a core construct in the World Health Organization's (WHO) International Classification of Functioning, disability and health (ICF), and a focus for outcomes in Occupational Therapy. Participation is considered an indication of health and well-being, influenced by environmental and personal factors, according to the WHO's bio-psychosocial, Model for Disability; the theoretical basis for the ICF. Similarly, the core domains of occupational therapy are focused on the performance of occupations in daily living; the impact of bodily functioning (physical, cognitive and affective) and environmental contexts (physical, institutional and social) on participation, with the goal to enable clients' optimal engagement in daily activities, promoting health and well-being (Canadian Model of Occupational Performance and Enablement, Townsend & Polatajko, 2007). Participation is a therapy outcome for the profession of occupational therapy, and an indicator of health and well being of individuals and communities world-wide (WHO, 2002).

1.2 Perspectives On Participation

1.2.1 United Nations: Division for Social Policy and Development

The year 2016 marked the tenth anniversary of the United Nations Convention on the Rights of Persons with Disabilities. This human rights treaty, presented guidelines

highlighting the importance of participation and involvement of individuals with disabilities in society. Guiding principles of the Convention on the rights of persons with disabilities include:

- Respect for inherent dignity and individual autonomy
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity,
- Equality of opportunity
- Accessibility
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

  (United Nations, 2006)

This UN treaty highlights the importance of participation, encouraging change in health and social policy for the integration and inclusion of individuals with disabilities in communities internationally. As a health-care profession, Occupational Therapy is thereby challenged to address current practice standards and adapt practices when necessary. The measurement of participation, which is the broad focus of this project, is essential to establish a baseline of participation within the population of disabled persons, and evaluate needs in accordance with UN guidelines.

1.2.2 The World Health Organization

The World Health Organization describes the importance of participation and environmental contexts in terms of health, integrating these concepts into a Bio-psychosocial Model of Disability. This model emphasizes the complex relationship between health and influencing factors of body function, activity and participation within

an individuals' environmental context (WHO, 2002). It forms a basis for the development of the International Classification of Functioning, Disability and Health (WHO, 2001), which was produced for application in research, clinical use and policy-making. The Model of Disability (WHO, 2002) encourages healthcare professionals, including Occupational therapists, to "move from impairment-focused" approaches, "gives external validation" and prioritizes participation as an indication of outcomes in health care (Wong & Fisher, 2015).

1.2.3 Occupational Therapy

Traditional and modern models of practice in occupational therapy are based on the importance of occupational performance and participation in the promotion of health and well-being. In occupational therapy, the term occupation refers to "everyday activities that people do as individual, in families and with communities to occupy time and bring meaning and purpose to life" (World Federation of Occupational Therapists, 2017). Occupation is explicitly linked to participation, which is the goal of rehabilitation efforts (Coster et al. 2012). Participation in everyday occupations, as the target for Occupational Therapy, is illustrated in current professional models: The Canadian Model of Occupational Performance and Engagement (Townsend & Polatajko, 2007), The Model of Human Occupation (Kielhofner, 2008), and Person-Environment-Occupation-Performance Model (Ashby and Chandler, 2010) (Wong & Fisher, 2015). These are the most commonly taught models in occupational therapy schools in Australia, Canada, the United Kingdom and United States of America (Ashby and Chandler, 2010). These Models are also included in the core curriculum in German-speaking Occupational Therapy Schools, as illustrated in a core German O.T. textbook by Sheepers, Steding-

Albrecht, Jehn (2015). As specialists in occupational performance, occupational therapists in Switzerland, Austria and Germany, a like North America, are encouraged to adopt an occupation-focused model, and work toward participation outcomes.

A shift in international focus toward participation, by the World Health Organization and United Nations, has induced a wave of theoretical discussion, and the development of tools to facilitate participation focused therapeutic intervention for children with disabilities (Jeong et al, 2016; Khetani et al., 2015; Pritchart-Wiart, 2017). In order to facilitate a participation-focus for interventions, a quality measurement tool focused on participation is required to provide evidence of best practice to key stakeholders. Within pediatric care, measurement tools have been developed with a focus on participation, such as the Pediatric Activity Card Sort and Children's Assessment of Participation and Enjoyment. However, key elements of participation and environmental barriers/supports, attendance and involvement, are suggested as important when choosing a participation measure (Imms et al. 2016). The recently developed Participation and Environment Measure: Child and Youth (PEM-CY), includes these key elements within the construct participation, and environments reflective of child and youth life situations. Evidence shows that the PEM-CY includes most items for participation and environment across all 9 domains set out by the ICF and therefore meets current standards to facilitate the collection of data and interdisciplinary communication about childhood participation (Chien et al., 2014).

1.2.4 Occupational Therapy in Switzerland

Community pediatric occupational therapists aim to enable their clients' participation at school, as well as in the community and home environments. This role is of current importance, especially since guiding principles from the U.N. convention on the rights of people with disabilities (2006) were formally adopted in Switzerland in 2014 (Schweizerische Eidgenossenschaft, 2014). Following these guidelines, children with mild to moderate disabilities have been integrated into the mainstream schools, and communities are encouraged to create access for those with disabilities. Environmental access includes both removing physical barriers and adjusting mindsets to facilitate societal acceptance and inclusion. The community occupational therapist is a partner within a multidisciplinary setting, supporting change, as an advisor, advocate and providing therapeutic support to enable their client's participation in homes, schools and wider communities.

Participation is a therapy outcome goal for clients within a family-centered, occupation-focused community occupational therapy practice model. An occupation-focused model is typical of a top-down approach, focusing on the goal of occupational performance and participation, which may be complimented by a bottom-up, performance skill approach. A battery of baseline measurement instruments is commonly used to assess underlying sensory-motor skills and occupational performance in order to set goals with clients and plan therapy intervention. Translated, valid and reliable assessment instruments used to measure occupation /participation in German-language therapy practices, include: the Movement Assessment Battery for Children, Assessment of Motor Processing Skills, Pediatric Assessment Card Sort, Pediatric Evaluation of

Disability Inventory, and Canadian Occupational Performance Measure. An instrument to measure participation frequency, level of involvement and client satisfaction across environmental settings (school, community and home), is not currently available in the German language. Such an instrument would be efficient and effective in measuring participation outcomes. Outcome measurement at the level of participation is recommended to best illustrate the benefits of rehabilitation (Depoy & Gilson, 2008). Current research in this area suggests the Participation and Environment Measure: Child and Youth (Coster, Law & Bedell, 2010) is a valid and reliable measure (original version: English language), with potential for clinical use by community occupational therapists working under an occupation-focused model of practice.

1.3 Measuring Childhood Participation

1.3.1 The Participation And Environment Measure: Child And Youth

Foundations of the PEM-CY are grounded in theory based on the WHO definitions of participation and environment as they pertain to children's everyday lives. The following are operational definitions of participation, involvement and environment established for the PEM-CY:

Participation: "a child's involvement in important everyday activities at home, in school, and in the community. … This includes both how often a child does activities and how involved he or she is when doing these activities" (Coster et al, 2010, p.2).

Involvement: the engagement, initiative and interest a child displays while participating "in an activity, using whatever supports, assistance, adaptations or methods he or she routinely uses or has available". (Coster et al., 2010, p.2).

Environment: the physical layout, sensory qualities, cognitive demands, social demands, and psychological network in the individuals' school, home and community (Coster et al., 2010)

The PEM-CY is divided into the three environmental categories, within which the parent is prompted to consider their child's participation and involvement in common activities. For example, in the school section, participation is focused on classroom activities, field trips and school events, school-sponsored teams, clubs and organizations, getting together with peers outside of class, and special roles at school. The responding parent is asked to answer the following questions about their child's participation in home, community and school settings respectively:

> Part A: Frequency of their child's participation (8 point, ordinal scale from no participation to daily participation)
>
> Part B: Extent of involvement (5 point ordinal scale from minimally involved to very involved)
>
> Part C: Parent's "desire for change" in their child's participation (nominal scale to clarify the type of change desired)

And about the environment:

- Environmental factors and activity demands (4 point ordinal scale from not an issue to usually makes it harder (to participate))
- Resources required (4 point ordinal scale from resources not needed to usually yes, resources are required)

- Resource availability (4 point ordinal scale including no resources not required, and availability; mostly yes, sometimes, mostly not)

(Coster et al. 2010)

In the form of open-ended questions, parents are also asked to list strategies they use, which help promote their child's participation (Coster et al., 2014).

The PEM-CY was designed as a self-report (parent on behalf of their child), descriptive measure, with demonstrated value in large-scale participation research across environmental contexts (Anaby et al., 2014; Bedell et al., 2013; Law et al., 2013). The outcomes of the PEM-CY, has been proposed for use in clinical settings (Coster et al., 2011) and collaborative care planning (Khetani, 2015) in the North American context. Scoring of the PEM-CY elicits a "Participation Profile", which is produced in report form by the online electronic version (not available in the German language) (Coster et al., 2014). The developers of the measure provide recommendations for manual scoring of each scale (refer to Table 1), which results in a similar profile of a child's participation.

In paper form, participation frequency results of the PEM-CY (Part A) can be summarized and presented according to each environmental setting, such as a Radar plot (using Microsoft Excel) illustrating how often an individual child participates in activities listed within either the home, school or community environment (Coster et al., 2010, 2014). Alternatively, Coster et al. suggest summary scores can be calculated indicating the "average frequency" of participation within a setting, and "percentage of activities in which the child participates" (2014, p.18). Part B of the PEM-CY may be summarized as an average level of involvement reported by the parent, and Part C, as "percentages of activities in which change is desired". Results of the environmental section of the PEM-CY can be calculated as a percentage of barriers reported according to each setting, and

"Percent of Maximum Possible score", which is proposed to indicate the level of support provided in each respective environment (Coster et al., 2014, p.20). For larger groups, the data would be combined to elicit 'group scores' (Coster et al., 2010, 2014).

Table 1: PEM-CY Measurement Scales (Coster et al., 2010, 2014)

Participation Items

Part A: Frequency

"Typically, how often does your child participate in 1 or more activities of this type?"

Select ONE response.

- o Daily
- o A few times a week
- o Once a week
- o A few times a month
- o Once a month
- o A few times in the last 4 months
- o Once in the last 4 months
- o Never

Part B: Level of Involvement

"Think about 1 or 2 activities of this type that your child participates in most often. Typically how involved is your child when doing these activities?"

- o Very involved
- o
- o Somewhat involved
- o
- o Minimally involved

Part C: Desire for Change

"Would you like your child's participation to change in these types of activities?"

Select ALL that apply.

- o No change desired
- o Yes, do more often
- o Yes, do less often

- Yes, be more involved
- Yes, be less involved
- Yes, be involved in a broader variety of activities

Environment Items

Do the following things help or make it harder for your child to participate in activities at home/ community / school?

- Not an issue
- Usually helps
- Sometimes helps, sometimes makes harder
- Usually makes harder

Are the following available and/or adequate to support your child's participation at home / community / school?

- Not needed (only an option for "Services in the home")
- Usually, yes
- Sometimes yes, sometimes no
- Usually, no

Is there additional help (ie. programs, services, equipment) that you need to support your child's participation at home / community / school?

- Yes
- No
- I don't know

(Coster et al., 2010, 2014, p.4, 5)

A "Users Guide" for administrators of the measure is provided in the English language, including scoring guidelines and a presentation of outcomes from the North American psychometric study (Coster et al., 2010, 2011). The data set is not normative, representative only of the population in the study, and therefore strictly provided for comparison purposes (Coster et al., 2014).

1.3.2 Quality Of The PEM-CY As A Measure Of Childhood Participation

Guidelines to evaluate descriptive instruments for use in clinical settings, demand the appraisal of research applied in its' development and psychometric testing (Law, 1987; Terwee et al., 2007). Valid descriptive items, content and construct validity, internal consistency, test-retest reliability, observer reliability, are essential to quality descriptive instruments (Law, 1987). Validity is the accuracy of measuring what the instrument/tool intends to measure, and reliability refers to consistency of measurement. Internal consistency, a measure of reliability, is often measured using Cronbach's Alpha, to indicate how consistently questionnaire items measure a targeted construct. A high Cronbach's Alpha score may be used to support claims of validity. These properties are vulnerable when translating and adapting a measure across cultures as the content changes slightly, and may be perceived differently across different cultural groups. Test-retest reliability supports the strength of a measure used over time, for purposes of reliable comparison of results, which is important once a measure has demonstrated validity for use within a target group.

Research into the conceptual basis of childhood participation and environment served as a foundation for the development of PEM-CY constructs and descriptive items (Bedell et al., 2011; Coster & Khetani, 2008), and was followed by psychometric testing of the measure (Coster et al. 2011). In background studies, the constructs, participation and environment, were based on the theoretical definitions set out by the International Classification of Functioning, Disability and Health (WHO, 2001), and feedback from a North American, English speaking demographic of parents with children age 5-17 (Bedell et al., 2011; Coster & Khetani, 2008). Construct and predictive validity of the

PEM-CY was tested against other similar measures of participation, and was found to cover all 9 domains of the ICF-CY Activities and Participation component (Chien, et al., 2014).

Psychometric testing of the PEM-CY conducted in North America by Wendy Coster, Gary Bedell, Mary Law, and colleagues (2011), demonstrated moderate to very good test-retest reliability, and internal consistency. Cronbach's Alpha scores (internal consistency) were reported for participation frequency (total score) at a moderate level for school (.58) and good for home and community (0.84 and 0.79) (Coster et al., 2011). Cronbach's Alpha, reliability scores are considered moderate from 0.50 -0.75 and good when above 0.75 (Jerosch-Herold, 2005, p.348). Coster et al. (2011) reported internal consistency of participation subscales applying Cronbach's alpha; within the moderate range for home (0.59), school (0.61) and community (0.70), and involvement at home (0.83), school (0.72), and community (0.75). Cronbach's alpha scores on the environmental section were reported at ≥0.80, except for Home supportiveness (0.67) and school resources (0.73). Re-testing was conducted using a random selection method, (every fifth participant), and analyzed using Interclass correlations (model 2,1) to "examine consistency and agreement of scores in re-test period" (Coster et al., 2011, p. 1033). Test-retest reliability scores were reported as moderate to good (Coster et al (2011).

Comparative data is provided in the PEM-CY User's Guide, based on Coster et al.'s (2011) study of 576 parents from Canada and the United States of America. These were provided to enable comparison of samples, with other studies. This data is not normative data but is useful to provide some guidelines for descriptive outcomes of the

PEM-CY. In a clinic environment the baseline outcomes of the PEM-CY are appropriate for development of an intervention plan (Khetani et al., 2013).

1.3.3 The German Version Of The PEM-CY (GPEM-CY)

The PEM-CY has been translated into several different languages, and researchers are beginning to evaluate its' validity across cultures. As there are no other known measure of this kind, the cultural validation of the German version of PEM-CY within a European context, would facilitate its' potential use across the population of German speakers in Austria, Germany and Switzerland. Although spoken dialects differ across these three countries, their common written language for education and literature is German.

The German translation of the Participation and Environment Measure for Children and Youth (GPEM-CY), was completed in 2014 by Christine Füssel and Laura Köstler at the University of Wien in Austria. This project was supported by Frau Mag. Novak and Dr. M. Freilinger, M.D., Associate Professor of Pediatrics at the Medical University of Vienna. A forward and backward translation covered the instructions for the respondent and the questionnaire booklet. Christine Füssel conducted an initial validation study in Austria, from which results in the form of an abstract were communicated in the personal communication (available upon request).

Results of the unpublished, initial validation study indicated large differences when differentiating between disability and non-disability groups on both the participation and environment scales. Objectivity and internal consistency were "presumed to be given and sufficient" (internal consistency 0.59 and above) for all but the school section which did not indicate sufficient reliability (C. Füssel, personal

communication, October 2014). It was concluded that the validity of the instrument was only partially confirmed through evidence of differentiation between disabled and non-disabled children's scores. Recommendations include further validation including subjective parent reports, and objective external criteria for measuring disability status, and consideration of content revision, particularly in the school section (C. Füssel, personal communication, October 2014). Following these recommendations, this pilot study was conducted with the aim to evaluate the face validity, internal consistency and applicability of GPEM-CY (German version of the PEM-CY), in the German-speaking region of Switzerland. A newly translated German language questionnaire is ideally tested with samples across all three German-speaking, European countries, but was beyond the means of this research project.

1.4 Evaluating The Quality Of Translated And Culturally Adapted Measures

Culture must be taken into consideration when adapting a measurement instrument for use in a context different from that for which it was developed (Beaton et al., 2000). Culture, a community's "ideas, customs, and social behavior of a particular people or society", influences the way people perceive, interpret, label and organize all aspects of their social and physical environments (Culture, 2017). In the process of cognitive and social human development individuals within a community adapt to the values and norms unique to the cultural environment where they grow up. The well-known theory of cognitive development by psychologist Jean Piaget specifies how an individual's environment effects the development of cognitive conceptualizations, in a process of accommodation and assimilation. Cognitive concepts are used to understand, organize and support interactions within the community each human exists (Altenthan et al. 2017). These concepts used to explain relationships between objects, experiences and events, can be more or less culturally specific. Cognitive concepts are defined and structured by language, which is explicitly linked to culture, in that the choice of words and phrases (semantics) are linked to aspects of a community-specific, social, psychological and physical environment. Therefore, an instrument to measure concepts such as participation, should adhere to the culture and language of the cultural group intended, in order for it to be understood, reliable and valid when put to use.

Research shows that threats to the validity and reliability of questionnaires may emerge when applied to contexts for which the questionnaire is not intended (Beaton et al., 2000; Herdman et al.,1998; Stevelink and Brakel, 2013). A process of cross-cultural

adaptation aims to ensure equivalence between the original and adapted version, supporting validity and reliability of the measure based on the content (Beaton et al., 2000). Content validity, applicability and internal consistency (reliability) emerge as key criteria for consideration in order to assess for the quality of translated measurement instruments, (Beaton et al., 2000; Herdman et al., 1998; Law, 1987; Stevelink and Brakel, 2013; Terwee et al., 2007).

