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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Epidemiology and Biostatistics

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ASSESSING THE STRUCTURAL VALIDITY OF THE MEASURE OF PROCESSES
OF CARE (MPOC-20) IN CHILDREN WITH EPILEPSY

(Thesis format: Monograph)

by

Kariym Christopher Joachim

Graduate Program in Epidemiology and Biostatistics

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science

The School of Graduate and Postdoctoral Studies
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Abstract

The goal of this thesis was to determine whether the 20-item Measure of Processes of Care (MPOC-20) questionnaire remains structurally/factorially valid among children with epilepsy, and to propose adaptations if it did not. Establishing the MPOC-20's structural validity in this population makes it possible to draw conclusions on the potential effects of parent-perceived Family-Centred Care (FCC) on health outcomes within this population. Data came from the Health-related Quality of Life for Children with Epilepsy Study (HERQULES). Confirmatory Factor Analysis (CFA) indicated that the original five factor model fit poorly in children with epilepsy. An exploratory analysis within a CFA framework identified a two factor model with 16 indicators with a 'good' fit. This revised factor structure may better reflect the treatment experiences of children with epilepsy and their families. Further research is needed to verify these results in another sample.

Keywords

child, paediatric epilepsy, family-centred care, family-centered care, measure of processes of care, MPOC-20, longitudinal study, confirmatory factor analysis, modification indices

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List of Abbreviations

AED	Anti-Epileptic Drug
CFA	Confirmatory Factor Analysis
CFI	Bentler's Comparative Fit Index
C.I.	Confidence Interval
CoC	Components of Care
EFA	Exploratory Factor Analysis
FCC	Family-Centred Care
HERQULES	Health-Related Quality of Life in Children with Epilepsy Study
HRQL	Health-Related Quality of Life
ILAE	International League Against Epilepsy
MD	Mahalanobis Distance
MI	Modification Index
MPOC	Measure of Processes of Care
NS-CSHCN	U.S. National Survey of Children with Special Health Care Needs
RMSEA	Root Mean Square Error of Approximation
SAS	Statistical Analysis Software
SD	Standard Deviation
SMC	Squared Multiple Correlation
SRMR	Standardised Root Mean Square Residual
TDM	Tailored Design Method

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Chapter 1 – Introduction

Family-centred care (FCC) is a clinical approach to the treatment of patients (usually children), within the context of the family. Espoused by healthcare professionals and institutions, it also encourages the planning, delivery, and evaluation of healthcare that considers the patient and family as both recipients of care and collaborative partners (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012; Shields et al., 2012). It is particularly relevant for paediatric patients, as they need their parents to advocate for them and provide a context of their lives to care providers.

The benefits of FCC are many, extending across several levels – from an entire healthcare system to care providers, family members, and individual patients. At the system-level, FCC is linked to greater cost-effectiveness, lower health service utilization, and higher staff satisfaction, potentially leading to less staff turnover and improved performance (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012). For family members, FCC has been shown to affect parental well-being, knowledge, and feelings of competency and efficacy (S. King, Teplicky, King, & Rosenbaum, 2004). Among children, FCC has been linked to less anxiety, better coping, decreased length of hospitalization, improved recovery from surgery and better patient safety (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012).

Given that one of the goals of FCC is to maximise quality of life (Stein, 1998), it is conceivable that FCC can improve the health-related quality of life (HRQL) for children

with epilepsy – a goal that is shared by care providers in the management of seizures (Wiebe, Matijevic, Eliasziw, & Derry, 2002). Children with epilepsy face not only the symptoms of the condition and its treatments, but also the side effects of those treatments. They may also confront stigmatisation, isolation, and restriction of activities; while their family members face many emotional, financial and social stressors (Austin, Shafer, & Deering, 2002; Ellis, Upton, & Thompson, 2000; Fisher et al., 2005; Hobbs, 1985). Hence, further investigation into the potential relationship between FCC and the HRQL of children with epilepsy is warranted. To do so however, a valid and reliable instrument that can measure FCC across various paediatric conditions is needed. This thesis focuses on one of the most widely used measures of FCC, the Measure of Processes of Care (MPOC), and assesses how well it performs within a sample of children living with epilepsy.

Initially developed for use in children with neurodevelopmental disabilities, this instrument ascertains, from a parent's perspective, the degree to which his/her child's care, within the past year, was family-centred. Treatment for children with epilepsy, however, differs from that of children with other illnesses and disabilities where the tool was initially validated. This has implications for the MPOC, because its validity and reliability are dependent on the characteristics of the population where it is being used. Because of this, the MPOC cannot be used to draw inferences about a new population where it has not been validated. It is recommended that whenever a tool is applied to a new setting or a different group of people, that its psychometric properties are re-assessed and re-established (Rosenbaum et al., 1990; Streiner & Norman, 2008).

To date, there has been some initial evaluation of the MPOC's reliability and validity in children with epilepsy, using data from the Health-Related Quality of Life for Children with Epilepsy Study (HERQULES) (Hunter, 2007). Though the tool performed well in several respects, its structural/factorial validity – how well the hypothesised constructs are being tapped by a tool (Streiner & Norman, 2008) – needed further assessment. This thesis contributes to this research by further investigating whether the MPOC reflects the experiences of children with epilepsy and their families, and whether it needs to be adapted to reflect differences in care.

1.1 Research Objectives

The objectives of this thesis are to:

1. Test whether the original five-domain structure of the MPOC-20 is observed in a sample of children with epilepsy.
2. If necessary, propose adaptations to improve the utility of the MPOC-20 in this population.

Chapter 2 – Background

2 Chapter Overview

This chapter provides a background on family-centred care (FCC) and presents evidence of its effects in children with chronic illness (Section 2.1). Also provided is an overview of epilepsy and its impact on the health-related quality of life of children (Section 2.2).

2.1 The Concept of Family-Centred Care

The American Academy of Paediatrics defines patient- and family-centred care as:

“... an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient’s life. When patient- and family-centered care is practiced it shapes health care policies, programs, facility design, evaluation of health care, and day-to-day interactions among patients, families, physicians, and other health care professionals.”

(Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012)

This clinical approach recognises that paediatric patients are not only unique children with specific healthcare needs, but also unique individuals who live within a larger social context, in need of emotional, social, and developmental support (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012). Chronic illness introduces a confluence of negative impacts which can, in turn, adversely affect the quality of life of the child and family. Potential areas of impact include the psychosocial status of the child and the ability of the family to function as effectively as it did before diagnosis (Franck & Callery, 2004). The biomedical approach, on the other hand, focuses exclusively on treating only the biological mechanisms that lead to disease – negating the psychosocial aspects of illness altogether (Bury, 2005).

To address these psychosocial issues, patient- and family-centred care places an emphasis on the 'interpersonal' processes of care delivery – where the development of a communicative rapport between care providers and patients is instrumental. This rapport improves the exchange of information, thereby fostering healthy, collaborative relationships (Donabedian, 1997). Relative to a solely patient-centred approach, FCC broadens its purview to include the interpersonal relationships of the family alongside that of the patient and care providers – in essence, making family members recipients of care themselves (O'Neil, Palisano, & Westcott, 2001; Shields, Pratt, & Hunter, 2006).

Thus, care is planned around the entire family. Care providers acknowledge the vital roles that family members fulfill in a child's life, and the value of involving them throughout the treatment process (Institute for Patient- and Family-Centered Care, 2010). As partners in care, family members can help to plan care while receiving support themselves (Centre for Addiction and Mental Health (CAMH), 2004; Espe-Sherwindt, 2008; Shields et al., 2006). Care providers become partners, listeners, facilitators, and consultants – demonstrating a respect for parental knowledge and an awareness of the impact of a chronic illness on quality of life (Espe-Sherwindt, 2008).

Family-centred care has seen widespread acceptance and support from numerous medical societies, healthcare institutions, and legislative bodies (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012; Kuo et al., 2012). It has been promoted in numerous treatment environments and treatment populations, producing numerous unique variants of FCC in response to the needs and challenges of

specific settings. Essentially, this means that FCC has become a fragmented, misunderstood, 'amorphous' concept with little consensus on its meaning (Campbell & Summersgill, 1993; Corlett & Twycross, 2006; Darbyshire, 1993; Franck & Callery, 2004; Hutchfield, 1999; S. King, Teplicky, et al., 2004; Kuo et al., 2012; Kuo, Bird, & Tilford, 2011; MacKean, Thurston, & Scott, 2005). There is a lack of agreement on a definition of FCC that could be applied in all treatment settings and conditions.

There is, however, some agreement on the principles of FCC (Kuo et al., 2012). Thus, to foster a clearer understanding of FCC, this section suggests several common elements of FCC, compiled through a review and synthesis of the literature, that appear to form the basis of most conceptual definitions (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012; S. King, Teplicky, et al., 2004; Kuo et al., 2012; Shelton & Stepanek, 1994). These elements are: i) Recognition that the family is a constant in the child's life, ii) Partnership and Collaboration, iii) Complete and Unbiased Information Exchange, iv) Respect, Awareness and Support, and v) Comprehensive, Coordinated and Continuous Care.

i) Recognition that the Family is a Constant in the Child's Life. A major assumption of FCC is that the family is both the anchor and primary source of a child's support and strength (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012). This contrasts heavily with the more transitory nature of medicine, where the attending care providers, and the healthcare system itself may fluctuate and change over time (Dempsey & Keen, 2008; S. King, Teplicky, et al., 2004; MacKean et al., 2005; Shelton &

Stepanek, 1994). Families and patients are to be treated as whole persons rather than simple consumers of services and supports (Shelton & Stepanek, 1994).

ii) Partnership and Collaboration. High-level family involvement and shared decision-making are thought to involve the strengths, values, and abilities of each stakeholder. This element is the foundation of FCC, as it brings families and care providers together as collaborative teams. Within these teams, decisions are made in the best interests of the child and family. This can happen at the individual patient level and at the systems and policy levels (S. King, Teplicky, et al., 2004; Kuo et al., 2012; Maternal and Child Health Bureau, 2005).

At the individual level, care is provided through collaborative decision-making. Care providers are technical experts on a condition and its treatments, and families are experts on their child (Rosenbaum, King, Law, King, & Evans, 1998). The nature of interaction is reciprocal, care plans are constructed jointly, and the ownership of all outcomes is shared (Betz, 2006; Kuo et al., 2012).

For children with chronic illness, this team dynamic is important, because the role of advocate and expert is often held by their parents (MacKean et al., 2005). This relationship mandates the building up of parental competencies and the support of family functioning. When parents are empowered, they feel more in control, more competent, and more self-efficacious (Judge, 1997). Child development is also a key part of this partnership – it is hoped that as the child matures, they will also enter the partnership (Judge, 1997; Maternal and Child Health Bureau, 2005).

It is important, however, that the role of team player does not overextend already stressed families. They must be allowed to define how much or how little of a role they wish to play in the decision-making process (Corlett & Twycross, 2006; Institute for Patient- and Family-Centered Care, 2010; Kuo et al., 2012).

At the systems/policy level, FCC is demonstrated through family presence in initiatives such as professional education, policy-making, and program development (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012; Shaller, 2007). More specific examples include; involvement of the family and/or child in the design or development of facilities, the existence of family advisory groups, family presentations on care experiences at Grand Rounds, and the hiring of experienced family members as consultants (Kuo et al., 2012; Shields et al., 2012). Essentially, the idea is to ensure that collaboration exists at all levels of care – from community to hospital care, from individual to systems or policy levels, and from program development to evaluation (Shelton & Stepanek, 1994).

iii) Information Sharing. This element refers to the fluid movement of information among care providers and families (S. King, Rosenbaum, & King, 1995; Kuo et al., 2012). Communication is open, objective, and unbiased, and information is accessible, affirming, and useful (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012; Kuo et al., 2012; Shaller, 2007). Relevant behaviours include; an openness for discussion and negotiation, receptivity to parent input, and the ability to facilitate the exchange of information (Bishop, Woll, & Arango, 1993).

Examples of information sharing activities include parental presence at daily interdisciplinary ward rounds, easily accessible medical records and collaborative child/care provider documentation of health issues and progress (Kuo et al., 2012; Shields et al., 2012)

iv) Respect, Awareness and Support. Key to the delivery of FCC is the development of mutual respect among care providers and family members (S. King et al., 1995). Here, family skills and expertise are recognised and appreciated, thereby restoring the dignity and control that had been lost as a result of a diagnosis. Care providers must also respect family perspectives, preferences, and choices (Institute for Patient- and Family-Centered Care, 2010; Kuo et al., 2012; Shaller, 2007). This element enables the creation of productive relationships, enhances information exchange, and ultimately facilitates the child's medical care in ways that would not be possible if an adversarial relationship had existed (Sunde, Mabe, & Josephson, 1993).

Care providers must also be aware that children and their families are diverse in many ways, including, but not limited to; race, education, linguistics, ethnicity, culture, geography, spirituality, and social interaction (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012; Garwick, Kohrman C, Wolman C, & Blum RW, 1998; Kuo et al., 2012; MacKean et al., 2005). Also important is awareness of the coping methods of each family, and their developmental, socioeconomic, emotional, and environmental needs (Shelton & Stepanek, 1994). Sources of strain on the family should also be recognised. Examples of such strain include the burdens faced by single-

parent families and restrictions placed on families by limited financial resources (R. T. Brown, 2008; Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012). Each of these familial attributes provides a context for their care choices, and colours the experiences and perceptions of provided care (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012; Institute for Patient- and Family-Centered Care, 2010; Kuo et al., 2012; Shaller, 2007).

It is not sufficient to simply recognize the family's diverse contexts and needs – support and accommodation is also necessary. Children and their families must receive treatment in an environment where family functioning is normalised – thereby reducing the impact of chronic illness (Franck & Callery, 2004; Shields et al., 2012). Thus, through the provision of both formal and informal support, families are able to mobilize further support, information and resources (Committee on Hospital Care & Institute for Patient- and Family-Centered Care, 2012; Kuo et al., 2012; MacKean et al., 2005; Webster, Johnson, & Institute for Family-Centered Care, 1999).

The practice of respectful, aware, and supportive care involves: the use of respectful language by care providers, the provision of interpreters, open visiting hours for siblings and extended family, parent-to-parent networking, payment plans where services are not covered by universal healthcare, the employment of chaplains, social workers, and patient representatives, and care provider training in culture awareness, cultural sensitivity, and cultural competency (Kuo et al., 2012; Maternal and Child Health Bureau, 2005; Purnell, 2012; Shields et al., 2012).

v) Comprehensive, Coordinated and Continuous Care. This is best described as the degree to which care is 'holistic, continuous, and consistent over time, settings, and people' (S. King et al., 1995). It encompasses child-specific and interdisciplinary care – key features in the treatment of children with chronic illness (Miller, Recsky, & Armstrong, 2004). It also encompasses the ideal of coordinated care, whether with respect to transitioning between care providers, between entire systems, or leaving the system altogether (Garwick et al., 1998; MacKean et al., 2005). Finally, it also recognises the need for continuity in care. Because children and their families have lives outside of the hospital or clinic, they require quality care and support at the home and community level.

By providing such services, parents no longer have to navigate the healthcare system or coordinate care on their own (Garwick et al., 1998; Lindeke, Leonard, Presler, & Garwick, 2002). Overall, this element represents FCC's ability to respond to unique circumstances of the child and family with flexible and competent support rather than a single-solution-fits-all approach (Shields et al., 2012). Care plans are no longer absolute and rigid, but flexible – all members of the team are ready and willing to negotiate (Kuo et al., 2012; Maternal and Child Health Bureau, 2005).

To provide this kind of care is to ensure proper assessment, planning, implementation, evaluation, monitoring, support, education, and advocacy at all levels of healthcare practice (Lindeke et al., 2002). The availability of Care Coordinators is also beneficial to the care process, whether they are part of the healthcare system, the community, or a

third party (Lindeke et al., 2002). Other ways of improving the continuity of care include; the networking and collaboration of care providers with community resources and partners, using health information technologies to facilitate care coordination and the exchange of information, continual assessment of child and family needs, and producing clearly stated, written goals for the patient, family, healthcare team(s), and system to follow (Turchi et al., 2014).

2.1.1 The Benefits of Family-Centred Care on Child Health Outcomes

The intention of FCC is to have a substantial impact on all stakeholders in the treatment process. Of particular interest, however, is the explicit effect of FCC on child health outcomes. An extensive literature search (see Appendix A for details on the search process used) yielded only five papers that used quantitative methodologies to report the impact of FCC on child outcomes.

Two of these papers (Kuo et al., 2011; Stevens, Pickering, & Laqui, 2010) performed secondary analyses on data from the U.S. National Survey of Children with Special Health Care Needs (NS-CSHCN). Both studies reassembled five questions from the survey as a summary measure which was thought to encompass FCC as a construct. The questions asked whether care providers: spent enough time with the child; listened carefully to family members; demonstrated sensitivity to family values and customs; provided specific information on their child's condition and care; and made the family feel like partners in care (CDC/National Center for Health Statistics, 2013). Four of the five elements of FCC described above are represented in this summary measure, but

‘Comprehensive, Coordinated and Continuous Care’ is not. By encompassing the majority of its principles, this measure appears to be a reasonable indicator for whether FCC has been delivered or not.

In the Stevens et al. (2010) paper, the authors examined whether the existence of a ‘medical home’ would affect school engagement and after-school participation among children with asthma. Medical homes are central locations for patients and families to receive necessary services in a manner that is accessible, coordinated, comprehensive, family-centred, culturally competent, continuous, and compassionate (Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2002). Using data from the 2005-2006 NS-CSHCN survey, 6357 children ages 6-17 with asthma were identified. The 5-item summary measure was subsequently adopted to measure FCC as one of the features of a medical home. Using this measure, FCC was associated with: i) more days where the child with asthma exercised in school; ii) an increased likelihood of involvement in sports; and iii) a lesser chance of parents being contacted by the school about issues their child was having.

Kuo et. al (2011) also used data from the 2005-2006 NS-CSHCN survey but focused on 38,915 children, aged 0 to 18 with any of various chronic illnesses as opposed to children with clinically-diagnosed asthma. FCC was treated as a dichotomous variable – individuals who ‘usually’ or ‘always’ received the behaviours described in the question were designated as having received FCC. Families that reported a consistent need for interpreters and received this service were also counted as having received FCC

regardless of their score on the index. While clinical adaptability and a commitment to information exchange are important features of FCC, the provision of an interpreter does not guarantee that FCC is being practiced. This raises questions about using the provision of an interpreter as a stand-alone indicator of FCC. In all, FCC was associated with the stabilisation of the chronic condition, reduced odds of emergency room visits, and fewer difficulties related to child health. Contrary to the results of Stevens et al. (2010), FCC was not found to be associated with the number of missed school days. In general, however, health services utilisation declined when FCC was practiced; again suggesting that FCC may have a direct effect on child health outcomes.

The remaining three studies each used the 20-item Measure of Processes of Care (MPOC-20) as a validated measure of FCC. McKean et al. (2012) conducted a randomized controlled trial to determine whether FCC would affect treatment goal attainment and impact speech-language testing scores. Ten children with speech sound and/or language disorders received a family-centred speech-language therapy program, while another ten children received the 'usual practice' program. Though MPOC scores were relatively high, there were no significant differences in scores for the two groups of children. Both treatment groups also saw a similar degree of goal attainment and speech-language improvements compared to scores collected before therapy was administered.

Palisano et al. (2011) created a model to identify and explain the determinants of participation in leisure and recreational activities by children with cerebral palsy. They

hypothesised that features of service delivery (including the delivery of FCC) would mediate the effect of child characteristics and family characteristics on participation. To test this model, a questionnaire including the MPOC-20 was given to parents of 288 children ages 6-12 with cerebral palsy. Though much of the variation in the intensity of participation was explained by the model (32%), the pathway between service delivery and participation was not found to be significant. Therefore, in these children with cerebral palsy, FCC did not have an effect on childhood participation in leisure and recreational activity.