1.4.1 Face Validity

Content validity provides "evidence about the degree to which the elements of the assessment instrument are relevant to and representative of the targeted construct" (Haynes et al., 1995, p.239). Face validity, a measure of content validity, is the subjective view of questionnaire respondents/ or other key stakeholders in terms of accuracy, acceptance/likeability and relevance (Thomas, Hathaway & Arheart, 1992). It is of particular importance to cross-cultural translation, as a method of checking that the translation adequately captures the concepts it intends to capture when compared to the original version, within the population intended (Haynes et al., 1995). Face validity demands equivalence in concepts, descriptive items and semantics as described by Herdman et al. (1998b) model for cultural equivalence. Measurement of face validity explores the question: Does the content of the instrument appear to represent the construct in context (Depoy & Gitlin, 2011)? An academic review of guidelines for cross-cultural adaptation of questionnaires indicated the importance of using expert committees and/or input from the target population (focus groups or interviews), to gather evidence of face validity within a specific context (Epstein et al, 2015a, Epstein et al., 2015b).

1.4.2 Internal consistency: Reliability

Internal consistency is an indicator of test reliability in the internal structure of an instrument. It is "the extent to which all items in the instrument measure the same construct", evaluated by use of correlation coefficients such as Cronbach's alpha (Depoy & Gitlin, 2011, p. 203, Herdman et al., 1998). The reliability of an adapted questionnaire should show evidence of internal consistency for use within a client group different to the group for which the instrument was developed. Correlation coefficients may also be used as an indicator of measurement equivalence when evaluating quality of health status questionnaires (Terwee et al., 2007).

1.4.3 Applicability

Applicability is "suitability for being put to practical use", determined by factors of respondent burden (invasiveness, administration time, respondent acceptability), and format capability (clarity of instructions, cultural relevance of items, language used) (Merriam-Webster (2005) in Augers, Denvers & Swaine, 2006). Included in applicability is operational equivalence (Herdman et al.,1998), which includes the suitableness of mode of administration (questionnaire format and instructions) within the target population. Measurement of applicability requires field-testing and consultation with key stakeholders who would put the measure to use. Applicability may also include administrator burden, which was not the focus of this research project.

1.5 Evidence Of Quality And Applicability Of The GPEM-CY

The PEM-CY, in its' original version, has undergone psychometric testing that supports its' validity and reliability in the North American context (refer to Introduction 1.3.2). Since the PEM-CY has been translated into several languages, researchers outside of Canada have been intrigued by its potential within cultures outside of Canada. For example, guidelines for the cross-cultural adaptation and translation of self-report measures by Beaton et al. (2000) were applied in a study on the Korean version of the PEM-CY (Jeong, et al. 2016), in close collaboration with the authors of the measure. Jeong and colleagues (2016) illustrates one approach that applied theoretical guidelines by Beaton et al (2000) and Herdman et al. (1998), which could be used as a template for cultural adaptation and quality evaluation of the PEM-CY in other languages.

Jeong and colleagues (2016) followed the process of translation and back translation, as recommended by Beaton et al. (2000): pre-testing, completion of a questionnaire and probing stakeholders (in Korea) to get understanding of items (Beaton, et al., 2000). Further, the criteria applied in the Korean study, addressed four levels of equivalence: semantic (wording), idiomatic (culturally related colloquialisms that might not have a direct translation), experiential (social relevance and acceptability of items) and conceptual (validity) (Jeong et al. 2016). These operational criteria reflect the existing cultural equivalence framework based on Herdman's Model of Equivalence (1998). Results of the Korean study, indicated modifications needed to be made, for example to the Korean terms for participation and involvement, specific participation

items and accompanying examples. Jeong et al. indicated that to ensure equivalence between original English version and the Korean version, direct translation was insufficient and required conceptual translation (2016). This outcome supports the view that, in order to ensure adequate cultural adaptation and equivalence of the PEM-CY, as with any newly translated questionnaire, a process of field-testing and evaluation of the cross-cultural adaptation for the target population is necessary (Beaton et al., 2000)

The German adaptation of the GPEM-CY used in this thesis was conducted in Austria in 2014 and has undergone preliminary evaluation (Christine Füssel, personal correspondence, October 2014), results of which are presented in the introduction (refer to Introduction, 1.3.3). It was reported that the PEM-CY was translated from English to German by Christine Füssel, and back-translated by a student translator, Laura Köstler. Following the translation, the GPEM-CY was applied in a validation study. Christine Füssel recommended that the GPEM-CY be subject to further field-testing, with particular attention to cultural equivalence of the school section (personal communication, 2014). If the translation process included back translation and committee review, these recommendations are synonymous with Beaton et al.'s (2000) guidelines stage IV and V, expert committee review and a pre-testing of the questionnaire. However, whether this would hold for the application to a Swiss German population, the target of this current thesis, is unknown. While the PEM-CY has undergone psychometric testing related to the original version (Coster et al. 2011), the German translation has not undergone a complete and successful field testing and cultural adaptation process and in particular for its applicability in Swiss-German populations.

Additionally, specific application of the GPEM-CY in clinical Occupational Therapy

practice in the Swiss-German context, has yet to be investigated. No evidence on this subject was found during the literature search for this project. The intention of this research is to investigate the possibility of integrating the GPEM-CY as an initial baseline assessment tool in children's Occupational Therapy services, similar to the clinical application for multidisciplinary care planning suggested by Khetani et al. (2015). In addition to the broader cultural validity, reliability and applicability of the GPEM-CY, these quality criteria must be evaluated in the specific context of clinical Occupational Therapy. Therefore, the population for field-testing need target parents of children attending Occupational Therapy in the Swiss-German part of Switzerland.

1.6 Research Objectives

The GPEM-CY has potential as a participation measure for use by Occupational Therapists working with children in German-speaking families in Switzerland. In order to facilitate a participation-focus for interventions, a quality measurement tool focused on participation is required to provide evidence of best practice to key stakeholders. Following the translation work completed by Christine Füssel and Laura Köstler, the GPEM-CY requires further evaluation to provide evidence of its' applicability and psychometric properties (face validity and internal consistency) within the targeted, German-speaking population. Evaluation of these measurement properties, may provide evidence of the quality of the translation and its' applicability, supporting its use in Occupational Therapy practice, or specify needs for further development and cultural adaptation.

This pilot study was conducted to evaluate the face validity, applicability, and internal consistency of the Participation and Environment Measure: Child and Youth, for use by German speaking parents of children receiving occupational therapy, age 5-17 in Switzerland.

1.6.1 Research Questions

1. Do parents' understanding of concepts and items in the GPEM-CY support its' face validity and applicability?
2. Are there any items on the GPEM-CY that need to be changed to reflect the German-speaking, Swiss cultural context?

3. Is the understanding of German-speaking parents in Switzerland, of the constructs participation and involvement, consistent with original PEM-CY meaning/definitions?

1.6.2 Thesis Goals

This project was completed as partial requirement for the post-professional title of Masters in Occupational Therapy, from Dalhousie University. The academic goal of the thesis was to demonstrate acquired knowledge through practical application of research theory and methods. The professional goals were to contribute to the body of knowledge for the cross-cultural translation of measurement instruments, and provide preliminary evidence of (face) validity and applicability of the GPEM-CY in the context of pediatric Occupational Therapy within Switzerland.

1.6.3 Ethical Considerations

This study was approved by the Dalhousie University Ethics Committee (REB # 2017-4080), according to the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans* (refer to Appendix O). This research was conducted as a Masters thesis project, with the intention to contribute to the professional occupational therapy knowledgebase. In order to protect the rights and well-being of participants, measures to promote confidentiality and ensure anonymity have been made. All Research Assistants signed written agreements to ensure confidentiality and anonymity of participants. Informed consent was received in writing from all participants. Confidentiality was ensured through the coding of all data received from participants. The original copies of completed questionnaires, and recorded interview data was kept in

a locked cabinet. All data was transferred to a password-protected computer in order to conduct data analysis. Names and personal identifiers were anonymized during the process of transcription. Digital recordings were destroyed upon completion of the transcriptions.

The researcher had no clinical relationships with participants at the time of the study or thereafter. The researcher has no affiliations that would create a conflict of interest. The researcher declares a dual role of Occupational Therapists at the Stiftung RGZ who facilitated recruitment of participants (parents of current clients). Parents were informed that their participation in the research had no influence over their child's treatment at the clinic.

The researcher received the PEM-CY survey instrument free of cost, for purposes of conducting this research only (Refer to Appendix G).

Chapter 2 Research Methods

2.1 Introduction

This study adopted a mixed-methods explanatory design with emerging approach to pragmatically evaluate the face validity, internal consistency, and applicability of the GPEM-CY in German-speaking Switzerland. This design was chosen as a means to field-test the GPEM-CY, gathering results from multiple completed GPEM-CY questionnaires in the form of quantitative data, and enable follow-up of emerging themes with in-depth qualitative interviews, for purposes of explaining the quantitative results (Cresswell et al., 2011). In section 2.2 the reader will find details of the participants and context within which the research took place. This is followed by details of the measurement tools used (Section 2.3), including the Demographic Questionnaire, the GPEM-CY, the Adapted QQ-10 questionnaire focusing on Face Validity, and Cognitive Interview Guide. Samples of these can be found in the Appendices (F-I). In Section 2.4, details of the research methods are explained. In Section 2.4, the reader will find a detailed explanation of the mixed-methods, explanatory design, which was applied to this study.

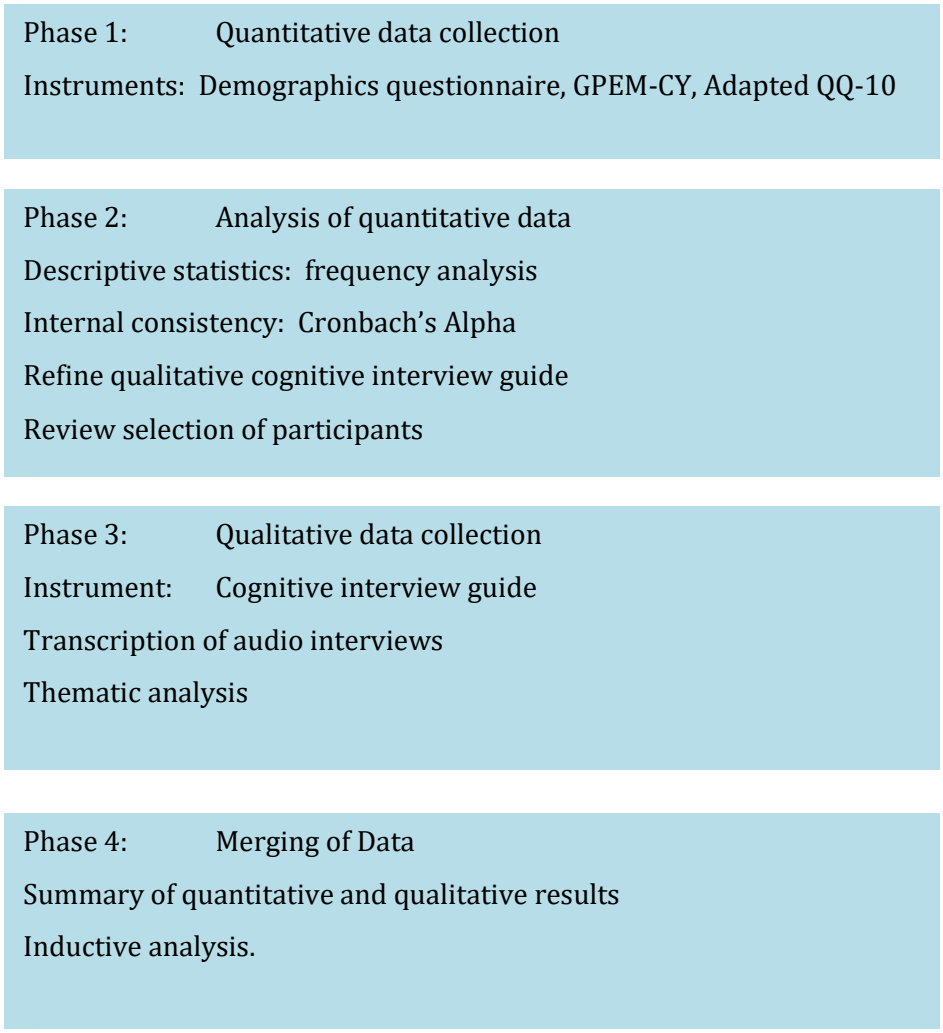
2.2 Participants And Setting

This study was conducted in cooperation with the Stiftung Regional Group Zürich (Stiftung RGZ), a non-profit foundation located in the canton of Zürich in Switzerland. Members of the Stiftung RGZ team of Occupational therapist's helped with recruitment;

which involved compliance with inclusion and exclusion criteria according to the research protocol (Refer to Appendix A). The sample was a convenience sample, selected for purposes of; cultural and semantic evaluation of the GPEM-CY, evaluation of the applicability of the GPEM-CY in the Swiss-German cultural context, and to meet GPEM-CY target age group guidelines.

Participants were purposively selected based on the following inclusion criteria: fluency in the German language, living in Switzerland, and parent to a child age 5-17 who had received occupational therapy in Zürich Switzerland at the time of the research. Parents of children age 5-17 are the target group for the PEM-CY, and are therefore ideal experts for evaluating face validity, internal consistency, and applicability of the PEM-CY (German version) in the (Swiss) German cultural context. This study took place over three phases (refer to Fig 1 below). The first phase included field-testing of the GPEM-CY. The second phase enabled the researcher to conduct initial evaluation of data, review the participant sample, and amend the administration guide for data gathering in the third phase of the study. Demographic details of the two sample groups from Phase 1 and Phase 3 of this study are presented below. A convenience sample, with inclusion /exclusion criteria was applied to select participants for Phase 1 of the study. The researcher had intended on purposively selecting participants for Phase 3 of the study in order to gain a diversity in opinions, however only five participants volunteered for interview. Convenience sampling was used in both Phase 1 and Phase 3 of the research. Results of each research phase are presented in Chapter 3.

Figure 1: **A Mixed-Methods Explanatory Sequential Design With An Emergent Approach** (based on Creswell, et al. 2011)



2.3 Measures

2.3.1 Demographic Questionnaire

A demographic questionnaire was designed to confirm the sample reflected the intended target audience for the GPEM-CY. Participant characteristics, including age

and relationship with the child, language and cultural background were considered essential to support the trustworthiness of the study. (Refer to Appendix F).

2.3.2 GPEM-CY

The GPEM-CY is the German version of the PEM-CY. It captures parent perceptions of their child's participation frequency, level of involvement and desire for change, across 3 environmental settings. (Refer to Appendix G for the English version of the PEM-CY). This instrument is the focus of this research study.

2.3.3 Adapted QQ-10

The QQ-10 is a valid and reliable, structured questionnaire designed to assess the face validity and applicability of health questionnaires (Moores et al. 2012). For purposes of this study, four questions were added to the original QQ-10 questionnaire. The additional questions were designed in the same format as the original questionnaire, but enabled the researcher to target each of the three environmental sub-sections of the GPEM-CY separately (refer to Appendix H). The additional questions focused on the relevance of participation items within each environmental section, and helpfulness in terms of communication of a child's level of involvement in each environmental setting. Responses were rated on a 5 point Likert scale indicating if the participant strongly agreed – strongly disagreed with each statement provided. This adaptation enabled the researcher to conduct separate and comparative analysis across the three environmental settings. The adapted QQ-10 questionnaire was translated into German and piloted with 2 mother-tongue speaking parents before being applied to this study.

2.3.4 Cognitive Interview Guide

A semi-structured, cognitive interview guide was informed by evidence-based, cognitive theory and guidelines for purposes of evaluating a survey instrument (Auger et al., 2006, Collins 2003, Willis, 1999) (Refer to Appendix I). The four stages Model by Tourangeau (1984), focusing on the cognitive demands of the questionnaire (Comprehension of the Question, Retrieval of relevant information from memory, Decision process, Response process) informed the design (Willis, 1999). Specific questions were then designed to focus on cultural applicability of concepts and descriptive items, semantics, and applicability of the measurement (Herdman et al.,1998, Stevelink and Brakel, 2013). Verbal prompts were included in the guide, following cognitive interview approaches recommended by Willis (1999).

2.4 Methods Of Enquiry And Data Analysis

A mixed method, explanatory sequential design with an emergent approach, was applied to pragmatically evaluate the face validity and applicability of the PEM-CY (German version) in the Swiss context (refer to Fig. 1, in Section 2.2). An emergent approach to data collection and thematic analysis was considered suitable for the identifications of strengths and weaknesses in the validity and applicability of the German PEM-CY translation. These research methods were based on recommended mixed methods as described by Creswell et al. (2011). Methods adopted within each of the four stages, as applied to this research, are described below.

2.3.1 Phase 1: Quantitative

Quantitative data collection included field-testing of PEM-CY (German Version), a demographics questionnaire and the Adapted QQ-10 Questionnaire. Field-testing is a method to enable researchers to gather information about a therapeutic method or as in this case, a measurement instrument, within the population intended for use.

2.3.2 Phase 2: Quantitative Analysis And Refining Of Qualitative Instruments

Data from the demographic questionnaire, the GPEM-CY and the Adapted QQ-10, were entered into SPSS software for calculations of frequency of responses (including missingness), correlations with the total, and Cronbach's Alpha (internal consistency) for each of the three environmental subsets of the PEM-CY. Missing values indicate when respondents gave no response to a question/item in the questionnaire. There were two issues for consideration of missingness. Firstly, the reasons for missing data in the data set, and its' impact on research outcomes. Secondly, dealing with missing data when preparing data for analysis. These issues followed by the methods of data analysis (descriptive frequency analysis and Cronbach's alpha) are described below.

Missing values are common in heath related questionnaires, resulting in incomplete data sets, which have an impact on outcomes of data analysis (Coste, et al., 2013). Missing values from field-testing of the GPEM-CY were expected and not substituted or replaced during the process of data preparation for analysis. Potential reasons for missing values discussed in the literature may include insufficient response

options, a lack of participant interest, lack of sufficient comprehension or concentration, or lower education and socioeconomic status (Coste, et al., 2013). Validity is a question of relevance and accuracy of representation of the questionnaire item or construct for the population it was intended (Haynes, Richard & Kubany, 1995). If a questionnaire item is not relevant and/ or inaccurate, then a respondent would likely have difficulty providing a response and potentially leave an answer field blank. When a questionnaire item has low validity, a high number of missing values would be expected.

Extrapolating missing values was not considered appropriate for the GPEM-CY questionnaire due to the sample size and structure of the questionnaire itself. Some researchers suggest that missing items should be extrapolated during data preparation, for example the mean replacing the missing value (Coste et al., 2013). This seems appropriate only when through the design of the questionnaire, a value (or response) is expected. The Participation section, Part A of the GEM-CY, is designed so that the researcher can expect a response to each question/item (ie. Standard set of items). During field-testing of the GPEM-CY, the very few missing values in Section A were left blank: 0-1 missing per item in the Home section, 1-2 per item in the Community section, and 2-3 per item in the School section. Completion of Participation section, Parts B of the GPEM-CY, is only expected when the response to Part A is positive (ie. the child does participate in that activity). Therefore, when a child does not participate in the activity indicated, Part B would be left blank. Children have varying interests and skills, and therefore would not be expected to participate in all the activities presented in the participation section. Since missing values are expected in Parts B of the GPEM-CY, it was not logical to adjust the data set. Participation section, Part C provides respondents

the opportunity to indicate their "desire for change" in their child's frequency and/ or level of involvement, based on two different scales (Coster et al., 2011). A parents' wish for change is influenced by many personal, socio-cultural and environmental factors. There were expected missing values in Part C, which the researcher did not extrapolate. In order to prepare the data for descriptive, frequency and internal consistency calculations, missing values were omitted through pairwise deletion using SPSS software. This allowed for the maximum use of data available.

The frequency of response for each questionnaire item on the Demographic Questionnaire, Adapted QQ-10, and GPEM-CY in terms of participation in the specified activity, involvement, and respondent's desire for change were calculated. Frequency of response and missing values, particularly in the Participation section Part A of the GPEM-CY, indicating how often a child participates in an activity, was targeted to inform the analysis of face validity and applicability. Frequency of response to items in Participation section Part C "desire for change", were targeted to support analysis of validity and applicability of the GPEM-CY for clinical use (Coster et al., 2010). Results from analysis of the Demographic Questionnaire, the Adapted QQ-10 and GPEM-CY, are presented in Chapter 3, section 3.2 and 3.3.

Cronbach's Alpha was calculated using the statistical package SPSS, to consider the internal consistency of participation items within each environmental subscale respectively. The outcomes of Cronbach's Alpha can be influenced by several factors including: sample size (N), number of items in the measure, interrelatedness of the items, dimensionality of the construct, and missing values (Tavakol & Dennick, 2011). A small sample size, as in this study (N=19), could have a negative impact on Cronbach's Alpha.

Effectively, missing values reduce the Cronbach's alpha scores, indicating a lower degree of internal consistency within the questionnaire. Fewer items in a measure can lower the Cronbach's Alpha, and underestimate the reliability. In the participation section of the PEM-CY, the Home and School sub-sections have ten items respectively, and the School section has five. Results should be observed with these factors in mind. Reliability scores are considered moderate from 0.50 -0.75 and good when above 0.75 (Jerosch-Herold, 2005, p.348). Although, some may argue these guidelines are slightly low for rating of outcome measures, where reliability coefficients are adequate between .60 and .79, and excellent there above (Law, 2004). Cronbach's Alpha scores for the GPEM-CY, based on this study sample, are presented in section 3.3. As reliability results particularly for the participation items were quite low, the researcher processed Item Total Statistics to examine whether any specific item alone greatly affected the overall Cronbach's Alpha within the respective participation scales (refer to Section 3.3). Factors affecting results of the Cronbach's Alpha will be discussed in relation to outcomes of this research, in Chapter 4, Section 4.3.

Following the initial analysis of quantitative data, the lead researcher reviewed the cognitive interview guide in light of findings. Concern with the limited number of returned questionnaires led the researcher to enquire about low participant uptake with the research team. These results supported the need to seek further information during cognitive interviews, about the applicability and face validity of the GPEM-CY, including the level of complexity and wording used for items and instructions. The cognitive guide was reviewed but not adjusted, as these themes were already included.

Five participants volunteered and were accepted for the cognitive interviews. Ideally, the researcher planned for 4-6 Interviewees, purposively selected for their variance in perspectives and responses on the GPEM-CY. However, this was not possible due to limited uptake. Therefore, the convenience sample used for this stage of the research did not fully represent the study population. Important considerations regarding the limitations and strengths of the study due to sample size, are explored in Chapter 4.

2.3.3 Phase 3: Qualitative

Cognitive interviewing was selected as an evidence-based method to evaluate the design and validity, and to set the foundation for reliability of the translated questionnaire, PEM-CY (German version) (Willis, 1999, Auger 2006, Collins 2003). The most commonly approach applied in cognitive interviewing for the evaluation of response error, is based on the four stages Model by Tourangeau (1984): Comprehension of the Question, Retrieval of relevant information from memory, Decision process (motivation, sensitivity and social desirability), Response process (can respondent match internally generated responses with response categories (Willis, 1999). These stages enable the interviewer to focus on the survey questions and the cognitive process required to answer these questions (Willis, 1999). During a cognitive interview, both verbal probing and think-aloud interviewing techniques may be employed. The think-aloud technique encourages the participants to share thought processes aloud while contemplating and answering interview questions. Verbal probing involves the interviewer strategically probing the participant for more specific information to expand on the answer given. Verbal probing technique enables greater interviewer control, to

gather more details on target issues raised by the participants and requires no participant training (Willis, 1999). For this research, Tourangeau's (1984) stages model was applied in the design of a semi-structured cognitive interview guide (refer to Appendix I), which was then supplemented with verbal probing to target emerging validity and applicability issues raised by the participants. Clarity and comprehensibility of the measure sets the foundations for measurement of reliability.

Qualitative data focused on further exploration of face validity and applicability of the PEM-CY (German version), was collected during Cognitive Interviews (N= 5) of 1-hour duration (refer to Appendix I). Each interview was conducted by the lead researcher on an individual basis, at a location of the interviewee's choice, either at home or at the O.T. clinic where their child receives therapy. The interviewees replied to the German-language cognitive interview questions in their language of preference (English, German or Swiss-German dialect). Data from the cognitive interviews were transcribed, anonymized and checked against the recording. Data was transcribed consistent with the language used in the interview (English, German and Swiss-German respectively). Systematic analysis of the qualitative data enabled the identification, labeling and coding of themes in the transcriptions. The coding was completed by the lead researcher due to limitations of this study, and the lack of availability of a qualified second coder. All five transcripts were initially read through and emerging themes were identified. Each transcript was read and re-read multiple times to elicit, identify (color code) and explore themes. Results can be found in Chapter 3, Section 3.4.

2.3.4 Phase 4: Merging of Data

Summarized quantitative data from the sample group as a whole, was combined and triangulated with results of thematic analysis, to elicit a set of comprehensive results. First, the researcher looked at the raw data and results of frequency analysis of the GPEM-CY and Adapted QQ-10 to identify and consider patterns, including missing values. Secondly, the summarized results of frequency analysis were linked, based on thematic content, to the themes identified during qualitative analysis. The researcher analyzed and explored emerging issues and focused on topics of face validity and applicability. Further, theoretical knowledge of cultural adaptation and equivalence stemming from previous research, Herdman's Model of Equivalence (1998), and the Guidelines for cross-cultural adaptation of self-report measures (Beaton et al., 2000) were considered in making sense of raw data and emerging themes, adding a further dimension to data triangulation. Data triangulation is known to increase the rigor, validity and reliability of qualitative research outcomes (Depoy & Gitlin, 2011). Results from data analysis are presented in Chapter 4.

Chapter 3 Results

3.1 Introduction

The results of this study are presented here and include sample demographics; themes that emerged from interview narratives; descriptive statistical analysis of data from the GPEM-CY and Adapted QQ-10 questionnaires; and internal consistency based on Cronbach's alpha scores. Demographic data from research stage one and three are presented separately in section 3.2. Sample demographics are described according to two phases of data collection: participants who completed phase one of the study (N=19) (the Demographic questionnaire, the GPEM-CY and adapted QQ-10 questionnaire), followed by the smaller sample who participated in cognitive interviews in phase three (N=5). Section 3.3 presents results of statistical analysis including: descriptive analysis of data from the GPEM-CY, Adapted QQ-10 questionnaires, and internal consistency (Cronbach's alpha scores). Results from the thematic analysis of cognitive interview data, is presented in section 3.4.

3.2 Sample Demographics

3.2.1 Sample Demographics: Phase 1

A total of 19 parents completed and submitted the questionnaires (GPEM-CY, Adapted Q-10 and Demographic questionnaire) for the first part of this study (Phase 1). An additional two parents submitted but did not sign a consent form and therefore their data was eliminated due to ethical regulation. Of the sample (N=19), eighteen

participants were mothers of children between the ages of 5 and 17, currently receiving Occupational Therapy treatment at a community clinic in the canton of Zürich in Switzerland.

All participants were fluent in the German language. Fifteen participants were of Swiss-German origin, two were of German origin, and two had a non-German mother-tongue. Parent participants were between 31 and 55 years of age. Twelve participating parents had children between the ages 5 and 8 years old, four had children aged between 9 and 12 years of age, and three between 13 and 17 years of age, receiving occupational therapy treatment. These demographics covered the age spectrum targeted for administration of the GPEM-CY (refer to Table 2). A summary of data from the demographic questionnaire, describing the participant sample is listed in Table 2.

3.2.2 Sample Demographics: Phase 3

Parents who participated in the first phase of the study, were eligible to volunteer for cognitive interviews during the third phase of the study. The lead researcher was unable to adopt purposive sampling for the cognitive interviews due to low uptake. There would have been an opportunity to do so, if more volunteers for phase 3 came forward. As a result, a small convenience sample (N=5) participated in retrospective cognitive interviews (in German) to explore their perceptions of the GPEM-CY: specifically, the understandability and applicability of items and the German translation of constructs *participation* and *involvement*. All participants who indicated their interest in volunteering for a cognitive interview were included. Each participant was informed about the study and completed a signed consent form prior to the cognitive interview

(refer to Appendix D). Table 2 provides a summary of results from the demographic questionnaire.

Cognitive interview participants were selected based on a convenience sample, and were not representative of the general Swiss population. Data from interviews indicated that as well as being parents of children attending Occupational Therapy, two of the five participants were health care professionals, and two were active in voluntary positions for local organizations representing their child's diagnostic group. One interviewee did not report a profession or voluntary role. This sample group had strength in their ability to reflect and analyze the GPEM-CY from a broader perspective than just their parenting role. It may be assumed that the sample, were among the population with higher education.

Table 2: Sample Demographics

Category	Phase 1	Phase 3
Nationality at birth		
German	2	
Swiss	15	3
Other	2	2
Mother-tongue		
German	17	3
Other	2	2
Relationship to child		
Mother	18	5
Father	1	
Parent age		
31-40 years	8	
41-55	11	
Child's age		
5-8 years	12	2
9-12	4	1
13-17	3	1
Total	19	5

3.3 Results Of Statistical Analysis

3.3.1 Descriptive Frequency Analysis Of GPEM-CY Data

Data gathered from field-testing of the GPEM-CY was analyzed using measures of frequency, including missing values, to assess evidence of (face) validity and applicability. In the GPEM-CY, participation section part A, the respondent is asked, "Typically, how often does your child participate in 1 or more activities of this type?" (Coster et al., 2011). The respondent is able to provide a positive response indicating the

frequency of participation, or a negative response (i.e. "never"), along a Likert scale. Missing values for participation frequency (part A) were overall relatively low. For each participation item there were few missing values: 0-1 for home participation items, 1-2 for community participation items, and 2-3 for school participation items (N=19). For details of missing values within the participation subsection, part A (frequency), please refer to Appendix P. Participation section, parts B (related to the level of involvement in an activity) and C (parent's wish for change in their child's participation) did not require a response if participants indicated their child did not participate in the activity in question. Therefore, due to the design of the questionnaire, missing values would be expected in participation sections B and C.

Data describing participation patterns: what types of activities, how involved and particularly a parent's wish to see changes in their child's participation, is valuable information for the identification of treatment goals in pediatric Occupational Therapy. In participation section, part C of the GPEM-CY, a range of 5-63% of (n=19) participants indicated that a some type of change in frequency and/or level of involvement was desired upon completion of the questionnaire (refer to Table 3). Details as to the type of change parents desired can be found in Appendix O.

Home

More than fifty percent of participants indicated they would like to see change in their child's participation in activities including: household chores, personal care management, and school preparation (other than homework). Thirty-one to thirty-seven percent of participants indicated they would like to see change in: playing computer and video games; indoor play and games; arts, crafts, music and hobbies; and watching TV,

videos or DVD's. A "desire for change" in participation in home activities was more prevalent than in the other environmental contexts (Coster et al., 2011).

Community

Fewer research participants indicated that they would like to see change in their child's participation in the community as in the home environment. One participant specifically indicated that their child was not yet old enough to participate in activities including: organized clubs and community groups, unstructured social time with peers in the community, and paid work. Twenty-six to thirty-seven percent of parents indicated that they would like to see change in their child's participation in: community events; organized physical activities; courses and lessons outside of school; organizations, clubs, groups and voluntary and leadership activities; religious or spiritual activities and getting together with other children in the community.

School

Part C, "Desire for change" in the participation section (GPEM-CY) had the most missing items in the data set (Coster et al., 2010). Only one to four participants indicated a wish for change in their child's participation at school for items 2-5 (field trips and school events, school teams and clubs, getting together with peers outside of class, and special roles at school). However, fifty-three percent of participants wished to see change in their child's participation in classroom activities.

Table 3: Percentages And Frequency Of Responses Indicating "Desire For Change" In Participation (N=19)

Participation and Environment Measure-Child and Youth (German version)

Participation scale, Part C (Coster et al., 2014)

Home		Parents (n) indicated Desire for change (% and n)	
Item			
Q1	Computer and video games	31%	(n=6)
Q2	Indoor play and games	31	(n=6)
Q3	Arts, crafts, music, and hobbies	31	(n=6)
Q4	Watching TV, videos, and DVD's	37	(n=7)
Q5	Getting together with friends	21	(n=4)
Q6	Socializing using technology	26	(n=5)
Q7	Household chores	63	(n=12)
Q8	Personal care management	53	(n=10)
Q9	School preparation (not homework)	53	(n=10)
Q10	Homework	63	(n=12)
School		Desire for change	
Item		(% and n)	
Q1	Classroom activities	53%	(n=10)
Q2	Field trips and school events	16	(n=3)
Q3	School-sponsored teams, clubs and organizations	21	(n=4)
Q4	Getting together with peers outside of class	21	(n=4)
Q5	Special roles at school	5	(n=1)
Community		Desire for change	
Item		(% and n)	
Q1	Neighborhood outings	16%	(n=3)
Q2	Community events	26	(n=5)
Q3	Organized physical activities	31	(n=6)
Q4	Unstructured physical activities	21	(n=4)
Q5	Classes and lessons (not school sponsored)	31	(n=6)
Q6	Organizations, groups, clubs, and volunteer or leadership activities	26	(n=5)
Q7	Religious or spiritual gatherings and activities	31	(n=6)
Q8	Getting together with other children in the community	37	(n=7)
Q9	Working for pay	16	(n=3)
Q10	Overnight visits or trips	16	(n=3)
Total		100	(n=19)

3.3.2 Descriptive Analysis Of Data From The Adapted QQ-10 Questionnaire Focusing On Face Validity

Data from the completion of the adapted QQ-10 questionnaire (refer to Table 4), was treated as categorical data, and applied to descriptive frequency analysis. Results of each question are presented to include the spread of responses arranged in a Likert scale. There were 0-2 missing items per question on the Adapted QQ-10 (N=19) questionnaire. A summary of participant perceptions of the GPEM-CY representing aspects of Face Validity, are presented below.

Participants (N-19) who completed the adapted QQ-10 questionnaire were almost equally divided in reporting about the overall difficulty of the questionnaire. Forty-two percent (n=8) of participants indicated the GPEM-CY was too complicated, and forty-two percent deemed the GPEM-CY was not too complicated (16% remained neutral). Similarly, the sample was divided about ease of completion. Forty-seven percent of participants indicated the questionnaire was easy to complete, and forty-two percent of participants indicated it was not easy to complete.

Completion of the GPEM-CY was considered enjoyable for sixty-eight percent of participants, and the same percentage would complete the measure again as a part of their child's occupational therapy. One participant indicated on the Adapted QQ-10 questionnaire, that the completion of the questionnaire was cumbersome and annoying. This participant did not complete the GPEM-CY in its' entirety and did not participate in the cognitive interviews. Forty-seven percent of participants considered the GPEM-CY too long.

Results of the Adapted QQ-10 questionnaire indicate that eighteen of nineteen parents considered the GPEM-CY useful to support communication of their child's participation at school, home and in the community.