The final paper to discuss FCC's effects on child health outcomes is that of Moore, Mah, & Trute, (2009). They investigated the potential association between FCC and health related quality of life (HRQL) in a cross-sectional study of 187 children with various neurological disorders, including epilepsy. One of the first steps in their study was to assess the MPOC-20's use in their sample. The MPOC-20 assesses FCC using five domains, or underlying constructs of FCC as described by the originators of the MPOC. Each domain corresponds to a score, thereby creating five subscale scores with no overall summary score (S. King, King, & Rosenbaum, 2004). Previous research had suggested that only two domains, and thus, two subscale scores were necessary to measure the family-centred caregiving. Thus, to identify the number of MPOC-20 domains in their sample, the authors performed a principal axis factor analysis, with a goal of identifying a potentially smaller number of domains. The conclusion was that only one domain was needed to evaluate the extent of family-centredness in a paediatric neurology clinic.

Together, severity of illness and FCC jointly explained 32% of the variance in children's total HRQL. When controlling for the severity of illness, FCC explained the variation in HRQL scores – specifically 7% of the variation in physical summary score, 13% of the psychosocial summary score, and 17% of the summary HRQL score. .

Overall, the small number of studies captured by this literature review suggested that relatively little known is about the quantitatively measured effects of FCC on child health outcomes. These studies also presented mixed results on whether FCC has an effect on those outcomes. Altogether, this means that more work is needed to determine whether FCC is useful as a clinical approach, and to identify health outcomes where FCC leaves a meaningful impact.

This thesis, as with Moore et. al (2009), focuses on HRQL as a health outcome for children. In this study, FCC was found to impact the HRQL of children with neurological disorders, including children with intractable epilepsy. Of note, however, is the fact that only a minority of the sample in this study was composed of children with epilepsy (31%). The majority of the sample was composed of children with a variety of different neurological conditions, each of them with unique symptoms and treatment regimens. In addition, the entire subsample with epilepsy had intractable epilepsy – individuals where seizures could not be controlled through standard treatments. Thus, the results of this study may not be generalizable to the majority of children with epilepsy whose seizures are controlled.

Therefore, more work is needed to characterise the effects of FCC on the HRQL of children living with epilepsy in general. A valid and reliable measurement tool, however, needs to be chosen for such a project. The MPOC-20 is a suitable choice, but its appropriateness of use in children with epilepsy needs to be determined by the re-assessing its validity.

The process of testing and re-establishing the MPOC-20's psychometric properties in children with epilepsy requires a contextual understanding of the needs and experiences that come with the condition. Thus, the next section (2.3) describes epilepsy as an illness and details the impact of the condition on children and their families.

2.2 Overview of Paediatric Epilepsy

2.2.1 Prevalence and Incidence of Epilepsy

Epilepsy can occur in anyone regardless of age, sex, race, social class, or geographic location. It is the most common neurological disorder worldwide (World Health Organization, 2005). In Canada, about 6 per 1000 residents has epilepsy, with 15,500 people of all ages being diagnosed each year (Epilepsy Canada, 2005a; Kotsopoulos, van Merode, Kessels, de Krom, & Knottnerus, 2002; Reid et al., 2012). Using data from the Canadian Community Health Survey and the National Health Survey, it was estimated that the prevalence of epilepsy in children 0 to 11 years old in Canada is 2.5 per 1000, and for children 12 to 14 years of age, 4.4 per 1000 (Tellez-Zenteno, Pondal-Sordo, Matijevic, & Wiebe, 2004; Wheless, Clarke, McGregor, Pearl, & Ng, 2012). Boys are more

likely to have epilepsy than girls, and the prevalence of epilepsy was found to increase with child age (Prasad, Sang, Corbett, & Burneo, 2011). According to Epilepsy Canada, over 8500 children in Canada learn they have epilepsy each year (Epilepsy Canada, 2005b).

2.2.2 Overview of the Clinical Features of Epilepsy

Epileptic seizures are the 'transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain' (Fisher et al., 2005).

The classification system for seizures and epilepsy syndromes was recently revised and updated by the International League Against Epilepsy (ILAE). All terms and descriptions used here have been taken from the most up-to-date revisions proposed by the organization. This new classification system replaces the accepted designations that were established in 1981 by the ILAE (Berg et al., 2010).

Seizures are grouped into 2 major classes by mode of onset – 'generalized seizures' and 'focal seizures' (Berg et al., 2010). Generalised seizures originate at a single point within the brain before quickly expanding to engage both hemispheres. Two of the most recognisable seizures in this class are tonic-clonic and absence. Focal seizures originate in a single part of the brain, and are limited to the one hemisphere. These seizures often produce localised, sensory and/or motor disruptions. Seizures that have not been clearly diagnosed by mode of onset are classified as 'Unknown' – pending future clarification which would allow physicians to classify the seizures as generalized or focal (Berg et al., 2010).

Epilepsy is the disease that presents an 'enduring predisposition' to these individual seizure episodes (Fisher et al., 2005, 2014). Epileptic syndromes are categorised by their etiology. 'Genetic' epilepsy occurs when seizures are the core symptom of a syndrome and are the direct result of one or more known or presumed genetic defects.

Alternatively, 'Structural-Metabolic' epilepsy is caused by a structural or metabolic syndrome within the brain. Where the underlying cause of an epilepsy syndrome is not clear, it is described as having an 'unknown cause.' Continued efforts to clarify the syndrome's etiology will lead to its classification as either genetic or structural-metabolic in origin (Berg et al., 2010; Maguire, Marson, & Ramaratnam, 2012).

The risk factors for epilepsy in children include; head injury, perinatal injury, central nervous system infections, febrile convulsions, genetic factors and history of epilepsy in the family (Daoud, Batieha, Bashtawi, & El-Shanti, 2003; National Institutes of Health, 2012).

Treatment normally involves drug therapy with anticonvulsant drugs/antiepileptic drugs (AEDs), and produces benefits for 60-70% of patients with epilepsy. Many children will go into remission regardless of treatment (Lehne, 2012). AEDs often produce negative side effects ranging from skin, hepatic, cardiovascular, neurological, and psychiatric changes. Specific symptoms that accompany AEDs can include blistering skin rashes to gastric distress, headaches, aggressiveness, and cognitive or memory problems (Meador, 2011; Willmore, Pickens, & Pellock, 2011).

When a patient's epilepsy is considered intractable, other alternatives such as surgery may be considered. Some paediatric patients receive a cortical resection or hemispherectomy, with 58-78% becoming seizure-free afterwards (Spencer & Huh, 2008; Wyllie, 1998). Another alternative is vagus nerve stimulation, which decreases seizures by 50% in one-half of patients who received the treatment (Elliott et al., 2011). Another final option is the Ketogenic diet, where foods high in fat and ketone bodies become the main source of nutrition (Lefevre & Aronson, 2000). About 16% of patients on this diet attain complete seizure control, and 33% of patients achieve a 50% reduction in seizures (Keene, 2006). Despite significant advances in the treatment of epilepsy, however, approximately 30% of children never achieve full clinical remission (Geerts et al., 2010).

2.2.3 Health-Related Quality of Life for Children with Epilepsy

Health-related quality of life (HRQL) is a multi-dimensional construct that focuses on the 'functional effect' of an illness or injury as well as the consequences of medical treatments and healthcare policies on the patient. HRQL has four core domains: disease state and physical symptoms, physical and occupational functioning, psychological functioning and social functioning (Spieth & Harris, 1996; Spilker, Schipper, Clinch, & Olweny, 1996). A defining feature of HRQL is that it encompasses both objective and subjective elements of how a health condition and its treatment can affect an individual (Cummins, 2005).

Between 37% to 77% of children with epilepsy experience challenges in their psychological functioning (Plioplys, Dunn, & Caplan, 2007) and experience 2 or 3 other psychological conditions simultaneously (Høie et al., 2006). Among the most common psychiatric co-morbidities are depression, (Dunn, 1999; Ettinger et al., 1998), anxiety disorders and increased suicide ideation (Caplan et al., 2005). Poor attentiveness, attention deficit hyperactivity disorder (Dunn & Kronenberger, 2005), aggressive behaviour (Freilinger et al., 2006), oppositional defiant disorder and conduct disorder (Caplan et al., 1998) have also been identified in this population.

Cognitively, most children with epilepsy have average intelligence, though intellectual delays are associated with more severe (Fessler & Treiman, 2009) and earlier-onset cases (Sánchez-Carpintero & Neville, 2003). As a whole, however, children with epilepsy still face a higher risk of learning disabilities and subsequently reduced academic performance (Williams, 2003).

Social functioning is affected as well, especially with respect to social exclusion, overprotection, and isolation (Fisher et al., 2005). An example of the social context surrounding epilepsy is the fear and unfamiliarity of the condition expressed by teenagers without epilepsy. Surveys have identified fears of epilepsy being contagious, feelings of danger from teens with the condition, apprehension towards dating someone with the condition (Austin et al., 2002), and a fear of having to respond to a seizure episode (Robson, 2006). Because of this social environment, children with epilepsy may avoid peer interactions and social situations for fear of having a seizure or

they may be restricted in their activities by their parents and care providers (Carpay et al., 1997; Cheung & Wirrell, 2006). Taken together, these factors may explain why these children have poorer social skills, are less assertive than their siblings, and are deficient in their social competency (Räty, Larsson, & Söderfeldt, 2003; Tse, Hamiwka, Sherman, & Wirrell, 2007). There is evidence that some social deficits are long term. In a study following persons 35 years after the onset of childhood epilepsy, adults were: less likely to pursue higher education; less likely to drive; less likely to be married and have children; more likely to have a pregnancy outside of a stable relationship; more likely to live alone; and more likely to have limited career options (Camfield & Camfield, 2010; Jalava, Sillanpää, Camfield, & Camfield, 1997; Sillanpää, Jalava, Kaleva, & Shinnar, 1998; Wakamoto, Nagao, Hayashi, & Morimoto, 2000).

Children with epilepsy are often thought to be at higher risk of injury, leading to restrictions in their activities, and by extension, their physical or occupational functioning (Elliot, Lach, & Smith, 2005). While there are no official guidelines on the restriction of activities, children with epilepsy may be advised by care providers to avoid bathing, swimming, climbing, or riding a bicycle (Carpay et al., 1997). Parental overprotection may limit sporting activity and play even further, even if there are no clinical recommendations concerning these activities (Kokkonen, Kokkonen, Saukkonen, & Pennanen, 1997). Restrictions may persist into adulthood. For example, many young adults with epilepsy do not attain the ability to drive, thus limiting their ability to network with their peers, and presenting long-ranging impacts on their careers (Drazkowski & Sirven, 2005).

Studies assessing HRQL using standardised multidimensional measures have determined that the HRQL of children with epilepsy is considerably lower than those without epilepsy. This difference exists regardless of the presence of an intellectual disability or whether the condition is in remission or not (Austin, Huster, Dunn, & Risinger, 1996; Sabaz, Cairns, Lawson, Bleasel, & Bye, 2001). Children with epilepsy have a generally lower HRQL than children with asthma (Austin et al., 1996) and diabetes (Hoare, Mann, & Dunn, 2000). Potential predictors of HRQL over time include; seizure frequency, type of AEDs and the consequent side effects of AEDs (Modi, Ingerski, Rausch, & Glauser, 2011). In terms of the trajectory of HRQL, a 2-year prospective study found that the HRQL of children with epilepsy was lowest at diagnosis, and highest two years later – although remaining below that of healthy children on average. It was also found that about half of the children did not experience a clinically-important improvement in HRQL over the first two years after diagnosis (Speechley et al., 2012).

A diagnosis of epilepsy affects families in ways that may further impact the HRQL of children with epilepsy. For example, after diagnosis, family members may face feelings of fear, anger, guilt, sadness, and a loss of control, and be forced to readjust their expectations (Austin & McDermott, 1988; Ellis et al., 2000). They may worry that their child will be stigmatised because of their condition, and also become increasingly frustrated and anxious (Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Ryan & Steinmiller, 2004). In the longer term, some families of children with epilepsy are likely to face financial challenges, difficulties in navigating medical services, decreased family functioning, parental psychosocial difficulties, marital problems, social isolation, and

negative social stigma (Ellis et al., 2000; Hobbs, 1985). This ultimately alters the relationship between a child and his/her family, as is shown in cases where poor parent-child attachment, and parental over-protection become a new familial reality (Ellis et al., 2000; Sheeran, Marvin, & Pianta, 1997). Together, these impacts on the family can adversely affect the HRQL of children with epilepsy. A prime example of these effects is the relationship between maternal depression and poorer HRQL in children with epilepsy (Ferro, Avison, Campbell, & Speechley, 2011).

Thus, given the inherent challenges that come with an epilepsy diagnosis, it is reasonable to suggest that FCC might be especially helpful for this population and that it would likely be well received. FCC has the potential to alleviate the effects of epilepsy not only on the child's HRQL, but also its impact of epilepsy on the family. There is still a gap in the literature, however, as to how FCC can be used to explicitly moderate the impacts of epilepsy on the child and family. As well, in order to quantitatively measure these impacts, it is necessary to have an instrument that can accurately measure FCC available for use. To this end, the goal of this thesis is to ensure that the MPOC-20 is appropriate for use in children with epilepsy. In doing so, it becomes possible not only to characterise the impact of FCC on HRQL in this population, but to identify specific behaviours and initiatives that can produce better child and family outcomes.

Taken together, this chapter has provided an understanding of both FCC and the impacts of epilepsy at an individual and family level. With this contextual background in place, the next chapter will detail the steps taken to assess the MPOC-20.

Chapter 3 – Methodology

3 Chapter Overview

Section 3.1 provides an overview of the data source employed in this thesis. The second section (Section 3.2) introduces several tools that have been used to measure FCC, and then introduces the Measure of Processes of Care (MPOC) instrument. This overview of the MPOC briefly outlines its development process, highlights some of its features and properties, and discusses efforts to adapt the survey tool to various populations. The final section of this chapter (Section 3.3) describes the analytical steps taken to achieve the objectives of this thesis.

3.1 Data Source and Sampling Methods

This study utilised data from the Health Related Quality of Life in Children with Epilepsy Study (HERQULES). The aim of this Canada-wide prospective cohort study was to measure the health related quality of life (HRQL) of children with epilepsy for 2 years following their diagnosis. Data were collected from 2004 to 2007 through questionnaires completed by paediatric neurologists and parents of children with epilepsy. Ethics approval was gained from all relevant research ethics boards (Appendix B). Utilising a two-stage cluster sampling strategy, 72 paediatric neurologists treating children with of new-onset epilepsy were invited to participate – 53 of whom went on to identify 456 eligible children whose parents were then approached to participate. To be eligible, children had to be between 4 and 12 years of age during diagnosis; seen for the first time by the neurologist during the data collection period; and had to have a

parent or guardian who had been their primary caregiver for at least 6 months complete the questionnaire.

Children were excluded: if their diagnosis had been previously confirmed by another physician; if they had other progressive or degenerative neurological disorders; if they had any major non-neurological, co-morbid disorders; or if their parents did not have an adequate understanding of English to complete the questionnaires.

In addition to inviting parents to participate in the study, attending neurologists completed a 2-page form that detailed the clinical characteristics of the child's condition. Physician surveys included questions on: seizure frequency and types, type of epilepsy syndrome and severity, medication, the adverse side effects of any of those medications, and other significant co-morbid conditions (Appendix C).

After being approached by a neurologist, interested parents signed a release of information form that would permit HERQULES personnel to mail them a letter of information (Appendix D). Following receipt of this letter, a call from the study coordinator determined whether the parents were interested in participating, and answered any outstanding questions the family may have had.

To achieve high participation and retention rates, a modified version of the Tailored Design Method (TDM) was used. The TDM is a set of guidelines and procedures that produce high quality survey data (Dillman, Smyth, & Christian, 2008). Consistent with this methodology, a systematic set of follow-up procedures was put in place, and

efforts were taken to forge and maintain a relationship with each participating family. With each subsequent mail-out of the survey, participating families received an informative letter, a \$5 token of appreciation, and a stamped return envelope.

Parents were asked to complete a self-administered questionnaire, of which the MPOC-20 is a part (Appendix E), that took approximately 45-60 minutes to complete. The first questionnaire was mailed out as soon as possible following diagnosis (Time 1); the follow-up questionnaires were sent approximately 6 months following diagnosis (Time 2), approximately 12 months following diagnosis (Time 3), and approximately 24 months following diagnosis (Time 4). The questionnaire measured HRQL, family demands, family resources, family functioning, parental depression, parental perception of FCC, and a number of other socio-demographic characteristics.

To ensure that there had been an opportunity for the vital relationships central to FCC to be formed among stakeholders, it is recommended that the MPOC not be administered until at least 6 months after the first interaction among care providers and families (King, Rosenbaum, & King, 1995). Thus, questionnaires completed approximately 6 months after the child's diagnosis of epilepsy (Time 2) were used in the analyses (n=336). Time 2 was chosen over Time 3 (12 months after diagnosis, n=305) and Time 4 (24 months after diagnosis, n=283) so as to maximise sample size.

3.2 The Measurement of Family-Centred Care

3.2.1 Current Limitations in the Measurement of FCC

The majority of research on FCC is descriptive, with a significantly smaller proportion of the literature focusing on evaluating its implementation or its effectiveness (Franck & Callery, 2004). In general, research on FCC has been hindered by a lack of ‘true, validated measures and outcome measures’ (Kuo et al., 2012). Available tools to measure FCC tend to either: i) conceptualise FCC through one or more individual aspects or ii) conceptualise FCC as a holistic, multi-dimensional construct.

Studies that focus on FCC through its individual aspects may, for example, report on the features of a parent-professional relationship or the openness of communication among stakeholders. An example of a tool used in such research is the Family-Provider Interaction Analysis, which only assesses verbal behaviours among participants in care (Goetz, Gavin, & Lane, 2000). These survey tools are important in furthering knowledge on FCC – but information on individual aspects of FCC do not represent the ‘integrated approach’ to service delivery that is central to the concept (S. King, Teplicky, et al., 2004).

Compared to the number of tools that focus on specific aspects of FCC, measurement tools that assess FCC as a multidimensional construct are far less common. The MPOC falls within this group – as well as the aforementioned 5-item indices of FCC that were developed for the NS-CHCN surveys (Kuo et al., 2011; Stevens et al., 2010). Other multidimensional measurement tools are the Family-Centered Care Self-Assessment

Tools, which allow clinicians to determine the strengths and weaknesses of their practice with regard to FCC (Family Voices, 2008). The reliability and validity of these tools are currently being evaluated. Their primary goal is to find areas for improvement at individual clinics, rather than for research purposes, though, in time, they may be found appropriate for use in empirical research (Family Voices, 2013).

Some other tools are available for measuring FCC in a holistic sense, but they are only applicable to homogeneous, rather than heterogeneous treatment populations. For example, the Family-Centered Program Rating Scale focuses exclusively on children in early childhood intervention programs, making it inappropriate for use in other treatment populations (Murphy, Lee, Turnbull, & Turbiville, 1995). Other tools gather self-reported ratings by care-providers on the family-centredness of their services rather than families' perceptions of received care (Bailey, 1992; Woodside, Rosenbaum, King, & King, 2001).

3.2.2 The Measure of Processes of Care (MPOC)

The MPOC was created in response to the limitations that beset many of the other questionnaires that measured FCC. It examines how care is provided, as well the potential impact that service delivery has on children with neurodevelopmental disabilities and their families (S. King, King, et al., 2004). One strength of the MPOC is that it focuses explicitly on the processes of care as perceived by the child's parents, rather than only measuring the parents' general satisfaction with care. More meaningfully, it measures the degree to which certain behaviours and practices actually

occurred, as opposed to reports by care providers that describe their activities. In short, the MPOC is a comprehensive measure that recognises and gauges all the key characteristics of care-giving that parents wish to receive, while also identifying the impact of healthcare delivery on children and their families (S. King et al., 1995).

3.2.2.1 The Development of the MPOC

The development of the MPOC began with a literature review, where 22 “Components of Care” (CoCs) were compiled primarily for children with neurodevelopmental disabilities and their families. A group of parents (n=213) and healthcare professionals (n=88) ranked the CoCs in order of perceived importance from high to low. The top seven CoCs were used as the basis for the generation of questionnaire items. They were: Parent Involvement, Education/Information, Treatment of Disability, Accessible and Available Care, Continuity and Consistency of Care, Coordination of Care, and Family-centred Approach to Care (S. King et al., 1995; S. King, Rosenbaum, & King, 1996).