Table 4: Percentages And Frequency Of Responses To The Adapted QQ-10 (adapted from Moores et al., 2010)

Adapted QQ-10 Item / Question Sample of N=19 respondents)	Missing responses	Strongly/ Mostly agree	Neither agree nor disagree	Mostly / Strongly disagree
The GPEM-CY helped me to communicate about my child's involvement in activities at home.	0	68% n=13	26% n=5	5% n=1
The GPEM-CY was relevant to my child's involvement in activities at home.	0	68 n=13	21 n=4	10 n=2
The GPEM-CY helped me to communicate about my child's involvement in activities in our community.	1	58 n=11	26 n=5	10 n=2
The GPEM-CY was relevant to my child's involvement in activities in our community.	1	68 n=13	26 n=5	0 n=0
The GPEM-CY helped me to communicate about my child's involvement in activities at school.	1	53 n=10	26 n=5	16 n=3
The GPEM-CY was relevant to my child's involvement in activities at school.	1	68 n=13	16 n=3	10 n=2
The GPEM-CY included all aspects of my child's participation that I am concerned about.	3	63 n=12	21 n=4	0 n=0
The GPEM-CY was easy to complete.	0	47 n=9	10 n=2	42 n=8
I enjoyed filling in the GPEM-CY.	0	68 n=13	26 n=5	5 n=1
I would be happy to complete the GPEM-CY again in the future as part of my child's occupational therapy.	0	68 n=13	21 n=4	10 n=2
The GPEM-CY was too long.	0	16 n=3	37 n=7	47 n=9
The GPEM-CY was too embarrassing.	0	0 n=0	10 n=2	89 n=17
The GPEM-CY was too complicated.	0	42 n=8	16 n=3	42 n=8
The GPEM-CY upset me. *Comment: "questionnaire was cumbersome"	0	5 n=1*	10 n=2	84 n=16

3.3.3 Evidence for Internal Consistency

Measures of internal consistency were calculated using Cronbach's Alpha, for each of the environmental subsections (home, community and school) on the GPEM-CY. Results are presented below in Table 5, alongside those from psychometric testing of the original PEM-CY (Coster et al. 2011).

Table 5: Evidence of Internal Consistency
GPEM-CY versus original PEM-CY (Coster et al. 2011)
Cronbach's alpha (*a)*

Home	Subset (10 items)	GPEM-CY (N=19)	PEM-CY (Coster et al. 2011) (N=576)
Participation	Frequency	0.539*a*	0.590*a*
	Involvement	0.655	0.830
Environment		0.706	≥0.80 (Home supportiveness 0.67)
Community	Subset (10 items)	GPEM-CY	PEM-CY (Coster et al. 2011)
Participation	Frequency	0.374*a*	0.700*a*
	Involvement	x	0.750
Environment		0.681	≥0.80
School	Subset (5 items)	GPEM-CY	PEM-CY (Coster et al. 2011)
Participation	Frequency	0.540*a*	0.610*a*
	Involvement	0.700	0.720
Environment		0.681	≥0.80 (School resources 0.73)

X = insufficient data (too few items for the analysis)

A summary of Cronbach's Alpha (*a*) scores according to each environmental section is below. The interpretation is based on guidelines by Jerosch-Herold (2005), where Cronbach's *a* 0.5 – 0.75 is moderate, and 0.75 – 1 is considered to indicate high consistency among items in the scale. Results from processing of Item Total Statistics will be considered in the summary, and are included in Table 6, below.

Table 6: Item Total Statistics For Participation Items

	HOME Total n=17 Cronbach's alpha = .546 Total items = 9*	Scale Mean if item deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Mean
1	Computer and video games	50.29	56.596	.488	.431*a*	4.24
2	Indoor play and games	48.59	84.007	-.189	.607	5.94
3	Arts, crafts, music and hobbies	49.00	70.750	.214	.518	5.53
4	Watching TV, videos and DVD	49.35	76.118	-.018	.592	5.18
5	Getting together with other people	47.76	80.816	-.012	.549	6.76
6	Socializing using technology	49.94	61.684	.465	.442	4.59
7	Household chores	48.59	73.632	.332	.506	5.94
8	Personal care management	47.53	81.015	.000	.546	*
9	School preparation (not homework)	50.24	54.816	.338	.479	4.29
10	Homework	49.47	50.390	.652	.343	5.06

* Item 8 had 0 variance and was therefore removed from the scale during reliability calculations (Cronbach's Alpha)

	COMMUNITY Total n= 16 Cronbach's alpha = .374 Total items = 10	Scale Mean if item deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Mean
1	Neighborhood outings	20.31	45.429	.158	.344*a*	3.88
2	Community events	21.69	48.496	.135	.356	2.50
3	Organized physical activities	20.94	45.129	.017	.420	3.25
4	Unstructured physical activities	19.00	42.533	.279	.295	5.19
5	Classes and lessons (not school sponsored)	22.75	42.200	.147	.348	1.44
6	Organizations, groups, clubs, and volunteer or leadership activities	22.75	46.067	.021	.410	1.44
7	Religious or spiritual gatherings and activities	22.50	40.533	.189	.327	1.69
8	Getting together with other children	20.06	33.663	.538	.133	4.13
9	Working for pay	24.13	52.783	-.298	.395	.06
10	Overnight visits or trips	23.56	51.596	-.048	.394	.63

	SCHOOL Total n= 16 Cronbach's alpha = .540 Total items = 5	Scale Mean if item deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Mean
1	Classroom activities	12.44	36.929	.361	.485*a*	6.31
2	Field trips and school events	16.00	28.267	.421	.406	2.75
3	School-sponsored teams, clubs and organizations	16.69	31.029	.195	.569	2.06
4	Getting together with peers outside of class	13.06	33.529	.344	.468	5.69
5	Special roles at school	16.81	28.429	.308	.487	1.94

Home

Cronbach's alpha scores for home participation and involvement were all within the moderate range, slightly lower when compared to psychometric testing of the PEM-CY (Coster et al. 2011). Results of Item Total Statistics, indicate that individual removal of item 2 would raise the score from 0.539 to 0.607.

Community

The Cronbach's alpha score for community participation was low (0.374); quite below the results psychometric testing of the PEM-CY (0.70) (Coster et al., 2011). Participation, involvement section provided insufficient data for analysis. Environment items were within the moderate range at 0.681, slightly lower than results from the study by Coster et al. (2011). Removal of question 3 would raise the score to 0.42, still remaining within an unsatisfactory range.

School

School participation items, frequency and involvement, and school environmental section Cronbach's alpha scores were within the moderate range, slightly lower than results by Coster et al. (2011). Removal of item 3 would raise the score only slightly to 0.569, remaining within the moderate range.

Cronbach's alpha scores are explored in the discussion section, Chapter 4.

3.4 Evidence From Thematic Analysis of Interview Data

Data obtained from the semi-structured, cognitive interviews (N=5) were transcribed and subject to thematic analysis by the researcher (refer to Appendix N). The following themes emerged out of the data:

- Core constructs
- Word choice for questions
- Word choice for items
- Cultural applicability of participation items
- Usefulness and applicability of GPEM-CY for parents
- Usefulness of GPEM-CY for parent-therapist communication in Occupational Therapy practices in Switzerland

Data from cognitive interview narratives are presented below according to identified themes.

3.3.1 Core Constructs

Key constructs from the GPEM-CY were discussed during the cognitive interviews, in order to explore and compare definitions provided in the PEM-CY instructions (Coster et al., 2012). The main construct, participation, is described in the PEM-CY instructions as, "a child's involvement in important everyday activities at home, in the school, and in the community. The meaning of participation includes both how often a child does activities and how involved he or she is when doing these activities" (Coster et al. 2011). All five participants explicitly and consistently associated "Teilnehmen" (participation) with either the English word participation, or "mitmachen", which is a direct synonym in German, meaning "to take part in something" ("Teilnehmen", 2017). All interview participants (N=5) described examples of active

participation in various activities of daily living within school, home and/or community settings, indicating their appropriate comprehension of the construct.

The construct, involvement, is described in the PEM-CY Instructions as, "engagement"; "initiative", "interest" and "attention" in an activity that "she/he and others are doing" (Coster et al., 2011). The German translation for involvement applied in the GPEM-CY is, 'Beteiligung'. Beteiligung has more than one meaning when translated into English; participation and involvement ("Beteiligung". 2017). Three participants reported no difficulty understanding this concept, and in their definition, specifically used 'involvieren" as a synonym for 'beteiligen', which is the German verb form meaning to be involved. One interview participant used the word 'engagement' to define involvement, and further described this as a "Messung der Stärke" (measure of intensity) ("Stärke", 2017). Another interviewee was able to translate into English, accurately reflecting the English definition of the construct as provided by Coster et al. (2011).

All interview participants offered examples of their child's involvement, to illustrate their understanding of the construct. Similar to the interview findings, all interview participants completed all sections of the GPEM-CY, including questions in part B related to their child's involvement. Of the 19 completed GPEM-CY questionnaires, eighteen completed questions relating to level of involvement (Section B). The PEM-CY constructs of participation and involvement, as presented in the GPEM-CY were equivalently understood and relevant within German-speaking target culture.

3.3.2 Word Choice for Core Constructs

Although the core constructs of participation and involvement expressed in German seemed to be understood, the question in Part B of the questionnaire asking, "Wie beteiligt ist Ihr Kind normalerweise, wenn es diese Aktivitäten macht?" (Typically, how involved is your child when doing these activities?) was reported as somewhat challenging to complete by three of five interview participants. Parents are required to indicate how involved their child is while participating in each activity, on a scale from ''very involved' to 'minimally involved'. Two participants stated that "Beteiligung" (noun, involvement) is not a word frequently used in Switzerland. These participants indicated that the supplementary information in the categories provided was necessary to support their comprehension of the word "Beteiligung" and the question as a whole. Reports from participants referring to questions in Part B included:

"Ich musste mehrmals durchlesen" (I had to read it more than once)

"Ich habe es nicht sofort verstanden, aber sofort verstanden von den Ganzen" (I did not understand it (the word Beteiligung) immediately, but immediately from the complete (question)".

"Ich brauchte mehr Zeit. Es ist viel geschrieben und einfacher A zu antworten als B" (I needed more time. There is a lot written and A was easier to answer than B).

To start, the German word 'beteiligen' (verb, to be involved), used as a translation for 'involved' in the participation section B question, proved difficult for three of the five interviewees. While the concept of involvement appeared to be retrospectively understood by all parents, following completion of the questionnaire these participants reported difficulty understanding question B. In addition, four of five participants

reported difficulty deciding which level of involvement reflects their child's participation on each item. Section B was reported to demand significantly more time than the other sections according to four of five interviewees. Participants indicated that factors including the use of the German word "beteiligen" (verb, to be involved), length and complexity of the GPEM-CY, Participation section, Part B, were potential obstacles to question comprehension.

3.3.3 Word Choice For Items

Word choice for participation items within the GPEM-CY were mostly well accepted and understood by interview participants. Three of five interview participants reported problems understanding the subtitles for four items in the community section: Item number one, "Nachbarschaftsausflüge" (Neighbourhood outings), Item number three, "Organisierte Körperliche Aktivitäten" (Organised physical activities), Item number four, "Unstruktuierte Körperliche Aktivitäten" (Unstrucutured physical activities), and Item number ten, "Übernachtungsbesuche oder Ausflüge" (Overnight visits or trips). It was reported that these subtitles were too complexly written, or inadequately representative of the examples provided for each. That being said, with the support of the examples provided by the measure, these four items were reported adequately understood and completed by interview participants. Missing item analysis indicated that all participants (N=19) completed Community Item number 10, and only one participant left Items #1, 3, and 4 unanswered. Whether every parent who completed the questionnaire adequately understood the questionnaire items is unknown. One interview participant discovered the use of Austrian dialect in two examples under item headings (homework and snack), and reported the word 'services' used in the

Environment section to be unclear. Despite the difficulties with the use of dialect and complex wording, reports from interview participants indicated a sufficient level of comprehension in order to complete the questions. Further information about level of understanding reported by the larger sample group was addressed in the Adapted QQ-10 questionnaire, results of which can be found below.

3.3.4 Cultural Applicability Of Participation Items

Equivalent relevance and acceptance of translated items when applied in a target culture, is an indicator of cultural applicability (Herdman et al., 1998) of a measure. Results of the Adapted QQ-10 questionnaire indicated that items in all sections of the GPEM-CY were overall relevant in the Swiss, target culture, however not all were considered acceptable.

Home

Home participation items were confidently scored and reported relevant, inclusive and acceptable within the target culture by all interview participants. All interview participants responded similarly. As an example, interview participants when asked about their confidence in answers to this section reported to be, “Sehr sicher. Weil da bin ich zu Hause” (very sure, (of her answers) because I am there at home), “Das weisst die Mutter am besten!” (the Mother knows that the best!), and “bei Hauslichen war das Alles drin“ (in the Home section, everything was included), „Diese deckt sehr gut ab. Wie wir zu Hause erleben“ (this covers everything very well, how we experience life at home).

Community

Community participation items were confidently scored by interview participants, and reported relevant within the target culture. Participants reported they were for example,

"fairly certain, fairly secure", in their confidence on answering questions in this section. However, four items in the community section were considered unacceptable to interview participants due to word choice, as reported above. Overall though, participants reported that the section covered all or most relevant activities in German-speaking Switzerland. One participant reported specifically, "Ich finde es deckt ab" (I think it covers it), but "das Vereins leben gehört hier" (the community club life belongs here), referring to the item for extra-curricular activities in the school section. Another suggested that hiking was not specifically included, which is a culturally relevant activity: "Tagesausfluge, da könnte Wanderung drin sein" (day outings could include hiking).

School

Interview participants consistently reported a lack of confidence and some difficulty in the completion of the school section of the questionnaire. Participants reported answering questions based on their general knowledge of their child's abilities, and limited and second-hand information from their child, teachers and support staff (refer to Appendix M). For example, parents reported they are, "Nicht so sicher, nein weil ich nicht so genau in der schule genau gesehen habe" (not so sure, no because I have not seen exactly (participation) in the school). Another parent stated, „dass ist nur eine ungefahr wissen... von die Heilpädagogin. Ich bin nicht da in der Schule" (That is just approximate knowledge from the special needs teacher. I am not present in the school). Another interviewee reported, "dass finde ich schwierig weil diese Klassenzimmer Aktivitäten, die erleben die Eltern schliesslich nur am Besuchsagen und an Besuchstagen es ist nicht ganz sowie sonnst" (That I find difficult because parents experience the

classroom activities only on (official) visit days, and on visit days it is not the way it usually is".

Item number three (of five) was not considered relevant and acceptable by all interview participants. Item #3 in the School section; "Von der Schule geförderte Teams, Clubs, Organization" (School sponsored teams, clubs and organizations), was considered culturally inacceptable in the school category. According to the interview participants, typically schools in German-speaking Switzerland do not offer extracurricular activities, but instead these are offered by community-based organizations. For example, one participant explained, "es ist nicht von der Schule, ein basketballteam oder ein schwimmteam... eigentlich verein leben" (it is not from the school, a basketball team or a swim team… actually (it is community) club life). Missing items analysis indicated that of the nineteen participants, eleven either left this question blank (N=3), or indicated no participation (N=8).

3.3.5 Usefulness And Applicability Of GPEM-CY For Parents

Most interview participants perceived the GPEM-CY as positive and useful, in particular, a helpful summary of their child's participation, an instrument to promote reflection about their child's participation across settings, and wish for change. Interview participants reported:

The GPEM-CY, „ hat für mich, schon ein bischien geholfen ... eine Zusammenerfassung vor mir" (it did help me a little, a summary in front of me).

The GPEM-CY, "was also very good because it was saying to me, the (level of) independence of your child, and just how involved they are".

The GPEM-CY was helpful to promote reflection: "iergendwie habe ich das Gefühl als ich das gesehen habe, dass ich etwas machen soll, ...dass es sollte nicht so bleiben (Somehow I had the feeling when I saw the (results of the GPEM-CY), that I should do something, that it (my child's participation) should not stay the way it is).

Interview participants reported a range of 40 to 90 minutes to complete the questionnaire.

3.3.6 Usefulness of GPEM-CY For Parent-Therapist Communication In Occupational Therapy

Diversity in opinion was observed between interview participants reporting on the potential use of the GPEM-CY. Interviewees were in agreement that the GPEM-CY could be used to support and facilitate efficient communication of their child's participation. For example, one interview participant explicitly reported about the use of the GPEM-CY: "Gewisse Sachen, sehen wo ist er? ... wo muss ich etwas ändern, aber mit der Zussammenarbeit mit der Ergo, dass finde ich sowas eine sehr gute hilfe " (Certain thiings, to see where he is, where I need to change something, and it was a very good help when working with the Occupational Therapist). The interview participant went on to explain:

„Weil die sehen dann eine Zusammenerfassung für dieses Kind, wie die Eltern dieses Kind sehen. Und wer kennt das Kind besser als der Mutter oder Vater? Die Ergo hat mir immer gefragt, was móchte ich! Erste mal als sie mich gefragt hat, ich sitze nur da und ich weiss nicht!" (Because they (the Occupational Therapist) sees a summary of the child (participation profile), how the parents see the child and who knows the child better as

the mother or father? The first time the Occupational Therapist asked me, I sat there and did not know anything (to answer)).

Further, two interviewees commented on the time-saving factor when using a questionnaire such as the GPEM-CY. The GPEM-CY was reported to have potential facilitating efficient communication between parent and therapist: „Da könnte man sehr gut Zeit sparren“ (one could save time there). Another interviewee stated, the “Grundstrukture kann Mann gut brauche“ (the basic structure could be well used). However, there were questions raised about how an O.T. would be able to facilitate improvement in a child’s level of involvement, and how this could be measured using the GPEM-CY.

Chapter 4 Discussion

4.1 Introduction

This research was a pilot-study to evaluate the face validity, internal consistency and applicability of the GPEM-CY for use in the Swiss, German-speaking context. Quantitative data from field-testing of the GPEM-CY, the Adapted QQ-10 Questionnaire focusing on face validity, was mapped into themes that emerged during qualitative analysis of transcribed, in-depth cognitive interviews. Theoretical knowledge from supporting literature enriched this process, including core constructs used in the PEM-CY, enabled an informed analysis of the GPEM-CY. Within this chapter, the researcher discusses the outcomes of this study, with a focus on the Face Validity, Internal Consistency and Applicability of the GPEM-CY in Switzerland. The reader may refer to the Conclusion section (refer to Chapter 5) for recommendations on further development of the GPEM-CY, and potential clinical use.

4.2 Face Validity

Face validity is a form of content validity based on the subjective view of questionnaire respondents in terms of accuracy, acceptance, likeability and relevance (Thomas, Hathaway & Arheart, 1992). The validity of a measurement instrument is strongly linked to the target population and culture, and the purpose and method of its application in that culture. This research focused on field-testing of the GPEM-CY in the target Swiss-German culture, which enabled the researcher to probe participants on factors of face validity.

The results of this study provided initial supportive evidence in terms of overall accuracy in the translation and cultural adaptation of the GPEM-CY. Investigation into the equivalency of the meaning and importance of the core concepts of the PEM-CY, participation and involvement was positive. The GPEM-CY appears to measure childhood participation as it was intended, according to background theoretical knowledge provided by Coster & Khetani (2008) and Coster et al. (2010), and evidence provided by interview participants regarding the cultural application of translated concepts. The core concepts presented in the GPEM-CY were well understood by the majority of participants. Further, all interview participants reported acceptance and understandability of most of wording used in the overall measure. However, minor problems with accuracy emerged in discussions about the structure of the school and community sections. Bedell et al. (2011) found that in order to evaluate a child's participation, a description of the context should be explicit. Based on feedback from participants, the contextual categorization of a few participation items, such as "School sponsored teams, clubs and organisations" did not accurately reflect the Swiss setting (refer to Table 7). It appears that minor issues of accuracy in word choice, construction and categorization of items may have had an impact on the complexity of the measure, slightly impacting user acceptance (Auger et al., 2006) and cultural applicability of a few specific items (Herdman et al., 1998).

Acceptance of the measure in terms of the questionnaire structure was divided within the overall participant sample. Results of the study showed that opinions were divided on issues of ease of completion, length and complexity of the measure (refer to results of the Adapted QQ-10). This issue was discussed with interview participants,

however the interview participants were mostly highly educated and therefore were not thoroughly representative of the Swiss-German population. Interview participants mentioned some challenges in the ease of completion, but this was more related to the time it took to reflect on their answers rather than difficulty in comprehension. One referring therapist (research assistant) commented during the process of the study, that approximately seven parents reported that the measure was difficult to complete. It is not known if all seven parents returned the research package. Interestingly, the study populations for both the original psychometric study done on the PEM-CY by Coster et al. (2011) and the Korean cross-cultural translation of the PEM-CY by Jeong et al. (2016), represented those with a higher education than the general population. Jeong et al. (2016) reported difficulties with Korean participants understanding of the main PEM-CY concept but did not report on ease of completion. It is not clear if problems with the ease of completion, length and complexity of the GPEM-CY, was due to translation or the nature of the constructs, or both. Uncontrolled variables that possibly contributed to large variability in the sample and results included the children's diagnoses, parent educational level and family's socioeconomic status.

Field-testing of the PEM-CY with a population of families with lower education and lower socioeconomic status would be useful to further develop and facilitate a broader catchment group for the measure. Lower socioeconomic status (SES), which can be associated with lower education levels, was found to have a negative impact on children's level of involvement during participation (Jeong et al. 2016). This raises the importance of developing a measure of participation that is accessible by families with

lower education and lower SES. Such a measure would also enable further investigation on the impact of family income on participation, as recommended by Coster et al. (2011).

Another factor of acceptance raised during the study was the value and purpose of the GPEM-CY for use in the occupational therapy clinical setting. For each GPEM-CY participation item, participants were asked to indicate if and how they would like their child's participation frequency and level of involvement to change. As participation is an overall occupational therapy goal, client's indication of a desire for change on specific participation items may be used as guidance for goal setting and a purpose for therapeutic input. Where no desire for change in participation is desired, there is no indication for therapeutic input. Participants indicated enjoyment in completing the measure, and acceptance of the GPEM-CY as a potential tool for clinical use. Results of the study showed that depending on the targeted participation item, varying percentages of participants indicated desire for change in their child's participation. This information is useful to inform client-centered, therapeutic goal setting as it highlights parent's level of satisfaction with their child's participation in a specific activity, and a potential motivation to address unsatisfactory participation frequency or level of involvement it in a therapy setting. These results reflect a study focusing on the original PEM-CY, which reported that close to 58% of families indicated a desire for some change in their child's participation in the community (Khetani et al. 2015). Interviewed parents specifically identified potential purposes for the GPEM-CY in supporting communication, facilitating the production of a participation profile for use in reflection and promoting action to elicit change. Acceptance of the measure is supported by indications of the measure's relevance as a tool to support children with challenges in participation.

Results of this study provide preliminary evidence that the GPEM-CY measures what it was intended to measure, supporting it's face validity within the Swiss-German cultural context. Still, minor improvements to raise acceptance and face validity, particularly of the school and community participation sections are suggested. Some adjustments to the structure and wording of the GPEM-CY would further improve it's face validity and make the measure more useful for a broader range of parents. Further, the school section may be completed more accurately by a child's teacher; with or without parent involvement. Overall, the GPEM-CY was reported likeable and relevant for use by parents of children receiving Occupational Therapy in Zürich, Switzerland.

4.3 Internal Consistency

Cronbach's coefficient alpha, may contribute to the evaluation of translated questionnaires, as it can be used as evidence to support or challenge the equivalence and reliability; the internal consistency of a measure (Terwee et al., 2007). Alpha scores were interpreted based on a recommended scale by Jerosch-Herold (2005), where moderate levels of consistency between items is indicated by an *a* score between 0.50 -0.75 and good when above 0.75. Factors affecting the score may include number of items in the measure, interrelatedness of items, dimensionality of the construct, and sample size, including missing values (Tavakol & Dennick, 2011). These factors should be taken into consideration in the interpretation of Cronbach's alpha scores for the GPEM-CY, and are discussed below.

The GPEM-CY, participation section includes three environmental sub-sections, for which the Cronbach's Alpha was calculated respectively. The Home and Community sections are made up of 10 items, and the School section of only five items. Lower *a* scores for the school section may be attributed to few items under the construct of school participation.

The interrelatedness of items under the construct participation, and the multi-dimensionality of the concept participation is likely to have had a negative impact on Cronbach Alpha (*a)* scores. Participation is an abstract, multi-dimensional concept, which has made it difficult to target in the form of a measurement instrument (Coster et al., 2012, Phillips et al., 2013, Jeong et al., 2016). Socio-cultural factors, individual skill levels and interests, and level of difficulty in participation items, all contribute to the multi-dimensionality and abstractness of the concept participation. High interrelatedness of items is therefore challenging to achieve under the concept participation.

Cronbach's Alpha is also effected by the sample group and sample size applied to the measurement scale. In addition, a few missing values slightly reduced the data set to less than n=19 in some cases. It is commonly known that larger sample sizes are linked to higher *a* scores. As a pilot study with a sample of n=19, the Cronbach's alpha scores would be expected to be slightly low.

Cronbach's alpha results for each environmental subsection of the GPEM-CY are listed in Table 5, alongside results of the psychometric study of the original PEM-CY (Coster et al.,2011). Results of the Coster et al. (2011) study provide a baseline for comparison that may contribute to the evaluation of quality of the translation and cultural adaptation of the GPEM-CY. Cronbach's Alpha results from the sample (N=19) were as

expected, overall slightly lower than those of the much larger, psychometric study on the original PEM-CY by Coster et al. (2011) (N=576).

Cronbach's Alpha scores were moderate in all but the community participation subsection, which was low (0.374). (The community involvement section had insufficient data for analysis). The lower Cronbach's Alpha may be attributed to instability in the measure where items were not very consistent in measuring, in this case, the concept of participation within the intended context (Goforth, 2017). Results of cognitive interviews indicated weakness in cultural relevance and wording specifically for community participation items, which may have had a negative effect on the interrelatedness of items. Both items 3 ("Organized physical activities") and 6 ("Organizations, groups, clubs and volunteer or leadership activities") are highlighted in item total statistics as weak (Coster et al., 2010). Likewise in the School section, item 3, "School sponsored teams, clubs and organizations" (Coster et al., 2010). Reflecting back on the discussion above, these items were also highlighted in the cognitive interviews as unacceptable. Removal (or cultural adaptation) of these specific items should be considered. These finding challenge the equivalence and reliability of the GPEM-CY.

When taking all factors into consideration, the internal consistency (reliability) of the GPEM-CY in the Home section at the moderate level may be sufficient. Although the reliability of individual items in the Home section may have also been highlighted by item total calculations, they were considered acceptable and relevant by interviewees. Moderate Cronbach's Alpha scores may be sufficient, particularly if the GPEM-CY is to be used as a communication tool. However, specific items in the community and school participation sections require further cultural adaptation and re-testing, as suggested

above. Stronger evidence of internal consistency would be desirable to support the validity of improved versions of the GPEM-CY, for use as an outcome measure.

4.4 Applicability Of The GPEM-CY In Switzerland

Applicability can be defined as, "Suitability for being applied" (Applicability, 2017). Applicability can be determined by factors of respondent burden (invasiveness, administration time, respondent acceptability), and format capability (clarity of instructions, cultural relevance of items, language used (Auger, Demers & Swaine, 2005).

Feedback from interview participants with regards to respondent burden indicated that the GPEM-CY was non-invasive, acceptable in administration time based on an annual expectation for completion of the measure, and had a high level of acceptability. The GPEM-CY was well accepted by all interview participants. Only one parent who completed the questionnaires for the study (n=19) did not accept the GPEM-CY, describing the measure as cumbersome.

The format of the GPEM-CY community and school sections were both praised and criticised by participants. Firstly, due to cultural differences, the way the participation items were sorted across environmental contexts caused confusion. More specifically, the items referring to extracurricular activities need to be moved to a different environmental section and in particular, some titles of items in the community section would require re-wording. A second criticism was related to the wording of instructions. The wording of the question for the participation section, part B, which included the word 'beteiligen' (verb, to be involved) proved challenging for some participants to understand.

In support of the GPEM-CY format, the overall cultural relevance was praised. All interview participants agreed that the GPEM-CY included all items relevant to their child's participation in the Swiss-German context. Additionally, interview participants, all of whom had children attending Occupational Therapy, indicated a valuable role for the GPEM-CY; as a tool to support their reflection about their child's participation, and to facilitate communication with their child's Occupational Therapist. As with all measurement tools, clinical judgment is advised to ensure the GPEM-CY is appropriate for the child receiving Occupational Therapy and their family.

The GPEM-CY has demonstrated to have good potential for use in the Swiss-German community. Its strengths lie in the content and face validity, over the value of the summed scores. It is suggested that the format be reviewed and amended for ease of comprehension and improved cultural applicability.

4.5 Implications

The measurement of children's participation was valued by participants of this study; parents of children receiving O.T. in Switzerland. This outcome supports the need for a tool such as the GPEM-CY for this population. A tool to measure participation is desired.

Similar to the work on Korean translation of the PEM-CY, results of this study emphasize the importance of cultural adaptation of translated questionnaires for use in a target culture that differs to the originally intended population. The GPEM-CY, has the potential for international application, but similar to the Korean version that required and underwent adaptation to fulfill validity requirements, the German version also requires some adaptation to support its' applicability and validity for use in the Swiss culture.

The Cronbach's alpha scores achieved in this study challenges the research community in reliably measuring the concept participation. Although the PEM-CY appears to cover the concept of participation as described by the WHO in the ICF well, the concept of participation is multi-dimensional; influenced by socio-cultural and individual factors, and therefore extremely challenging to capture. Psychometric testing of the PEM-CY in North America elicited Cronbach's alpha scores reaching 0.8 and greater for Environment scales and Home involvement scales, but equivalent or below 0.72 for Home, Community and School participation frequency, and involvement scales (Coster et al., 2011). Despite scores at moderate level, Coster et al. (2011) and Khetani et al. (2015) deemed the PEM-CY acceptable for use within North America. This conclusion contradicts the idea that an outcome measurement tool should ideally have higher reliability coefficients (Law, 2004). Perhaps high internal consistency between

items measuring the concept participation may simply be very difficult to achieve. The author challenges the idea that the PEM-CY may be used as a clinical 'measurement' tool as suggested in its' title. The strength of the PEM-CY / GPEM-CY is in creating a profile, for use in communication between client and therapist.

4.6 Limitations

This research was conducted as a small pilot study, and therefore can offer only preliminary evidence on the validity and applicability of the GPEM-CY. Results are informative but not conclusive. Adaptations to the GPEM-CY may be made based on the the results of this study, however the population studied was not representative of the European German population for which the measure was ideally translated.

For purposes of this research, the original QQ-10 (Moores et al. 2012) was adapted, translated and back-translated, to maximize retention of the psychometric properties of the original version. The original version had undergone initial psychometric testing in its' development indicating validity and reliability for health-related quality of life questionnaires (Moores et al., 2012). Despite best efforts to ensure equivalence in the translated version, the researcher discovered some slight misinterpretation of the final question, due to wording used in the translation. The Adapted QQ-10 questionnaire used to evaluate face validity, may have weaknesses in validity and reliability, which may have effected the results.

This study had a significant selection bias. In convenience sampling, the researcher must accept that participants may not represent the general population. There were interested parents who accepted the participation package of questionnaires, but did

not complete them. A few of these reported to the research team, that they felt unable or unqualified to complete the questionnaires. It is unknown how many were not returned due to this issue. Voluntary participants who completed the questionnaires may not have represented the general population of interest. In this study, the cognitive interview participations in particular, were self-selecting. The tendency of participants to volunteer appeared to reflect those with a special interest in the development of tools for Occupational Therapy practice and/ or association with a non-profit organization related to their child's diagnosis. These participants were welcomed for their above-average educational level and strengths in providing in-depth analysis of the questionnaire, however their perspectives did not reflect the general population in Switzerland.

Chapter 5 Conclusion

The main objective of this study was to evaluate the face validity, applicability, and internal consistency of the Participation and Environment Measure: Child and Youth, for use by German speaking parents of children receiving occupational therapy, age 5-17 in Switzerland. Three research questions formed the focus of this study:

1. Do parents' understanding of concepts and items in the GPEM-CY support its' face validity and applicability?
2. Are there any items on the GPEM-CY that need to be changed to reflect the German-speaking, Swiss cultural context?
3. Is the understanding of German-speaking parents in Switzerland, of the constructs participation and involvement, consistent with original PEM-CY meaning/definitions?

A second objective was to investigate the specific applicability of the GPEM-CY in Occupational Therapy practice within Switzerland. Results provided initial evidence of face validity, internal consistency and applicability, and highlights areas for amendment of the GPEM-CY for use in Switzerland. With some refinement, the GPEM-CY has potential for application in Switzerland for assessment of childhood participation, particularly useful in the field of Occupational Therapy. Recommendations for the application of findings from this study, and potential use of the GPEM-CY in the field of paediatric Occupational Therapy are presented below.

Firstly, addressing research questions one and three, results indicate that parents who took part in this study understood the main concepts of the GPEM-CY, but

identified some problematic wording, partially supporting its' face validity and applicability in the Swiss context. Face validity demands equivalence in concepts, descriptive items and semantics as described by Herdman et al. (1998) model for cultural equivalence. Equivalent meaning of key concepts participation and involvement, was evaluated using a data triangulation technique. Results showed an equivalent understanding of the concept 'participation' among study participants, reflecting the definition provided in documentation for the PEM-CY (Coster et al., 2011). However, the German word 'beteiligen' (verb, to be involved), applied as a translation for the concept 'involvement' in the GPEM-CY, appears not to be a common word used by laypeople and was therefore an obstacle to comprehension. To promote effective communication between therapist and clients, the therapist should be aware of potential misunderstandings when using the term 'beteiligen' with their clients.

Further, to address question two, the researcher was able to identify specific items that need to be changed to reflect the Swiss cultural context. Some of the wording and categorisation of items within the GPEM-CY (school and community items) were problematic. It appears that the structure of school and community activities differs between America and Switzerland. Problems with the validity of the school section were identified in the unpublished, translation and validation study by Füssel in Austria (2014), and were not addressed (C. Füssel, personal communication, October 2014). Wording should be revised to consistently meet German language standards used in written documentation, avoiding dialect. Field-testing of a revised version with a larger sample across all three German-speaking regions of Europe is recommended to address dialect issues and potentially enable a broader range of use.

The second research objective was to investigate the possibility of integrating the GPEM-CY as an initial baseline assessment tool in children's Occupational Therapy services in Switzerland. The GPEM-CY, with some amendments, has the potential to fill the gap in the available tools, uniquely addressing environmental factors that influence the participation of children. Parents who participated in this research indicated their support of the GPEM-CY as a clinical tool to produce a summary of their child's participation, and as a communication tool for use with their child's therapist for purposes of therapy planning. Parent respondents indicated on the GPEM-CY, their wish for change in their child's participation in specific childhood activities, useful information to focus client-centered, therapy goal setting. However, similar to recommendations by Joeng et al (2016), there is evidence to show that change toward a focus on participation, and use of the GPEM-CY in clinical settings requires support. Education for Occupational Therapists on occupation-focused approaches, and the measurement of participation is recommended.