A group of 19 parents of children with varying ages and medical conditions helped to generate 300 survey items that reflected the content of each CoC. Afterwards, the research team, by consensus, eliminated redundant items, refined the content of remaining items, and ensured good item readability. This process yielded a pool of 101 items. Additionally, two CoCs (i.e., Education/Information and Treatment of Disability) were subsumed within the remaining five CoCs. A group of 40 parents and 11 rehabilitation center staff members then provided feedback on the relevance, meaning appropriateness, acceptability and readability of the items (S. King et al., 1995, 1996)

The next goal was to reduce the number of items and identify the constructs underlying groups of questions. Inappropriate items – ones that created problems with interpretability, face validity, homogeneity, and discriminatory power – were removed (S. King et al., 1995, 1996; Streiner & Norman, 2008).

The authors wanted scale construction to be empirical and statistics-driven, so a convenience sample was drawn from a number of ambulatory rehabilitation centres.

The total number of usable questionnaires was 653. Children with a variety of chronic conditions were represented, though a majority had a neurodevelopmental disability.

Nine items were dropped before analysis because they were negatively worded, irrelevant, or not applicable to a majority of respondents (S. King et al., 1995, 1996).

Principal Components Analysis (PCA) was used to reduce the remaining pool into a more 'manageable and meaningful' set of items, as it identifies a smaller number of underlying constructs among questionnaire items (Harrington, 2008; S. King et al., 1995). Assuming that the underlying constructs of FCC are theoretically and statistically inter-related, a five-domain solution with 56 items was retained as the most interpretable solution. This tool was found to be both valid and reliable, and thus became the MPOC-56 questionnaire (S. King et al., 1995, 1996)

In 2004, the originators opted to create a shorter and improved MPOC. The goal was to reduce the time needed to complete the questionnaire, and to increase its ability to discriminate among programs with different service delivery models (S. King, King, et al.,

2004). As the original five scales were thought to represent key aspects of FCC, the originators wanted to ensure that the shorter MPOC would retain them.

The creation of a shorter MPOC involved reviewing the test results of the preliminary 101-item questionnaire (n=653). The originators examined the frequency distributions of each item, the perceived importance of each item (as scored by respondents) and item correlations. Upon identifying 35 items that were the best exemplars of all five domains, internal consistency analyses and principal component analyses were used to reduce the MPOC into a 20-item questionnaire format, still with five domains, called the MPOC-20. To reduce the uncertainty associated with unlabeled options and to increase the variability of domain cores, refinements were made to the response scaling (e.g. descriptive phrases on all response options rather than the midpoint and endpoints). Both the utility of the MPOC-20 and its ability to discriminate among different models of service delivery improved as a result (S. King, King, et al., 2004).

3.2.2.2 The Properties of the MPOC-20

Both the MPOC-56 and MPOC-20 measure FCC within five domains: (i) Enabling and Partnership; (ii) Providing General Information; (iii) Providing Specific Information; (iv) Coordinated and Comprehensive Care; (v) and Respectful and Supported Care. Each question is answered on a Likert scale from 1 to 7, with 1 representing 'Not at All' and 7 representing 'To a very great extent.' Respondents can also answer 'Not Applicable' to allow discrimination between those to whom an item does not apply, and those who did not receive the behaviour described in the question (S. King et al., 1995).

For each of the five domains, a mean score is calculated, resulting in five individual subscale scores. If more than one third of the items belonging to a domain is left blank or indicated as 'Not Applicable,' the score for that domain cannot be calculated. A 'total' family-centred score is not calculated. This is because the originators reasoned that it was more clinically informative to examine and compare the relationships of the individual MPOC subscales to other variables (S. King et al., 1995).

The MPOC-20 performed well in terms of test-retest reliability (intra-class correlations from 0.81 to 0.86), and internal consistency (Cronbach's alphas ranging from 0.77 to 0.90). Moreover, with respect to concurrent validity, the MPOC-20 was positively correlated with a measure of parental satisfaction with care ($r=0.35$ to 0.72), and negatively correlated with a measure of parental stress associated with the care of an ill child ($r=-0.18$ to -0.48). Social desirability response bias was assessed as well. Rather than gauging socially desirable responses reflecting ideal experiences, responses to the MPOC-20 also appeared to reflect real experiences. The MPOC-20 also demonstrated suitable discriminate validity, in that it was able to discriminate among different parental experiences of caregiving (S. King, King, et al., 2004).

Based on these results, the MPOC appears to be a versatile tool with potential application in clinical, research, and advocacy contexts. Healthcare administrators and clinicians can rely on summary statistics to determine potential strengths and weaknesses in their services or employ item-by-item analyses to determine specific areas of care that require improvements. Researchers are able to examine the

relationship between service delivery and outcomes, and advocacy groups can use MPOC results to provide critiques of areas that need improvement (S. King et al., 1995).

3.2.2.3 The Adaptation of the MPOC-20

This thesis tested the suitability of the MPOC-20 in children with epilepsy. Before doing this, it was important to examine how the MPOC-20 performed when it was adapted to suit new circumstances. The MPOC-20 has seen continuous and widespread usage and application in populations other than the one for which it was developed (S. King, Teplicky, et al., 2004). Adaptions of the MPOC-20 were either; translations for non-Anglophones, or adaptations for individuals without neurodevelopmental disabilities.

The MPOC-20 has been translated into several languages – Arabic, Danish, Dutch, French, German, Hebrew, Italian, Japanese, Latvian, Portuguese (Portugal), Spanish, and 2 dialects of Traditional Chinese (CanChild, 2013). It has also been adopted or adapted for use in paediatric neurosciences (Mah, Tough, Fung, Douglas-England, & Verhoef, 2006; Moore et al., 2009; Speechley et al., 2012), paediatric oncology (Klassen et al., 2009, 2011), complex medical illness (Stone et al., 2008), adult post-stroke patients (Lovat, Mayes, McConnell, & Clemson, 2010), mental health and behavioural disorders (Chu & Reynolds, 2007), functional constipation (Poenaru et al., 1997), cleft lip and palate (G. King, Rosenbaum, & King, 1997; S. King et al., 1996), and acquired head injuries (Swaine, Pless, Friedman, & Montes, 1999). Other adaptations include surveys for care providers (Woodside et al., 2001) and adult patients (Bamm, Rosenbaum, & Stratford, 2010).

Overall, the MPOC-20 is widely used, easily adapted to new treatment populations, and appropriate for use in research. It cannot be assumed, however, that a survey tool can automatically be applied in a new population or for purposes other than that for which it was designed. It is therefore recommended that the psychometric properties of a measure (e.g. validity and reliability) be re-assessed when deploying it in a new group of people other than the one for which it was validated (Rosenbaum et al., 1990; Streiner & Norman, 2008). Thus, the psychometric properties of the MPOC-20 have often been re-assessed when moving it from children with neurodevelopmental disabilities to groups of children with other conditions and/or new treatment environments – in general, the MPOC-20 generally demonstrates reasonable validity and reliability.

The MPOC-20's structural (or factorial) validity, however – the degree to which scales in a questionnaire reflect the dimensionality of an underlying construct (Harrington, 2008; Mokkink et al., 2010) – does not tend to remain constant when applied to new treatment populations or environments. This means that the MPOC-20 may not adequately reflect the domains as they are delivered and/or perceived in a new setting. This is likely because the validity and reliability of measurement tools are sensitive to the changes in sample characteristics – specifically the nature of the people being measured, as well as the circumstances in which it is being assessed (Streiner & Norman, 2008).

Several authors have identified cases where the MPOC-20's factor structure changes when the target sample or setting is modified. For example, the Dutch translation has a

3-domain structure (Siebes et al., 2007) while the Singaporean adaptation has 4 domains (Chong, Goh, Tang, Chan, & Choo, 2012). Large differences in societal values and economic wealth between western nations and South Africa meant that the MPOC-20 was not suitable for use in a South African context (Saloojee, Rosenbaum, Westaway, & Stewart, 2009). The Moore et. al (2009) study of children with neurological disorders found a 1-domain solution, while a 2-domain solution was identified within the paediatric oncology setting (Klassen et al., 2009). Applying the MPOC-20 to children with neurodevelopmental disorders in the United Kingdom also resulted in a shift of its domain structure – likely because of the differences in rehabilitative care delivery models between Canada (where the MPOC was developed) and the United Kingdom (McConachie & Logan, 2003).

With regards to the psychometric properties of the MPOC-20 amongst children with epilepsy, some work has been done to test its validity and reliability (Hunter, 2007). Using data from HERQULES, the MPOC-20 demonstrated itself to be highly reliable in terms of test-retest reliability (intra-class correlations from 0.78 to 0.96), and internal consistency (Cronbach's alphas ranging from 0.81 to 0.86). In terms of convergent validity, the MPOC-20 was moderately correlated with the Patient Perceptions of Patient-Centeredness questionnaire ($r=0.48$ to 0.67) (Hunter, 2007; Stewart et al., 2014). In contrast to the results reported by King et. al (2004), a weak association was found between domains of the MPOC and parents' stress. The weak association may be explained by the fact that the stress variable available to Hunter was derived from a

single question about parental stress in general, rather than stress specifically related to their child's care as was the case in King et al (2004) (Hunter, 2007).

Thus, the MPOC-20 demonstrates reasonable reliability and validity in children with epilepsy in some respects (e.g. face and convergent validity). Additional work must be done to ascertain the structural – and by extension, construct validity of this tool in this population. For this reason, this thesis builds upon the work of Hunter (2007) by determining whether the original MPOC-20 domain structure is retained in this population. Prior psychometric testing of the this tool suggests that it may not. If it is the case that the domain structure is not valid, the MPOC will be modified in a manner consistent with the literature, so that a structurally valid domain solution emerges.

3.3 Data Analysis

The first step was a descriptive analysis using SAS 9.4 to examine the characteristics of parents who returned the questionnaire and their children through frequencies and percentages. Parental characteristics examined were parent's gender, marital status, age, level of education, work status, and annual household income. For children, the characteristics of interest included the child's gender, age, the type of seizures the child experienced, and the severity of their epilepsy. Summary statistics for the MPOC-20 (i.e. individual item and subscale scores) were examined as well – in particular, their means and medians.