The aim of this study was to provide initial evaluation of the face validity and reliability of the GPEM-CY for use as a measurement tool in Occupational Therapy in the Swiss context. The UN, WHO and World Federation of Occupational Therapists are have recommended that under the bio-psychosocial model of Health, participation is a primary goal and indicator of well-being and health internationally. It is recommended that outcome measurement at the level of participation should be used to best illustrate the benefits of rehabilitation (Depoy & Gilson, 2008). According to results of this study, the GPEM-CY, following some amendments, would be useful and acceptable as a communication tool, and a baseline outcome measure for Occupational Therapy in the

Swiss-German context. Further adaptation, refinement of items, and field-testing, capturing all three German-speaking regions of Europe is recommended to develop the German version of the Participation and Environment Measure: Child and Youth (Coster et al., 2010).

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Appendix A: Occupational Therapist Recruitment Email

(for distribution in English)

Dear Occupational Therapist:

I am conducting a pilot study exploring the cross-cultural face validity, internal consistency and applicability of the Participation and Environment Measure: Child and Youth (PEM-CY). The PEM-CY is a questionnaire developed in North America for research into the ways children with and without disabilities participate in activities in their daily lives, and how their environment affects their participation. It was recently translated into German and requires field testing before it can be used in practice. Information about the PEM-CY can be found at: https://canchild.ca/en/resources/228-the-participation-and-environment-measure-for-children-and-youth-pem-cy-an-innovative-measure-for-home-school-and-community

I am seeking your help with recruitment and distribution of questionnaires. The study requires input from parents of children age 5-17, who currently receiving Occupational therapy at the Stiftung RGZ. Parents must have a German mother-tongue; be able to read, write and speak fluently in German. Parents who do not speak fluent German, or do not have a child within this age band (5-17 years old) may not participate in this study.

Occupational therapists participating in this study will be asked to sign a confidentiality form, to ensure all participant information remains secure.

Parents who volunteer for this study will be asked to complete an informed consent form. Parents will then be asked to complete 2 questionnaires: the PEM-CY (German) and a few questions related to the content/wording etc. This should take approximately 40-60 minutes to complete. Questionnaires will then be made anonymous (coded) and returned to the head researcher.

In the second stage of my research, I will be asking for 6 parent volunteers to participate in an interview to discuss the cultural validity of the questionnaire.

The Health Research Ethics Board at Dalhousie Univeristy (Canada) has reviewed the methods for this study. There is no reimbursement for participation in this study.

If you are interested in helping with recruitment in this study, or if you would like more information, please contact Christian Lüder (christian.lueder@stiftung-rgz.ch).

Thank You,

Jillian Boyd, Occupational Therapist
MSc OT (Post Professional) Candidate
School of Occupational Therapy
Dalhousie University

Boyd.jillian@dal.ca

+49 (0)151 014 9382

Appendix B: Cognitive interview and Consent

(to be translated into German)

The lead investigator, Jillian Boyd, will read the following phone script to request participation in the focus group and to acquire voluntary consent to participate from those who agree.

JB: Hello, my name is Jillian Boyd, I am calling you to thank you for completing the questionnaires for my research project and ask for your participation in a follow-up group discussion. I am organizing a small group of parents to discuss the wording and content of the PEM-CY. We will be meeting at the Stiftung RGZ on (date). The interview will take 1 hour of your time. You may choose what information you wish to share or not share. If at any point in the discussion, you no longer wish to participate, you may leave the discussion**,** however your contributions up to this point will be retained. The discussion will be audio recorded in order for me to transcribe the information and analyse the results. A copy of the interview consent details (Appendix E) will be sent to you, and discussed again on the day of the cognitive interview.

Do you have any questions?

Are you interested in taking part in an interview?

☐ YES ☐ NO

Do you agree that the interview ~~discussion~~ will be audio-recorded?

☐ YES ☐ NO

Do you agree to the use of direct, anonymous quotations in any presentation or publication from the research study?

☐ YES ☐ NO

Would you like to receive a summary of the results?

☐ YES ☐ NO

Email address: Mailing address:

Arrange interview date and time for interview with interviewee.

Please take time to read through the interview Information and Consent form, which I will send you by mail. You will be asked to sign this form upon attending the interview. If you decide not to participate, please let me know by email or phone.

If you have any concerns about your participation, you may contact the Human Research Ethics Administration at Dalhousie, University. Further information about the project and all contact information can be found in the consent form that you received with the PEM-CY questionnaire.

Appendix C: Study Information Cover Letter to Parents

(to be translated into German)

Dear Parent

Thank you for taking the time to consider volunteering for this research project. I am an Occupational therapist and part-time student at Dalhousie University, working toward the Masters degree in Occupational Therapy. To complete my degree, I am conducting a research project to evaluate a newly translated questionnaire for use in Switzerland. The questionnaire is called the Participation and Environment Measure: Child and Youth (PEM-CY). The PEM-CY is a questionnaire developed in North America for research into the ways children participate in activities in their daily lives, and how their environment at home, school, and in the community affects their participation. The PEM-CY has been translated into German but needs to be used and evaluated by parents like you. -Information about the PEM-CY can also be found online: https://canchild.ca/en/resources/228-the-participation-and-environment-measure-for-children-and-youth-pem-cy-an-innovative-measure-for-home-school-and-community

Parents with a German mother-tongue, with a child age 5-17 who is currently receiving Occupational therapy at the Stiftung RGZ are invited to participate in the study.

The information which I am gathering will help to determine if the translated PEM-CY can be understood by parents in Switzerland, and if it would be useful. Your contribution to this research will be very helpful to get this process started.

If I can answer any questions that will help you decide whether or not to participate, please contact me directly. Further information about how, participants' privacy, confidentiality and anonymity will be protected, is detailed in the Consent Form provided. Please read through this carefully, and if you agree to participate please sign the consent form.

The PEM-CY and accompanying questionnaire will take 40-60 minutes to complete.

Thank you for your consideration.

Jillian Boyd, Occupational Therapist, Stiftung RGZ
MSc OT (Post Professional) Candidate
School of Occupational Therapy, Dalhousie University
Boyd.jillian@dal.ca / Tel: +49 (0)151 014 9382 (Germany)

Appendix D: Consent Form (Expert group)

(to be translated into German)

Project title: Pilot study, evaluating the face validity, internal consistency and feasibility of the German version of the Participation and Environment Measure: Child and Youth in Switzerland

Lead researcher: Jillian Boyd
Occupational Therapist, Stiftung RGZ
MSc OT (Post professional) Candidate
School of Occupational Therapy, Dalhousie University
boyd.jillian@dal.ca
+49 151 014 9382 (Germany)

Other researchers: Dr. Joan Versnel
Department of Occupational Therapy, Dalhousie University
jversnel@dal.ca
+1 902 494 2601

Introduction

We invite you to take part in a research study being conducted by me, Jillian Boyd, a student at Dalhousie University as part of my post-professional Masters program in Occupational Therapy. Whether or not you take part in this research is entirely your choice. There will be no impact on the services you receive at Stiftung RGZ if you decide not to participate in this research. The information below tells you about what is involved in the research, what you will be asked to do and about any benefit, risk, inconvenience or discomfort that you might experience.

Please ask as many questions about the study as you like. If you have any questions later, please contact the lead researcher.

Purpose and Outline of the Research Study

The purpose of this research is to evaluate a newly translated questionnaire. The questionnaire called, Participation and Environment Measure: Child and Youth, was developed in North America for research into the ways children participate in activities in their daily lives, and how their environment affects their participation.

This research offers German-speaking parents the opportunity to use and provide feedback about the Participation and Environment Measure: Child and Youth.

Who Can Take Part in the Research Study

You may participate in this study if you are a parent of a child age 5-17 years of age, who is receiving occupational therapy at the Stiftung RGZ. You must be able to read, write and speak German as a native (mother-tongue).

What You Will Be Asked to Do

If you choose to participate, you will be given a study package, and asked to complete an enclosed consent form, the PEM-CY, and an accompanying short questionnaire. This should take approximately 40-60 minutes of your time. Although the information you will provide will be about your child, your answers will remain anonymous. Please do not write your name or your child's name on your questionnaire. This information will be kept confidential and anonymous at all times. Please send the completed forms using the enclosed stamped return envelopes, to Christian Lüder at the Stiftung RGZ.

If you agree, you will be contacted after the questionnaires are collected, and offered the opportunity to participate in a follow-up discussion group.

Your participation is entirely voluntary. You may choose to participate; completing and returning the questionnaires in the envelope provided. If you choose not to participate in the study, incomplete questionnaires need not be returned.

Possible Benefits, Risks and Discomforts
The risks in this study are minimal. By taking part in this study, you will be encouraged to think about your child's participation at school, home and in the community. You may find some questions help you reflect on your child's abilities, their daily routine, and activities within which they participate. Completing the questionnaire may raise positive or negative emotions. In the unlikelihood that you experience any discomfort as a result of participating in this research, consultation with your family doctor is recommended.

Your participation in this study will help develop this measurement for possible future clinical or research uses.

How your information will be protected:
Privacy: The head researcher, lead recruiter or recruiting Occupational Therapist, will be the only people aware of your participation in this study. Any communications with you will be direct, via telephone or email.

Anonymity: No one will be able to link you or your child with the information you share on questionnaires. We will collect your name and contact email/telephone number in order to contact you for any follow-up. This information will not be shared with anyone outside the research team.

Confidentiality: We will not disclose information about participants, or who they were. A list of contact details for participants will be kept separately from the completed questionnaires. Informed consent forms will be kept separately from the completed questionnaires (returned in a separate envelope provided). Questionnaires will be labeled with a number in advance of distribution, and upon return, stored in a locked cabinet to ensure confidentiality. Reports and any publication of results will not include names of participants.

Data retention: Information that you provide to us will be kept secured and confidential. Only the research team at Dalhousie University will have access to this information. You will not be identified in any publications resulting from this research. We will use a participation number, not your name, in our written and computer records and the information will be securely stored. All electronic records will be kept secure in an encrypted file on the researchers' password-protected computer.

We will not disclose any information about you or your child in this research to anyone unless compelled to do so by law. That is, in the unlikely event that we witness child abuse, or suspect it, we are required to contact authorities.

If You Decide to Stop Participating
You have a right to withdraw from voluntary participation. You are not obliged to return questionnaires if you choose not to participate.

How to Obtain Results
A summary of the results of the study will be made available to you. If you wish, please include your contact details on the signature form attached, and a summary of results will be sent to you.

Questions
We are happy to talk with you about any questions or concerns you may have about your participation in this research study. Please contact Jillian Boyd (boyd.jillian@dal.ca) or Joan Versnel (jversnel@dal.ca) (in English only) or Christian Lüder, Head of Therapy Services at Stiftung RGZ
(christian.lueder@stiftung-rgz.ch). We will let you know if any new information comes up that could affect your decision to participate.

If you have ethical concerns about your participation in this research, you may also contact Research Ethics, Dalhousie University at 1-902-494-1462 or email ethics@dal.ca (and reference REB file #).

Conflict of Interest
The researcher has no affiliations that would create a conflict of interest.

Consent Form: Signature Page
(to be translated into German)

Project Title: Pilot study, evaluating the face validity, internal consistency and feasibility of the German version of the Participation and Environment Measure: Child and Youth in Switzerland

Lead Researcher: Jillian Boyd
Occupational Therapist, Stiftung RGZ
Masters student, Dalhousie University, Canada
boyd.jillian@dal.ca
+49 (0)151 014 9382 (Germany)

I (the research participant) have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I have been asked to fill in questionnaires and submit them within 2 weeks. I agree to take part in this study. I understand that direct quotes of things I write may be used without identifying me. My participation is voluntary and I understand that I am free to withdraw from the study up until 2 weeks after my questionnaire is submitted.

_____ _____ _____

Name Signature Date

In the second stage of this research, I will be looking for volunteers to participate in a 1-hour interview about the PEM-CY. We will be discussing the wording and cultural applicability of items in the questionnaire. Please provide your contact details below, if you think you might like to participate. You will be contacted by telephone with more information.

Are you interested in participating in an interview? ☐ YES ☐ NO
Do you wish to receive a research summary by email? ☐ YES ☐ NO

Please enter your contact details here:

Email: _____

Telephone: _____

Appendix E: Consent Form (Cognitive Interview)

(to be translated into German)
Project title: Pilot study, evaluating the face validity, internal consistency and feasibility of the German version of the Participation and Environment Measure: Child and Youth in Switzerland

Lead researcher: Jillian Boyd
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Other researchers: Dr. Joan Versnel
Department of Occupational Therapy, Dalhousie University
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+1 902 494 2601

Introduction
Thank you for participating in the first stage of this research project: the completion of the PEM-CY (German version) and accompanying questionnaire. We invite you to take part in the second stage of this research study being conducted by me, Jillian Boyd, a student at Dalhousie University as part of my post-professional Masters program in Occupational Therapy. The second stage is an interview covering the wording and content of the PEM-CY (German version).

Whether or not you take part in this research is entirely your choice. There will be no impact on the services you receive at Stiftung RGZ if you decide not to participate in this research. The information below tells you about what is involved in the research, what you will be asked to do and about any benefit, risk, inconvenience or discomfort that you might experience.

Please ask as many questions about the study as you like. If you have any questions later, please contact the lead researcher.

Purpose and Outline of the Research Study
The purpose of this research is to evaluate a newly translated questionnaire. The questionnaire called, Participation and Environment Measure: Child and Youth, was developed in North America for research into the ways children participate in activities in their daily lives, and how their environment affects their participation.

This research offers German-speaking parents the opportunity to use and provide feedback about the Participation and Environment Measure: Child and Youth.

Who Can Take Part in the Research Study
You may participate in this study if you are a parent of a child age 5-17 years of age, who is receiving occupational therapy at the Stiftung RGZ. You must be able to read, write and speak German as a native (mother-tongue).

Should more than 4-6 participants volunteer, the researcher will select participants to enquire about the wording and cultural applicability of the PEM-CY, based on analysis of the completed questionnaires. The researcher will contact volunteers by telephone if they have been selected to participate or not.

What You Will Be Asked to Do
If you volunteer to participate, you will be asked to attend a private interview.

If at any point in the interview, you no longer wish to participate, you may leave the discussion. The interview will be audio recorded in order for me to transcribe the information and analyze the results.

On the day of the interview, you will be asked to sign, giving written consent of your participation.

On the day of the discussion, you will be asked to sign, giving written consent of your participation.

Possible Benefits, Risks and Discomforts
The risks in this study are minimal. By taking part in this study, you will be encouraged to think about the content of the PEM-CY (German version). You may find some questions encourage you to reflect on your child's abilities, their daily routine, and activities within which they participate. Participation may raise positive or negative emotions. In the unlikelihood that you experience any discomfort as a result of participating in this research, consultation with your family doctor is recommended.

Your participation in this study will help develop this measurement for possible future clinical or research uses.

How your information will be protected:
Privacy: The head researcher and other participants will be the only people aware of your participation in this study. You may choose what information you wish to share or not share.

Anonymity: No one will be able to link you or your child with the information you share on questionnaires. We will collect your name and contact email/telephone number in order to contact you for any follow-up. This information will not be shared with anyone outside the research team.

Confidentiality: I will not disclose information about participants, or who they were. Transcription of the audio recording will not include names. Participants will be assigned a pseudonym. Reports and any publication of results will not include names of participants.

Data retention: Information that you provide to us will be kept secured and confidential. Only the research team at Dalhousie University will have access to this information. You will not be identified in any publications resulting from this research. We will use a participation number, not your name, in our written and computer records and the information will be securely stored. All electronic records will be kept secure in an encrypted file on the researchers' password-protected computer.

We will not disclose any information about you or your child in this research to anyone unless compelled to do so by law. That is, in the unlikely event that we witness child abuse, or suspect it, we are required to contact authorities.

If You Decide to Stop Participating
You are free to withdraw anytime during your participation in the focus group. You may request

to remove the data from your interview at any time during the interview and up to 2 weeks thereafter. After 2 weeks, the data will be anonymous, in the data analysis process and cannot be removed.

How to Obtain Results
A summary of the results of the study will be made available to you. If you wish, please include your contact details on the signature form attached, and a summary of results will be sent to you.

Questions
We are happy to talk with you about any questions or concerns you may have about your participation in this research study. Please contact Jillian Boyd (boyd.jillian@dal.ca) or Joan Versnel (jversnel@dal.ca) (in English only) or Christian Lüder, Head of Therapy Services at Stiftung RGZ (christian.lueder@stiftung-rgz.ch). We will let you know if any new information comes up that could affect your decision to participate.

If you have ethical concerns about your participation in this research, you may also contact Research Ethics, Dalhousie University at 1-902-494-1462 or email ethics@dal.ca (and reference REB file #).

Conflict of Interest
The researcher has no affiliations that would create a conflict of interest.

Consent Form (Interview): Signature Page
(to be translated into German)

Project Title: Pilot study, evaluating the face validity, internal consistency and feasibility of the German version of the Participation and Environment Measure: Child and Youth in Switzerland

Lead Researcher: Jillian Boyd
Occupational Therapist, Stiftung RGZ
Masters student, Dalhousie University, Canada
boyd.jillian@dal.ca
+49 (0)151 014 9382 (Germany)

I (the research participant) have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I have been asked to attend and participate in an interview. I agree to take part in this study. I understand that direct quotes of things I say may be used without identifying me. My participation is voluntary and I understand that I am free to withdraw from the study at any time.

_____	_____	_____
Name	Signature	Date

Do you wish to receive a research summary by email? ☐ YES ☐ NO

Please enter your contact details here:

Email: _____

Telephone: _____

Appendix F: Demographic Information Form

(to be translated into German)\

Age of parent participant:

☐ 20-30

☐ 31-40

☐ 41-55

☐ 56-65

Country of birth:

☐ Switzerland

☐ Germany

☐ Austria

☐ Other

Mother-tongue

☐ German

☐ Other; _____

Age of child attending occupational therapy:

☐ 5-8

☐ 9-12

☐ 13-17

Relationship to child:

☐ Mother

☐ Father

☐ Legal Guardian

Appendix G: Participation and Environment Measure: Child and Youth

Permission to include a Review Copy of the Participation and Environment Measure: Child and Youth (PEM-CY) in this thesis was received from the distributers. A copy of the email received is included below. A Review Copy of the PEM-CY (English version) follows.