The goal of this thesis was to assess whether the MPOC-20 retains its structural validity (i.e. whether the factor structure remains constant) when applied within the context of children with epilepsy, and to re-establish that structural validity if it was not retained. This was done through the use of factor analysis.

3.3.1 Introduction to Factor Analysis

Factor analysis is a statistical method for describing the relationships among a set of variables using a potentially smaller number of latent, underlying domains or ‘factors’ (T. A. Brown, 2006; Mardia, Kent, & Bibby, 1980; Norman & Streiner, 2008). Factors are not measured directly, but are inferred through the measurement of variables that are thought to be explained by, or ‘loaded’ onto them (Streiner & Norman, 2008). For the purpose of the analyses reported here, the individual variables or items of the MPOC-20 will be referred to as ‘indicators,’ while the domains will be referred to as ‘factors.’

There are two kinds of factor analysis – Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA). EFA is descriptive or exploratory in that it examines the data for patterns of relationships among indicators (Norman & Streiner, 2008). EFA is more applicable in cases where new measures are being developed and it is unknown how the indicators interact. Work is then done to understand and interpret the underlying construct reflected by each factor (T. A. Brown, 2006). CFA also examines the relationships among indicators and factors, though, unlike EFA, it is hypothesis-driven, rather than exploratory. The researcher must have an idea, based on ‘past evidence and theory’ of the number of factors in the model, as well as of the relationship among

factors and indicators (T. A. Brown, 2006). This is the case with the MPOC-20, where there is *a priori* evidence of the number of factors in the model, and information on the relationships between factors and indicators (T. A. Brown, 2006).

As the factor structure of the MPOC-20 was already identified in children with neurodevelopmental disabilities, this thesis performed a CFA to test how well that model fits data from children with epilepsy. Performing the CFA rendered results that met the first objective of this thesis. If the hypothesised model did not fit, revisions to the model were to be enacted by performing a post hoc analysis within the framework of a CFA. Hence, a better fitting model would be achieved through an exploratory analysis of the hypothesised model instead of an exploratory analysis that assumed that there was no *a priori* knowledge of the MPOC-20's factor structure. In this manner, a more parsimonious and interpretable factor solution would emerge, thereby fulfilling the conditional objective of this thesis (T. A. Brown, 2006).

3.3.2 The Factor Structure of the MPOC-20

As mentioned previously, the MPOC-20 consists of 20 indicators measuring 5 factors: i) Enabling and Partnership, ii) Providing General Information, iii) Providing Specific Information, iv) Coordinated and Comprehensive Care, and v) Respectful and Supportive Care. Each of these factors corresponds to a scale of the MPOC. There is considerable overlap between the core 'elements' of FCC described in Section 2.1 and the five original factors described by the MPOC-20's originators.

A diagram of the original factor model identified in children with neurodevelopmental disabilities is displayed in Figure 3.1. The relationships between factors and indicators (i.e. questionnaire items) are demonstrated as well.

3.3.3 Confirmatory Factor Analysis and Assessment of Model Fit

The primary goal of this thesis was to test whether the factor structure found in children with epilepsy conformed to the original MPOC factor structure identified in children with neurodevelopmental disabilities. To achieve this objective, a Confirmatory Factor Analysis (CFA) was performed using MPLUS 7 software.

Prior to the CFA analysis, a number of steps were taken to screen and prepare the data. These diagnostic steps addressed: level of measurement, presence of missing data, potential presence of outliers, adequacy of sample size, univariate and multivariate normality, multicollinearity, and singularity (T. A. Brown, 2006; Harrington, 2008; Raykov & Marcoulides, 2012; Tabachnick & Fidell, 2012). The goals were to assess whether the data met CFA requirements, to identify potential issues that could affect the analysis, and to determine which estimators of model parameters and goodness-of-fit statistics were appropriate for the data. More detailed information on the following data steps is described in Appendix F.

The first steps of this process yielded the decision to treat the data as having a continuous level of measurement. To address the fact that a majority of respondents had at least one missing data point, it was determined that an estimator that uses all available data to produce parameter estimates and test statistics would need to be used

for the CFA. Twenty-four respondents had more than 50% missing data, which made them ineligible for analysis, as according to the MPOC's developers.

The search for outliers identified 16 respondents as potential outliers. Each respondent was examined on a case-by-case basis to determine whether their responses reflected potentially realistic outcomes of care. All 16 cases were retained in the analysis, which meant that a total of 311 respondents had analyzable data. Sample sizes larger than 200 are considered 'large' and acceptable for most CFAs (Harrington, 2008; Kline, 2011).

The next step was to identify whether the data demonstrated multivariate normality, which is an assumption of CFA. Test statistics identified the data as having moderately non-normal multivariate distributions – a violation of the assumption of multivariate normality. The final diagnostic test searched for signs of bivariate and multivariate multicollinearity and singularity. There was no evidence of multivariate or bivariate or multivariate multicollinearity or singularity, though Questions 7 and 8 had a notably high bivariate correlation ($r=0.856$). They were therefore monitored throughout the CFA.

Overall, the majority of requirements for a CFA were met, though there were concerns about missing data and moderate univariate and multivariate non-normality. To account for the 'mild' violation of normality while also retaining respondents with some missing data, the Robust maximum likelihood estimator (MLR) was chosen. MLR is essentially a version of the full information maximum likelihood estimator (FIML) with a robust 'scaling method' to account for non-normality of data (T. A. Brown, 2006; Finney & DiStefano, 2013; Muthén & Muthén, 2012; Rhemtulla, Brosseau-Liard, & Savalei, 2012).

HERQULES employed a two-stage cluster sampling strategy where families of children with epilepsy were recruited through paediatric neurology practices (i.e. 41 practices or clusters). It is therefore likely that the nature of the health care received within a paediatric neurology practice will have been more similar than care received across practices. Thus, analyses were performed on data where respondents had been classified by Physician ID into 41 groups – corresponding to the 41 different paediatric neurology practices (Muthén & Muthén, 2012).

Model Fit. The CFA yielded a number of model fit statistics. The fit statistics were examined to assess whether the original factor structure was appropriate for use in this population. First examined was the χ^2 model fit statistic – the result of a likelihood ratio test where the hypothesised model was compared to a saturated model with perfect fit. In saturated models, all possible paths are specified among all variables (Raykov & Marcoulides, 2012). Rejection of the null hypothesis, in this case, a non-significant χ^2 value ($p > 0.05$) would demonstrate an acceptable fit. Another ‘very rough’ indicator of good fit is when the ratio of χ^2 /degrees of freedom is less than 2.00. These fit statistics are sensitive to sample size as well as other features of the model and data (e.g. choice of estimator, continuous or ordinal data) (T. A. Brown, 2006; Schmitt, 2011).

Other fit indices examined included the Root Mean Square Error of Approximation (RMSEA), the Comparative Fit Index, and the Standardized Root Mean Square Residuals. The Root Mean Square Error of Approximation (RMSEA) provides an estimate of the amount of unexplained variance in the model (T. A. Brown, 2006). A good fitting model

would have lower amounts of unexplained variance, which would be reflected in a lower RMSEA estimate (T. A. Brown, 2006). The Comparative Fit Index (CFI) compares the hypothesised model to a basic one where all the indicators are unrelated (T. A. Brown, 2006). Finally, the Standardized Root Mean Square Residual (SRMR) represents the average discrepancy between correlations identified in the data and those that were predicted by the model. Lower SRMR values signify a smaller average discrepancy, and therefore a better model fit overall.

The corresponding guidelines for interpreting goodness of fit statistics are:

- RMSEA: <0.05 suggests a good fit, 0.05 to 0.08 is acceptable, $\geq 0.08-0.10$ is mediocre.
- CFI: >0.95 suggests a good fit, 0.90-0.95 is marginal.
- SRMR: 0.08 and below indicates an acceptable fit.

(T. A. Brown, 2006)

3.3.4 Identifying Potential Areas for Model Revisions

It is conceivable that applying the MPOC in children with epilepsy might result in the original factor solution having a poor fit. To prepare for this possibility, a conditional series of steps was put in place to identify potential sources of ill fit, and to propose revisions to the model to improve its fit post-hoc.

Poorly fitting models are thought to have been misspecified. Specifying a model essentially means creating a hypothesis-driven map of relationships among indicators and factors. When a model fits the data poorly, it is re-specified, estimated, and then tested for adequate fit once again (Hoyle, 2014). There are three primary ways that a model can be misspecified; i) there may be an incorrect number of factors ii) the

specified relationships among indicators and factors may be erroneous and iii) there are error covariances among indicators that require specification (T. A. Brown & Moore, 2014).

Thus, the first step was to assess whether the number of factors specified in the model was appropriate. Estimates of factor correlations were to be examined through the use of a factor correlation matrix. If two factors were highly inter-correlated (i.e. $r > 0.85$), they were concluded to have poor discriminant validity. Any two overlapping constructs with correlations above the cut-off were to be merged, provided that there was a strong theoretical justification to do so (T. A. Brown, 2006). Collapsing these factors would then improve the interpretability and parsimony of the resulting model, but also worsen the fit of the model to some degree (T. A. Brown & Moore, 2014).

To assess whether indicator-factor relationships and/or error covariances were sources of ill-fit, Modification Indices (MIs) would also have to be examined. Otherwise known as Lagrange multiplier tests, these statistics estimate the drop in χ^2 (and subsequent improvement in model fit) if a proposed revision of model is implemented. MPLUS 7 normally generates two types of MIs.

The first type of MI ('BY' Statements) suggests that the fit of a model could be improved if an indicator was allowed to 'cross-load' on a new factor in addition to the originally-specified factor (T. A. Brown & Moore, 2014; Raykov & Marcoulides, 2012). These MIs are the most substantively interpretable, as they identify cases where: i) an indicator does not load onto any factor in a model (though it had been specified to) ii) an

indicator loads onto multiple factors (though it had been specified to load onto one) and
iii) an indicator cross-loads on an entirely different factor than the one specified (T. A. Brown, 2006).

The second type of MI ('WITH' Statements) suggests that the fit of a model could be improved if the error terms of two indicators were permitted to co-vary (T. A. Brown & Moore, 2014; Raykov & Marcoulides, 2012). These MIs imply that the covariance between two indicators cannot entirely be explained by their relationship to their common factor. Such cases may arise when two indicators are similarly worded, reverse-worded, or differentially prone to social desirability (T. A. Brown & Moore, 2014). This type of MI is difficult to justify because any error covariance between indicators should be explained by their own factor. Therefore, to consider any MIs of this type, the size of the MI would need to be abnormally large relative to the size of other MIs of the same type (Raykov & Marcoulides, 2012).

Thus, the second step of model revision was to use MPLUS 'BY' statements to identify areas where cross-loadings were needed. The third step was to use 'WITH' statements to identify indicators that should have their error terms co-vary, provided that the size of the MI was significant enough to warrant doing so.

A 'simple structure' would therefore be the preferred outcome of this analysis, as it makes the interpretation of a model easier and more reliable (Cattell, 1978; Thurstone, 1947). To attain a simple structure in a CFA, each indicator must load onto a single factor, and there must be no correlated errors (Kenny, Milan, & Hoyle, 2014). Thus, the

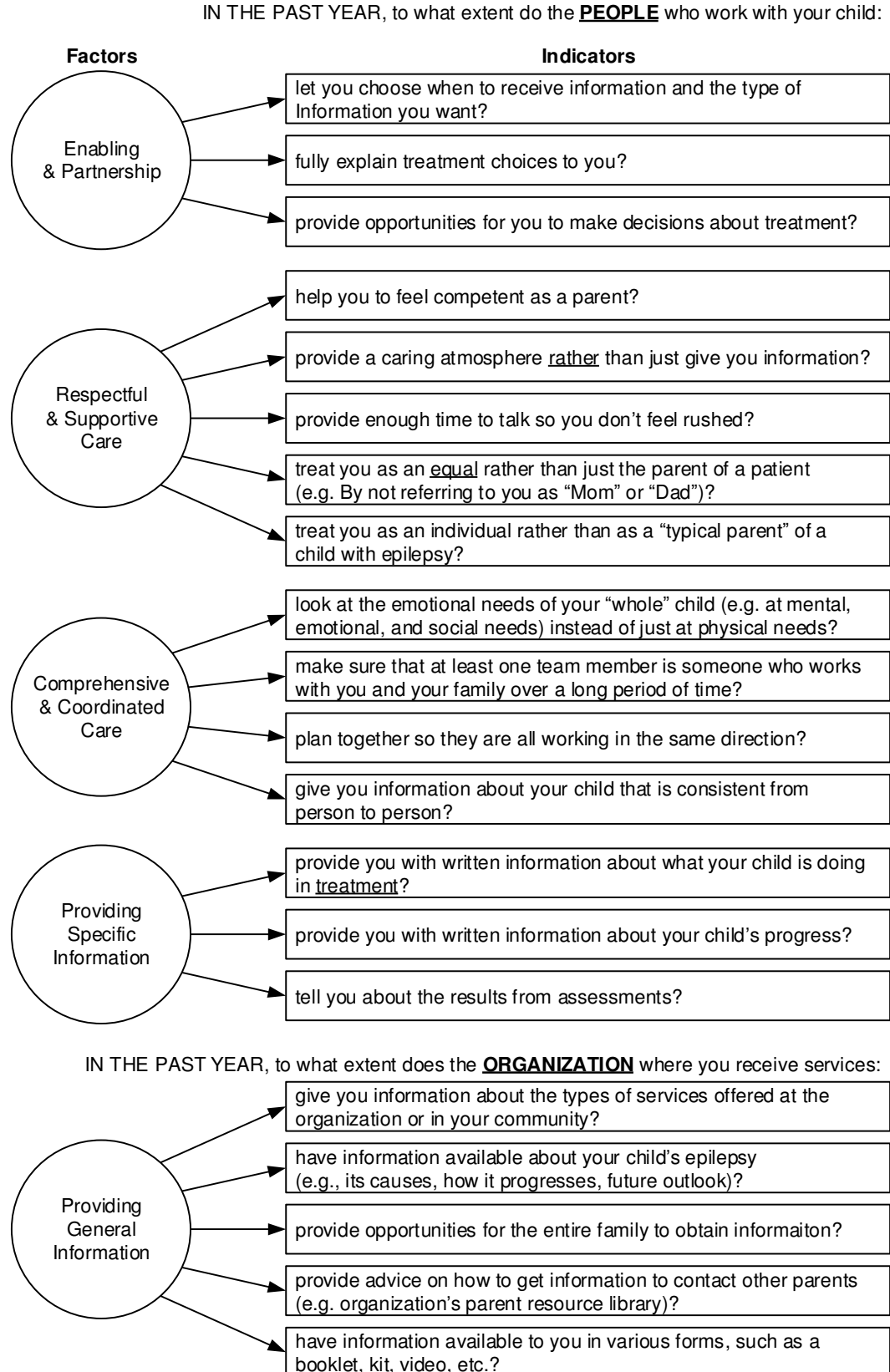
following options for achieving a simple structure would be considered: removal of non-significant or problematic (e.g. cross-loading) indicators, and the movement of an indicator from one factor to another (Bowen & Guo, 2012).

The largest and most justifiable MI-proposed revisions would be implemented one at a time, with the model fit being re-assessed after each successive modification. Though the critical value for MI size was 3.84, only MIs with a magnitude at or above 10.0 would be investigated, as per the default minimum set in MPLUS (Muthén & Muthén 2012).

Before making any modifications permanent, a substantive, justifiable and theory-backed rationale would be sought – as recommended in the literature (T. A. Brown, 2006; Harrington, 2008; Raykov & Marcoulides, 2012). The literature would be considered for: the MPOC's development, FCC as a construct, as well as the characteristics of epilepsy and its effects on the child, family, and the treatment process. Furthermore, a clinical opinion on the MPOC-20's indicators would be sought through consultation with a paediatric neurologist. A review of each of the indicators would be conducted, gathering information on their relevance to clinical practice and to children with epilepsy in general.

The process would be iterative – if a sufficiently adequate model fit was attained, the process would end. Each step of the process would be repeated sequentially until the list of justifiable MIs revisions had been exhausted, such that the model fit would demonstrate an 'acceptable' fit at minimum (T. A. Brown, 2006; T. A. Brown & Moore, 2014; Furr, 2011).

Figure 3.1 MPOC-20 Model Identified in children with Neurodevelopmental Disorders



Chapter 4 – Results

4 Chapter Overview

This chapter presents the findings. First, section 4.1 describes the sample characteristics of parents, children, and the MPOC-20 data at Time 2 of HERQULES. The following sections (4.2-4.3) present the findings for each of the individual study objectives.

4.1 Sample Characteristics

There were 456 children deemed eligible for inclusion. Parents of 374 children participated by returning their questionnaires at Time 1, for a response rate of 82%. Subsequently it was determined that one child had become ineligible and thus was removed from the sample, leaving 373 children. These results exceed the typical mail survey response of 60-70% or lower (Aday & Cornelius, 2006). Retention rates were high as well. At Time 2, 90% of Time 1 participants were retained. Time 3 retained 91% of Time 2's participants, and Time 4 retained 93% of Time 3's participants.

Time 2 data (six months following diagnosis) are analyzed here. After following instructions from the developers of the MPOC-20 regarding how to handle non-responses and not applicable responses, data from 24 respondents were deemed unanalyzable (see Appendix F for further details) leaving a final sample of 311.

Parent Characteristics. Of the eligible 311 respondents, the majority of responding parents were the biological mothers of the children with epilepsy (90.4%). The majority of parents were currently married (79.3%), with ages ranging from 24 to 61, with a

mean age of 38 years old. A considerable proportion of parents had completed university or another form of post-secondary training (69.6%), and were employed either on a full-time or part-time basis (70.3%). Average annual household income was high, with 39.7% of families earning \$80,000 or more.

Child Characteristics. The mean age of children in the sample was 8 years at Time 2, with ages ranging from 4 to 13 years. Approximately half (51.5%) of the sample were boys. Focal seizures were the most common type of seizure (59.09%). ‘Unknown’ type seizures made up 1.1% of the sample. Almost three quarters of children were reported as having either “a little severe” or “not at all severe” epilepsy by their neurologists.

Summary statistics for parental and child demographic characteristics can be found in Table 4.1 and 4.2 respectively.

Summary Descriptive Statistics. Overall, MPOC-20 scores were relatively high at the indicator level. Indicator means ranged from 3.49 (SD=2.29) to 5.44 (SD=1.47), while indicator medians ranged from 3 to 6. Summary statistics are shown in Table 4.3.

4.2 Confirmatory Factor Analysis

The results of the CFA demonstrated that the original five-factor solution was not valid for children with epilepsy. The χ^2 value itself was significant ($\chi^2=427.45$, $p<0.0001$), and the $\chi^2/\text{degrees of freedom}$ ratio was 2.67, which is larger than the 2.00 limit for reasonable fit. These two fit statistics suggested that the null hypothesis be rejected – the model did not fit the data well. The RMSEA estimate was 0.07 (90% confidence

interval 0.065-0.082) – which, by virtue of having an upper confidence limit of 0.08, suggests that this model had a ‘mediocre’ fit. The CFI statistic was 0.92, which, by falling within the range of 0.90 to below 0.95, is considered ‘marginal.’ The SRMR implied a ‘good’ model fit at 0.05, well below the 0.08 cut-off. All corresponding goodness-of-fit statistics are presented in Table 4.4 under the column “Original Model”.

Taken together, the results of the CFA were mixed – both of the X^2 tests and the RMSEA 90% confidence intervals implied that the model fit was poor, while the CFI and SRMR suggested a ‘marginal’ to ‘good’ fit. Thus, it is possible to interpret this model as having either an acceptable fit or a poor fit. Given that this scale had been shown to capture parents’ perceptions of caregiving regardless of age or diagnosis, however, (S. King, King, et al., 2004), we had expected a better model fit.

The fact that the results of the CFI and SRMR are incongruent with that of the RMSEA (i.e. acceptable vs. poor fit) suggests that the model may lack parsimony. More specifically, this means that there may be too many unnecessary indicators or factors in the model. In addition, there was sufficient room to move the goodness-of-fit indicators from an area of ‘mixed’ fit results to an area of reasonably good fit. Thus, it was concluded that the original factor structure of the MPOC-20 was not retained in this sample of children with epilepsy. The model needed to be re-specified so as to ensure the tool reflects the experience of FCC for children with epilepsy and their families.