Please do not copy or circulate.

Gmail Jillian Boyd <boyd.jillian@gmail.com>

Re: PEM-CY sample copy

Teplicky, Rachel <teplicr@mcmaster.ca> Fri, Feb 23, 2018 at 11:02 PM
To: Jillian Boyd <Jillian.Boyd@dal.ca>
Cc: Joan Versnel <jversnel@dal.ca>

Hi Jillian,

It is fine for you to include the Review Copy in your thesis. I have attached the most recent copy that includes “Please do not copy or distribute.”

Great to hear you are so close to submitting!

Rachel

Rachel Teplicky, OT Reg. (Ont.)

Business and Engagement Officer
McMaster University
905-525-9140 ext. 26851
http://www.canchild.ca/

CanChild
Generating Knowledge
Transforming Lives

From: Jillian Boyd <Jillian.Boyd@Dal.Ca>
Date: Friday, February 23, 2018 at 11:39 AM
To: "Teplicky, Rachel" <teplicr@mcmaster.ca>
Cc: Joan Versnel <jversnel@Dal.Ca>
Subject: PEM-CY sample copy

Dear Rachel

FOR OFFICE USE ONLY: _____ (ID)

Participation and Environment Measure – Children and Youth©

Wendy Coster, Mary Law, Gary Bedell

SURVEY INSTRUCTIONS

Participation refers to a child's involvement in important everyday activities at home, in school, and in the community. The meaning of participation includes both how often a child does activities AND how involved he or she is when doing these activities.

The survey asks a set of questions about your child's participation in 25 types of activities that take place in three environments: home, school, and community. We give a few examples to illustrate each type of activity. However, you should think about all of the activities that belong to the category when answering these questions.

For each type of activity we ask:

1. how often your child has participated over the last 4 months
2. how involved your child is when participating in 1 or 2 activities of this type that he or she does most often
3. whether or not you would like your child's participation to change, and if so, how you would like it to change

IMPORTANT

This survey is not asking about your child's level of independence when participating in activities. "Involvement" refers to how engaged your child is in an activity, using whatever supports, assistance, adaptations, or methods he or she routinely uses or has available.

When selecting your response, please think about your child's level of attention, concentration, emotional engagement, or satisfaction (using whatever supports or assistance are usually available).

Very involved*!=!*In general, child is engaged throughout the activity. He or she shows a lot of initiative and/or interest in and attention to what he or she and others are doing during the activity.

Somewhat involved*!=!*Child is engaged in the activity some of the time. He or she shows some initiative and/or interest in and attention to what he or she and others are doing during the activity.

Minimally involved*!=!*Child is engaged in a small part of the activity. He or she only shows a little initiative and/or interest in and attention to what he or she and others are doing during the activity.

If there are things that help or make your child's participation more difficult, such as equipment or support from others, you can tell us about their impact in the home environment, school environment, and community environment sections of this survey.

HOME Participation

	A) Typically, how often does your child participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑								B) Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities? CHECK ONE RESPONSE ☑					C) Would you like your child's participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑						
	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	Never (skip to Question C)	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
1) Computer and video games																			
2) Indoor play and games (e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up)																			
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)																			
4) Watching TV, videos, and DVDs																			
5) Getting together with other people (e.g., interacting with peers, family, other houseguests)																			
6) Socializing using technology (e.g., telephone, computer)																			
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)																			
8) Personal care management (e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup)																			
9) School preparation (not homework) (e.g., gathering materials, packing school bag, packing lunch, reviewing schedule)																			
10) Homework (e.g., daily reading, homework assignments, school projects)																			

HOME Environment

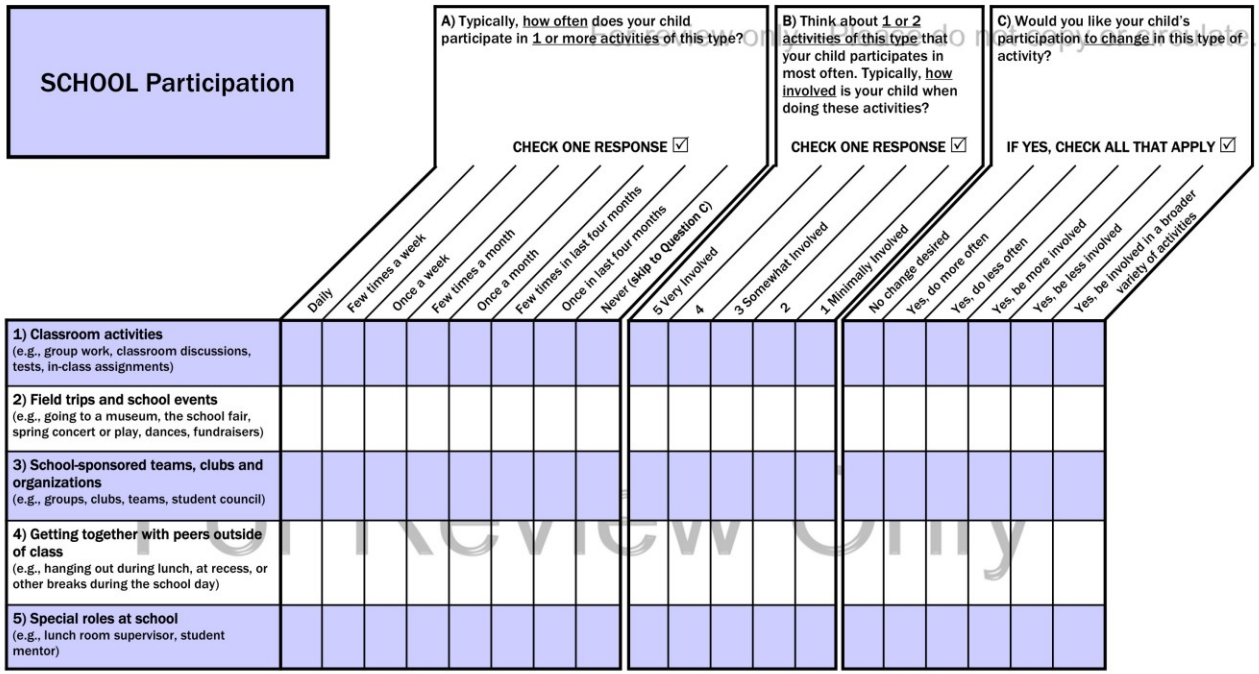
Do the following things help or make it harder for your child to participate in activities at home? CHECK ONE RESPONSE ☑	Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout or amount of space and furniture in your home				
2. The sensory qualities of the home environment (e.g., amount and/or type of sound, light, temperature, textures of objects)				
3. The physical demands of typical activities in the home (e.g., strength, endurance, coordination)				
4. The cognitive demands of typical activities in the home (e.g., concentration, attention, problem-solving)				
5. The social demands of typical activities in the home (e.g., communication, interacting with others)				
6. Your child's relationships with family members in the home (e.g., siblings, parent, grandparent)				
7. The attitudes and actions of babysitters, therapists, and other professionals who care for your child at home				

CHECK ONE RESPONSE ☑	Not need-ed	Usually, yes	Sometimes yes; sometimes no	Usually, no
8. Are services in your home available and/or adequate to support your child's participation?				

HOME Environment

Are the following available and/or adequate to support your child's participation at home? CHECK ONE RESPONSE ☑	Usually, yes	Sometimes yes; sometimes no	Usually, no
9. Supplies in the home (e.g., sports equipment, crafts supplies, reading materials, assistive devices or technology, picture or word schedules)			
10. Information (e.g., about activities, services, programs)			
11. Do you (and your family) have enough time to support your child's participation at home?			
12. Do you (and your family) have enough money to support your child's participation at home?			

What are some things that you or other family members do that help your child participate successfully in activities at home? PLEASE LIST UP TO 3 STRATEGIES
1.
2.
3.



SCHOOL Environment

Do the following things help or make it harder for your child to participate in activities at school? CHECK ONE RESPONSE ☑	Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout or amount of space in the classroom, on the playground, or on other parts of school premises (e.g., presence of sidewalks, availability of ramps or elevators in school building)				
2. The sensory qualities of the school environment (e.g., noise, crowds, lighting, etc.)				
3. Outside weather conditions (e.g., temperature, climate)				
4. The physical demands of typical school activities (e.g., strength, endurance, coordination)				
5. The cognitive demands of typical school activities (e.g., concentration, attention, problem-solving)				
6. The social demands of typical school activities (e.g., communication, interacting with others)				
7. Attitudes and actions of teachers, coaches, or staff towards your child				
8. Your child's relationships with peers				
9. The safety of the school (e.g., supervision, crime, violence)				

Are the following available and/or adequate to support your child's participation at school? CHECK ONE RESPONSE ☑	Not needed	Usually, yes	Sometimes yes; sometimes no	Usually, no
10. Access to personal transportation to get to school (e.g., family car, bicycle)				
11. Access to public transportation to get to school (e.g., school bus, train, subway)				
12. Programs and services (e.g., after school, recreational, special resources, educational assistant/aide)				
13. School–related policies and procedures (e.g., eligibility criteria for services, rules for behavior)				

SCHOOL Environment

Are the following available and/or adequate to support your child's participation at school? CHECK ONE RESPONSE ☑	Usually, yes	Sometimes yes; sometimes no	Usually, no
14. Supplies (e.g., assistive devices or technology, reading materials, sports equipment, crafts supplies)			
15. Information (e.g., about activities, services, programs)			
16. Do you (and your family) have enough time to support your child's participation at school?			
17. Do you (and your family) have enough money to support your child's participation at school?			

What are some things that you or other family members do that help your child participate successfully in activities at school? PLEASE LIST UP TO 3 STRATEGIES
1.
2.
3.

COMMUNITY Participation

	A) Typically, how often does your child participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑								B) Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities? CHECK ONE RESPONSE ☑					C) Would you like your child's participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑						
	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	Never (skip to Question C)	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
1) Neighborhood outings (e.g., shopping at the store/mall, going to a movie, eating out at a restaurant, visiting the local library/bookstore)																			
2) Community events (e.g., attending a play, concert, sports game, parade)																			
3) Organized physical activities (e.g., sports teams or classes such as baseball, hockey, martial arts, dance, horseback riding, swimming, gymnastics)																			
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)																			
5) Classes and lessons (not school-sponsored) (e.g., music, art, languages, computers)																			

COMMUNITY Participation

	A) Typically, how often does your child participate in 1 or more activities of this type? CHECK ONE RESPONSE ☑								B) Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities? CHECK ONE RESPONSE ☑					C) Would you like your child's participation to change in this type of activity? IF YES, CHECK ALL THAT APPLY ☑						
	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	Never (skip to Question C)	5 Very Involved	4	3 Somewhat Involved	2	1 Minimally Involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
6) Organizations, groups, clubs, and volunteer or leadership activities (e.g., Boy Scouts, Brownies/Girl Guides, youth groups, public speaking)																			
7) Religious or spiritual gatherings and activities (e.g., attending places of worship, religion classes, groups)																			
8) Getting together with other children in the community (e.g., hanging out, informal gatherings outside of the home or school)																			
9) Working for pay (e.g., babysitting, paper route, working in a store, doing chores or running errands for pay)																			
10) Overnight visits or trips (e.g., sleepovers, vacations, camp)																			

COMMUNITY Environment

Do the following things help or make it harder for your child to participate in activities in the community? CHECK ONE RESPONSE ☑	Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout or amount of space outside and inside buildings (e.g., distances to stores, presence of sidewalks, availability of ramps or elevators)				
2. The sensory qualities of community settings (e.g., noise, crowds, lighting)				
3. The physical demands of typical activities (e.g., strength, endurance, coordination)				
4. The cognitive demands of typical activities (e.g., concentration, attention, problem-solving)				
5. The social demands of typical activities (e.g., communication, interacting with others)				
6. Your child's relationships with peers				
7. The attitudes and actions of other members of the community towards your child (e.g., shopkeepers, instructors, coaches, other families)				
8. Outside weather conditions (e.g., temperature, climate)				
9. The safety of the community (e.g., traffic, crime, violence)				

Are the following available and/or adequate to support your child's participation in the community? CHECK ONE RESPONSE ☑	Not needed	Usually, yes	Sometimes yes; sometimes no	Usually, no
10. Access to personal transportation to access community activities (e.g., family car, bicycle)				
11. Access to public transportation to access community activities (e.g., bus, train, subway)				
12. Programs and services (e.g., inclusive sports programs, personal support worker)				

COMMUNITY Environment

Are the following available and/or adequate to support your child's participation in the community? CHECK ONE RESPONSE ☑	Usually, yes	Sometimes yes; sometimes no	Usually, no
13. Information (e.g., about activities, services, programs)			
14. Equipment or supplies (e.g., sports equipment, craft supplies, reading materials, assistive devices or technology)			
15. Do you (and your family) have enough time to support your child's participation in the community?			
16. Do you (and your family) have enough money to support your child's participation in the community?			

What are some things that you or other family members do that help your child participate successfully in activities in the community? PLEASE LIST UP TO 3 STRATEGIES
1.
2.
3.

Appendix H: Adapted version of the QQ-10

Short Questionnaire about the PEM-CY

(to be translated into German)

Thank you for taking the time to complete the ***Participation and Environment Measure: Children and Youth (PEM-CY)***. Please circle the answers below each of the following statements that best fit your feelings about the PEM-CY. Please use the space at the bottom of the next page to make additional comments.

1. The PEM-CY helped me to communicate about my childs' involvement in activities at **home**.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

2. The PEM-CY was relevant to my child's involvement in activities at **home**.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

3. The PEM-CY helped me to communicate about my childs' involvement in activities in our **community**.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

4. The PEM-CY was relevant to my child's involvement in activities in our **community**.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

5. The PEM-CY helped me to communicate about my child's involvement in activities at **school**.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

6. The PEM-CY was relevant to my child's involvement in activities at **school**.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

7. The PEM-CY included all aspects of my child's participation that I am concerned about.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

8. The PEM-CY was easy to complete.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

9. I enjoyed filling in the PEM-CY.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

10. I would be happy to complete the PEM-CY again in the future as part of my child's occupational therapy.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

11. The PEM-CY was too long.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

12. The PEM-CY was too embarrassing.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

13. The PEM-CY was too complicated.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

14. The PEM-CY upset me.

Strongly agree Mostly agree Neither agree nor disagree Mostly disagree Strongly disagree

Please write your comments here:

(Adapted from the QQ-10 (Moores et al. 2012)

Appendix I: Cognitive Interview Guide

(to be translated into German)

Introduction and Consent Script:
Thank you for volunteering and coming in today. Today I would like to discuss your impressions of the PEM-CY; specifically the wording and items. The PEM-CY is a measure that is meant for use by parents, to report on their child's participation in school, the community and at home. This interview will be limited to a 1-hour duration, and is meant to expand on the questionnaires you completed.

This interview will be audio recorded for research purposes and your individual contribution will be made anonymous.

Your contributions are entirely voluntary. You may choose what information you wish to share or not share. Direct quotes of things you say may be used without identifying you individually. If for whatever reason you decide to withdraw from the interview, you may do so at any time. Please feel free to interrupt the interview and let me know.

The study information and concerns of privacy, confidentiality and anonymity are clarified in detail in the consent form that I sent to you by mail. Please take this opportunity should you wish to read through the form again. If you agree, please sign the form.

Gain written consent of all participants before proceeding. Allow all participants sufficient time to read through the consent form. Some participants will have received a copy of Cognitive Interview Consent Form in the mail prior to the inteview date (Refer to Appendix L).

Interview Guide:

The PEM-CY is a measure that is meant for use by parents like yourselves, to report on their child's participation in school, the community and at home.

(researcher to provide a copy of the PEM-CY)

1. What does the term participation mean to you?

   What does the term involvement mean to you?

2. From your experience, does the PEM-CY (german version) sufficiently cover areas of children's participation in Switzerland **at school**?

- Think about the things your child does during his day/week at school. Are these included in the items on the PEM-CY?
- Are there items that do not reflect your childs' activities or those available to children in Switzerland?
- Did you have particular situations or moments in mind when you reported on the participation and involvement of your child at school?
- How sure of your answers for the school section are you?

From your experience, does the PEM-CY (german version) sufficiently cover areas of children's participation in Switzerland **at home**?

- Think about the things your child does during his day/week at home. Are these included in the items on the PEM-CY?
- Are there items that do not reflect your childs' activities or those available to children in Switzerland?
- Did you have particular situations or moments in mind when you reported on the participation and involvement of your child at at home?
- How sure of your answers for the home section are you?

From your experience, does the PEM-CY (german version) sufficiently cover areas of children's participation in Switzerland **in your community**?

- Think about the things your child does during his day/week in the community. Are these included in the items on the PEM-CY?
- Are there items that do not reflect your childs' activities or those available to children in Switzerland?
- Did you have particular situations or moments in mind when you reported on the participation and involvement of your child in the community?
- How sure of your answers for the community section are you?

3. Did any of the wording not make sense to you or was hard for you to understand? Which words/ item(s)?

4. Are there any items on the PEM-CY (german version) that need to be changed to suit the german-speaking, Swiss cultural context? Why do you think that? How do you think it could be changed?

Thank you for your contribution

Appendix J: Email from Canchild Centre For Childhood Disability Research

Gmail Jillian Boyd <boyd.jillian@gmail.com>

PEM-CY german version

Teplicky, Rachel <teplicr@mcmaster.ca> Tue, Nov 8, 2016 at 3:04 PM
To: Jillian Boyd <boyd.jillian@gmail.com>

Hi Jillian,

Great to hear from you and I am so happy that you are interested in continuing to work on the PEM-CY. I have put answers to your questions below.

As mentioned in my notes below, I will connect you with a member of Michael's team so that you can learn more about their process and study.

Rachel

Rachel Teplicky, OT Reg. (Ont.)
Research Coordinator
CanChild Centre for Childhood Disability Research
McMaster University
905-525-9140 ext. 26851

From: Jillian Boyd <boyd.jillian@gmail.com>
Date: Tuesday, November 8, 2016 at 8:42 AM
To: R_B Teplicky <teplicr@mcmaster.ca>
Subject: PEM-CY german version

Dear Rachel

We spoke earlier this year about my plans to do a study on the german version of the PEM-CY. Thank you again for putting me in touch with Dr. Michael Freilinger. I also had the pleasure to meet and speak with Wendy Coster during her visit to Zürich last year, and we discussed the PEM-CY translation and issues that might come up with regards to validity and relevance of the school section.

Having finished my masters course work, I am now in the planning stages of my research and hope to gather data in February 2017. I have a couple of questions for you.

1. As a student researcher, am I able to acquire the german version of the PEM-CY without charge? We generally charge students to use the measures ($99 Canadian), but given that you are doing work to further develop the translated version I would be willing to waive the fee.

2. What protocol did the german translation include? (Dr. Freilinger referred me back to you on this question). Did they do back translation, for example? The german translation included a back translation and some modification of the wording and examples to fit their context. I know that there were concerns about the school environment because they felt it was set up differently than in North America. I will connect you with the person who worked with Michael on the translation.

3. Could you please confirm that no study has been done on the PEM-CY, german version as of yet? I read an article indicating there may be an unpublished study out there (perhaps they were referring to my study?) Michael's team did a validation study.

Appendix K: Support Letter from the Stiftung RGZ

Stiftung RgZ
Für eine unbehinderte Entwicklung

Frühberatungs- und Therapiestellen für Kinder, Rautistrasse 75, 8048 Zürich

Research Ethics
Dalhousie Research Services
Henry Hicks Building, Rm 231
Dalhousie University
PO Box 15000
Halifax, Nova Scotia

Zürich, 03. Januar 2017

Masters thesis research project by Jillian Boyd

Research title:

Pilot study, evaluating the face validity, internal consistency and feasibility of the German version of the Participation and Environment Measure: Child and Youth (PEM-CY) in Switzerland

To whom this may concern,

The Stiftung RGZ is a non-profit organisation based in Zürich, Switzerland. The organisation offers multidisciplinary therapy services for children at 7 clinics around the lake of Zürich, and assisted living and employment for adults with disabilities.

I, Christian Lüder, Head of therapy services, agrees to support recruitment and research activities for the masters research project, conducted by Jillian Boyd.
Support will include:

- Recruitment of participants
- Distribution of study information letter, consent form and data collection instruments

Adherence to the ethical protocols of the Stiftung RGZ and local health authorities, in relation to privacy, confidentiality and data protection, are required. Approval of this research project through the Dalhousie University Ethics Board is sufficient to conduct this project.

Please contact me should there be any questions or concerns.

[redacted]

Christian Lüder
Head of Therapy Services

Frühberatungs- und Therapiestellen für Kinder, Zentrales Sekretariat
Rautistrasse 75, 8048 Zürich, Telefon 058 307 17 11
sekretariat.zuerich@stiftung-rgz.ch, www.stiftung-rgz.ch, Spendenkonto 80-7555-7

Zuständig: Christian Lüder, Telefon direkt 079 662 67 79, christian.lueder@rgz-stiftung.ch

Appendix L: Research Staff Confidentiality Agreement

(for use in English)

This agreement is between:

Jillian Boyd
Occupational therapist, Stiftung RGZ
MSc OT (Post Professional) Candidate
School of Occupational Therapy
Dalhousie University

and

_____

(Name and title of Stiftung RGZ Staff)

Stiftung RGZ, Rautistrasse 75, 8048 Zürich, Switzerland

For the pilot, cross-cultural validation study, focusing on the face validity, internal consistency and applicability of the German version of the Participation and Environment Measure: Child and Youth in Switzerland

Summary of job description/service provision:

To identify potential study participants, distribute information about the study as provided by the lead researcher and collect returned study packages, to be returned to the lead researcher.

I agree to:

1. keep all the research information shared with me confidential. I will not discuss or share the research information with anyone other than with the *Researcher(s)* or others identified by the *Researcher(s)*.
2. keep all research information secure while it is in my possession.
3. return all research information to the *Researcher(s)* when I have completed the research tasks or upon request, whichever is earlier.
4. destroy all research information regarding this research project that is not returnable to the *Researcher(s)* after consulting with the *Researcher(s).*
5. comply with the instructions of the *Researcher(s)* about requirements to physically and/or electronically secure records (including password protection, file/folder encryption, and/or use of secure electronic transfer of records through file sharing, use of virtual private networks, etc.).
6. not allow any personally identifiable information to which I have access to be accessible from outside the Stiftung RGZ (unless specifically instructed otherwise in writing by the *Researcher(s)*).

Research staff:

_____ _____
_____

Name *Signature* *Date*

I agree to:

1. Provide detailed direction and instruction on my expectations for maintaining the confidentiality of research information so that *research staff at the Stiftung RGZ* can comply with the above terms.

2. Provide oversight and support to *research staff at the Stiftung RGZ* in ensuring confidentiality is maintained in accordance with the Tri Council Policy Statement *Ethical Conduct for Research Involving Humans* and consistent with the Dalhousie University Policy on the *Ethical Conduct of Research Involving Humans*.

Researcher:

_____ _____
_____

Name *Signature* *Date*

Appendix M: Ethics Approval

Dalhousie University Research Services (REB# 2017-4080)

REB # 2017-4080 Letter of Approval

K Keerthi.Luthra@dal.ca
Wed 2/8, 4:50 PM
Jillian Boyd; Joan Versnel; Keerthi Luthra

Reply all

Inbox

DALHOUSIE UNIVERSITY
Research Services

Health Sciences Research Ethics Board
Letter of Approval

February 08, 2017

Jillian Pamela Boyd
Health Professions\Occupational Therapy

Dear Jillian Pamela,

REB #: 2017-4080
Project Title: A pilot cross-cultural validation study, focusing on the face validity, internal consistency and applicability of the German version of the Participation and Environment Measure: Child and Youth in Switzerland

Effective Date: February 08, 2017
Expiry Date: February 08, 2018

The Health Sciences Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans.* This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.

Sincerely,

Appendix N: Qualitative evidence from cognitive interview data

Theme	Area of Equivalence	Evidence from the data (English translation)
Core constructs	Conceptual Face validity	Construct: "Teilnehmen" (participation) "mitmachen" : 4/5 Parents used this synonym "gleich als Partizipation" (the same as Participation) "Participation" Construct: "Beteiligung" (involvement) "kommunikation ist Beteiligung" (communication is involvement) "involviert": 3/5 Parents used this synonym "Messung der Stärke" (measure of intensity) "aktiver Mitmache" (active participation)
Word choice for questions	Semantics Face Validity	<u>Participation section, Part B (Involvement)</u> 3/5 Parents reported difficulty with the word "Beteilligung" (involvement): "schwierig einzukreuzen" (difficult to cross off) "Ich musste mehrmals durchlesen" (I had to read it through multiple times) "ich brauchte mehr Zeit… es ist viel geschrieben und einfacher A zu antworten als B" (I needed more time, there is a lot written and easier to answer A than B)

		"habe ich manchmal überfordert zu denken" (I was sometimes overextended in my thinking)
		"generell schwierig wie beteilligt ist das Kind", (how involved is the child, is generally difficult (to judge)
		Beteilligen ist "nicht ein Wort das man in der Schweiz wirklich viel braucht" (*Beteiligen* is not a word that is often used in Switzerland)
		"A musste ich korrigieren, aber bei B und C bin ich sehr klar" (I had to correct my answers for A, but B and C were clear)
		"ich habe es nicht sofort verstanden, aber sofort verstanden von den Ganzen (mit Beispiele)", aber,"Das Ergebnis es verändert nicht dieser Wort (Beteilligung)". Allgemein, "die Fragebogen ist sehr verständlich" (I did not immediately understand, but with the examples I understood. the outcome is not changed depending on the word *Beteiligung*)
Word choice for items	Descriptive Items	Dialect differences identified: "*Hausübung*" (homework) "*Jause*" (snack)
	Semantics	Unclear meanings: "*Services*" (Environment section)
	Face Validity	Participants (3/5) reported the labeling (subtitle) of Neighbourhood Outings and Physical Activities were complicated and confusing:
		Item *#1 "Nachbarschaftsausflüge"* (Neighborhood outings)
		Item #3 "Organisierte Körperliche Aktivitäten"(Organised physical activities)

		Item #4 "Unstruktuierte Köreperliche Aktivitäten" (Unstructured physical activities) Item #*10 Ûbernachtungsbesuche oder Ausflüge* (Overnight visits or trips) *Ausflüge* can be associated with a day trip and here the focus seems to be on overnight.
Cultural applicability of items	Descriptive Items Face Validity	<u>Community participation items</u>: Parents reported high confidence in their answers. One parent reported strong opposition to the relevance and appropriateness of question #7 within the context of this questionnaire. Item *#7 Religiöse oder spirituelle Zusammenkünfte und Aktivitäten* (Religious or spiritual gatherings and activities) <u>School participation items:</u> Participants were least confident in their ability to answer this section due to a lack of information or only very limited, second-hand information: "das könnte ich eher lehr ausfüllen" (that I could fill out blank) , "ich gar nicht weiss wie mein Kind in Kindergarten ist" (I have no idea how my child is in Kindergarten) "die erleben die Eltern schließlich nur am Besuchstagen" (Parents experience school only on school open days) "die Lehrer erzählt oder ich habe gehört (von Kind/Schulpersonal)" (the teacher tells or I have heard from the school staff) "Die Eltern sind nicht in der Schule… es hängt einfach ab wie oft sie mit dem Betreuungsperson oder Klassenlehrperson Besprechungen haben, wie diese Gespräche laufen.. ist nur eine ungefähre wissen" (The parents are not in

		the school. It depends on how often parents meet with the school staff/ teachers for a conference and how the conference goes)
		"I would be fairly certain because of the feedback we get from the teacher …and I know him well enough in terms of his abilities"
		Item *#3 Von der Schule geförderte Teams, Clubs, Organisations* (School-sponsored teams, clubs and organisations)
		It is very seldom that school offers extracurricular sport activities or clubs. These are typically organised by community groups.
		"das gibt es nicht im gleichen Maß" (that does not exist in the same way)
		"in Switzerland there is no book club, no sport teams, no school council in the same way as it is in America"
		<u>Home participation items</u>:
		Participants (5/5) reported all items appropriate and inclusive
		Participants (5/5) reported high confidence in their answers
Usefulness and applicability	Applicability	"Man merkt dann auch wo ist er selbständig und wo noch nicht" (one realizes than as well where the child is or is not independent)
		"1.5 Stunde" zum ausfüllen gebraucht, "einmal pro Jahr" ware in Ordnung (1.5 hours to fill in the questionnaire, once a year would be o.k.)
		"40 Minuten zum ausfüllen" (40 minutes to fill in)
		"wäre schon einfacher wann es einfacher gestellt ist" (it would be easier if the questionnaire was structured simpler)
		"Mühsam war es nicht. Für mich,.."schaue wo es steht heute und den Weg das wir gemacht haben" (it was not arduous. For me, it shows where the child is today and the journey we made)

		"schon ein Bisschien geholfen… eine Zusammenerfassung für mich…" und "das es sollte nicht so bleiben" (certainly a little helpful. A summary for me. And that it (participation) should not remain the way it is)
		Helpful to show current participation profile of child for comparison with past and encourage change for future
Encouraged change	Applicability	Parents reported reflecting on what changes could be made to improve their childs' participation
		"um dass es Man mehr wünscht wie es sein sollte oder könnte mit dem Beteiligung" (so that one can wish for more, how it should or could be with involvement)
		"It brought up a lot of considerations…. How does my child spend his life? What is enriching for him, what is not enriching?"
		"ich habe das Gefühl… dass ich etwas machen soll, in irgendeine Richtung so dass er (das Kind) mehr sport macht" (I had the feeling that I should do something in one direction or another, so that he (my child) did more sports)
Usefulness for parent-therapist	Applicability	Parents reported (5/5) that the GPEM-CY could support communication between parent and therapist, particularly for efficiency of communication about their child's participation, and therapy goal setting.
		The basic structure of the questionnaire could be useful, but the fine details need to be addressed in order for parents to understand the questions.

Appendix O: Percent and Frequency of Response Indicating "Desire for Change" In Participation

Participation and Environment Measure for Children (GPEM-CY) (Part C) (Coster et al., 2014)

The reader should be aware that respondents were asked to respond to all appropriate answers. Individual respondents may have indicated that both or either a change in frequency and involvement is desired. Missing values were calculated in two sections: 'No change desired' and 'change in frequency of participation'; and desire for change in level or type of involvement.

	HOME	No change desired		Desire for change: in frequency of child's participation		Missing Values (frequency and "no change desired")		Desire for change: in child's involvement		Missing Values (involvement)	
	Total n=19	% and n		% and n		% and n		% and n		% and n	
1	Computer and video games	53	n=10	26	n=5	21	n=4	5	n=1	95	n=18
2	Indoor play and games	53	n=10	26	n=5	21	n=4	26	n=5	74	n=14
3	Arts, crafts, music and hobbies	53	n=10	37	n=7	10.5	n=2	26	n=5	74	n=14
4	Watching TV, videos and DVD	53	n=10	26	n=5	21	n=4	5	n=1	95	n=18
5	Getting together with other people	58	n=11	26	n=5	16	n=3	26	n=5	74	n=14
6	Socializing using technology	53	n=10	26	n=5	21	n=4	16	n=3	84	n=16

7	Household chores	21	n=4	68	n=13	10.5	n=2	32 n=6	68 n=13
8	Personal care management	37	n=7	16	n=3	47.4	n=9	37 n=7	63 n=12
9	School preparation (not homework)	31	n=6	42	n=8	26.3	n=5	42 n=8	58 n=11
10	Homework	16	n=3	21	n=4	63	n=12	58 n=11	42 n=8

	SCHOOL	No change desired	Desire for change: in frequency of child's participation	Missing Values (frequency and "no change desired")	Desire for change: in child's involvement	Missing Values (involvement)
	Total n=19	% and n	% and n	% and n	% and n	% and n
1	Classroom activities	16 n=3	37 n=7	63 n=12	42 n=8	47 n=11
2	Field trips and school events	53 n= 10	0 n=0	47 n=9	18 n=3	84 n=16
3	School-sponsored teams, clubs and organizations	53 n=10	10.5 n=2	37 n=7	16 n=3	84 n=16
4	Getting together with peers outside of class	53 n=10	10.5 n=2	37 n=7	16 n=3	84 n=16
5	Special roles at school	68 n=13	0 n=0	32 n=6	5 n=1	95 n=18

	COMMUNITY	No change desired	Desire for change: in frequency of child's participation	Missing Values (frequency and "no change desired")	Desire for change: in child's involvement	Missing Values (involvement)
	Total n=19	% and n	% and n	% and n	% and n	% and n
1	Neighborhood outings	74 n=14	16 n=3	10.5 n=2	5 n=1	95 n=18
2	Community events	58 n=11	16 n=3	26 n=5	10.5 n=2	89.5 n=17
3	Organized physical activities	47 n=9	26 n=5	26 n=5	16 n=3	84 n=16
4	Unstructured physical activities	56 n=11	16 n=3	26 n=5	16 n=3	84 n=16
5	Classes and lessons (not school sponsored)	53 n=10	21 n=4	26 n=5	16 n=3	84 n=16
6	Organizations, groups, clubs, and volunteer or leadership activities	56 n=11	16 n=3	26 n=3	10.5 n=2	89.5 n=17
7	Religious or spiritual gatherings and activities	47 n=9	10.5 n=2	42 n=8	21 n=4	79 n=15
8	Getting together with other children	37 n=7	37 n=7	26 n=5	10.5 n=2	89.5 n=17
9	Working for pay	63 n=12	10.5 n=2	26 n=5	10.5 n=2	89.5 n=17
10	Overnight visits or trips	63 n=12	16 n=3	21 n=4	5 n=1	95 n=18

Appendix P: Missing Values GPEM-CY, Participation Frequency

Participation and Environment Measure for Child and Youth (GPEM-CY) (Part A) (Coster et al., 2014)

Missing values indicate when respondents left a response box empty.

	HOME, Participation Items N=19	Participation Frequency: Missing values
1	Computer and video games	0
2	Indoor play and games	1
3	Arts, crafts, music and hobbies	0
4	Watching TV, videos and DVD	0
5	Getting together with other people	0
6	Socializing using technology	0
7	Household chores	0
8	Personal care management	0
9	School preparation (not homework)	0
10	Homework	1

	COMMUNICATION, Participation N=19	Participation Frequency: Missing values
1	Neighborhood outings	1
2	Community events	1
3	Organized physical activities	1
4	Unstructured physical activities	1
5	Classes and lessons (not school sponsored)	1
6	Organizations, groups, clubs, and volunteer or leadership activities	1
7	Religious or spiritual gatherings and activities	1
8	Getting together with other children	2
9	Working for pay	1
10	Overnight visits or trips	1

	SCHOOL: Participation N=19	Participation Frequency: Missing values
1	Classroom activities	3
2	Field trips and school events	3
3	School-sponsored teams, clubs and organizations	3
4	Getting together with peers outside of class	2
5	Special roles at school	3