4.3 Revisions to the MPOC-20

An exploratory analysis within a CFA framework was employed to modify the MPOC-20's factor structure, aiming for a better fit in children with epilepsy.

The first step ensured that the model had an optimal number of factors. Examination of the inter-factor correlation matrix revealed a number of factors with intercorrelations of 0.85 and more – evidence of poor discriminant validity. Thus, any factors with $r \geq 0.85$ were combined as long as there was a suitable theoretical justification for doing so (T. A. Brown, 2006). The two factors with the highest correlation were collapsed iteratively until all remaining inter-factor correlations were below 0.85.

The highest correlation identified in the hypothesised model was between the “Respectful and Supportive Care” and the “Comprehensive and Coordinated Care” factors ($r=0.988$). These factors were collapsed into a single factor. The next highest correlation ($r=0.917$) was between “Enabling and Partnership” and the newly collapsed factor – which led these two to be merged. The last high correlation value ($r=0.895$) suggested that “Providing Specific Information” be absorbed into the collapsed factor as well. The iterative process was stopped here, because the factor inter-correlation between the two remaining factors was 0.608 – below the cut-off for factor collapse.

These revisions resulted in a 2-factor model. The 15 indicators from the collapsed factors became part of Factor 1, while the remaining 5 indicators from the “Providing General Information” factor became part of Factor 2. As predicted, the model fit

worsened slightly (Table 4.4 under the column “Model 1”). There were still, however, a number of MI-based revisions for improving model fit to be employed.

We believe that the collapse of these factors is justified, as they were originally intended to collectively represent holistic FCC by the tool developers. A five factor solution was chosen by the MPOS developers because they had *a priori* interest in a five factor solution in children with neurodevelopmental disabilities. It was therefore conceivable that this original number of factors was not applicable in children with epilepsy.

The second step of the revision was then initiated, and the Modification Indices (MIs) were examined (Table 4.5). The goal of Step 2 was to properly identify the relationships among indicators and factors. The largest MI found in the first set was 19.61, and it related to Question 2 (*In the past year, to what extent do the people who work with your child provide you with written information about what your child is doing in treatment?*).

This MI suggested cross-loading Question 2 onto the “Providing General Information” factor while also remaining loaded onto Factor 1. Relatively small, but still noteworthy MIs for the ‘WITH’ statement suggest that this indicator co-varies with 5 other indicators. Though ‘WITH’ Statement MIs were examined in a separate process, we wanted to point out the notable MI of 38.72, which suggested that Questions 2 and 14 had a relationship beyond what could be explained by their common factor (they were both loaded onto the newly collapsed factor). Both indicators were thematically similar in that they assessed whether care providers gave written information about the child’s progress or treatment.

A consultative review of MPOC indicators with a paediatric neurologist suggested that written information about what children are doing in treatment is not usually that common in the treatment for children with epilepsy. Thus, Question 2 appeared to measure a behaviour that was not as relevant to this population. This conclusion is supported by the fact that the indicator had among the highest amounts of ‘not applicable’ responses (14.15%) out of all indicators in the MPOC-20.

Therefore, by virtue of cross-loading onto two factors, correlating with multiple indicators, and tapping a clinical practice considered to be infrequent and less central, this indicator was deemed problematic. To lead to the most interpretable and reliable factor structure possible, the indicator was permanently removed from the model. Re-assessment of the goodness-of-fit indicators found that removing Question 2 from the model yielded a slightly improved model fit (Table 4.4 under the column “Model 2”).

After removing Question 2 and reassessing the model’s fit, a new set of MIs were generated (Table 4.6). The largest MI had a value of 20.74, and pertained to the aforementioned Question 14 (*In the past year, to what extent do the people who work with your child provide you with written information about your child’s progress?*). This MI suggested that Question 14 should be cross-loaded onto the “Providing General Information” factor while also remaining loaded onto Factor 1 as well. This indicator received the same clinical opinion as Question 2 – because it tapped the provision of written information by care providers, it was also not as central to the treatment of

children with epilepsy. As with Question 2, the percentage of 'not applicable' responses (15.43%) was among the highest among HERQULES data.

Question 14, as with Question 2 before it, cross-loaded onto two factors and tapped an infrequent and less relevant clinical practice. This meant that the indicator was a source of ill model fit. In the continued search for a 'simple structure' factor solution, the indicator was permanently removed from the model. Re-assessment of the goodness-of-fit indicators found that removing Question 14 from the analysis yielded an improved model fit (Table 4.4 under the column "Model 3"). The upper bounding limit of the RMSEA statistic still rested at the 0.08 limit for 'mediocre' fit – this meant that more model revisions needed to be pursued.

A new set of MIs was generated as part of the iterative model refinement process (Table 4.7). The final MI that pertained to potential indicator cross-loading was Question 4 (*In the past year, to what extent do the people who work with your child let you choose when to receive information and the type of information you want?*). With an MI of 13.22, it was suggested that this indicator also cross-loaded onto both of the remaining factors in the model. An additional 2 MIs suggested permitting this indicator to co-vary with 2 other indicators in the model.

This last MI likely pertains to this indicator because the timing of information delivery is different for children with epilepsy than it is for children with neurodevelopmental disorders. Though epilepsy is a chronic condition, seizure episodes themselves are sporadic – making the clinical course of the condition somewhat unpredictable. This has

implications for the timing of information delivery, since children and their families will see their care provider intermittently, likely in conjunction with the frequency and severity of the child's seizures. 11.25% of respondents stated that this clinical behaviour did not apply to them. The indicator was thus deemed to capture a clinical behaviour that was less central in case of children with epilepsy.

Therefore, by virtue of cross-loading onto both factors in the model, bearing error covariances with multiple indicators, and being clinically less central, Question 4 was deemed a problematic indicator. It was subsequently removed from the model. Re-assessment of the goodness-of-fit indicators found that removing Question 4 again yielded an improved model fit (Table 4.4 under the column "Model 4"). The confidence limits for the RMSEA statistics were now within the range of 'good' fit.

Among the newly generated MIs, there were no more suggestions for the cross-loading of MPOC-20 indicators. The third and final step was therefore initiated, with the goal of identifying indicators with correlated errors. As the use of error covariance MIs is less interpretable than that of indicator cross-loading, the selection and implementation of these MIs was cautious and conservative. Only MIs with a significant size would be chosen for further investigation.

The largest MI among the error covariance suggestions was 54.30, which was roughly 2 to 5 times larger than the other MIs in the same table (Table 4.8). The suggested modification was for Questions 7 (*In the past year, to what extent do the people who work with your child fully explain treatment choices to you?*) and 8 (*In the past year, to*

what extent do the people who work with your child provide opportunities for you to make decisions about treatment?) to receive correlated error terms. Both of these variables were identified during data screening and management (see Appendix F) as having a bivariate correlation of 0.856 – higher than the recommended 0.70 limit for non-structural analysis (Tabachnick & Fidell, 2012). In addition, Question 7 appeared to be a precursor to Question 8. Before parents can make a decision on which treatment to pursue, they need to have had the treatment choices explained to them.

Because both indicators appeared to be statistically and clinically redundant, they were short-listed for removal from the model. Only one of the two indicators would have to be removed to improve model fit, however. Since the behaviour described in Question 8 logically and temporally follows the behaviour described in Question 7, it was decided that the latter implies the delivery of the former. Therefore, to improve model fit and achieve a 'simple solution,' Question 7 was dropped from the model.

At this point the model refinement process was stopped, having exhausted all MIs above the set cut-off value of 10 that were theoretically justifiable (Table 4.9). The final model contained 16 indicators which loaded onto two separate factors. Factor 1 contained all of the indicators of the four collapsed factors, save for the 4 that were removed in this analysis. Factor 2 retained all 5 indicators from the original "Providing General Information" factor. Because at least five or more indicators had a loading of at least 0.71 on their respective factor, it is reasonable to assume that this is a stable factor

solution (Tabachnick & Fidell, 2012). Factor 1 had the highest mean score (5.02, SD=1.44), while Factor 2 had the lowest mean score (4.00, SD=1.87).

Interpretation of Factors. To identify these factors, we first consulted the literature for instances where the assessment of the MPOC's structural validity yielded a two-factor solution. Two studies were identified. The first study pertained to children with cancer. Here, 15 indicators formed a single factor, while the 5 indicators from "Providing General Information" formed another factor. The first factor in their model was designated a summary measure of general FCC, while the second factor measured the extent to which care providers met parents' need for general information (Klassen et al., 2009).

In the second study, the structural validity of the MPOC-56 was assessed in a sample of children with neurodevelopmental disabilities. Thus, even in a population for which the MPOC had been validated, there is a precedent for using a smaller number of factors to measure FCC. Here, one factor was described as a measure of "Providing Support," while "Providing General Information" again formed its own distinct factor (G. King, King, Rosenbaum, & Goffin, 1999). In both studies, the authors concluded that family-centred caregiving was better measured with two rather than five factors. The findings of this study align with earlier conclusions by the MPOC developers that the MPOC's original five-factor structure was well-aligned with two themes – interpersonal caregiving, and the need for information. (G. King, King, & Rosenbaum, 1996; S. King, King, et al., 2004).

For children with epilepsy, we believe that the two-factor solution identified reflects these themes as well. Factor 1 encompasses the interpersonal processes of caregiving. This means that its underlying construct reflects behaviours that build a communicative rapport among stakeholders, foster information exchange, and form collaborative partnerships among all involved in the healthcare process (Donabedian, 1997).

The original four factors that folded into Factor 1 align well with this concept. They measured interpersonal behaviours such as: providing consistent, comprehensive, and coordinated care; empowering parents and practicing shared decision-making; encouraging a relationship of mutual respect and support; and fulfilling parents' need for information on their child's condition (S. King, King, et al., 2004; S. King et al., 1995). Factor 1 also encompassed a number of elements of care described in Section 2.1 – 'the Concept of Family-Centred Care'. The behaviours tapped by these elements are interpersonal as well – including: recognition that the family is a constant in the child's life; partnership and collaboration; respect, awareness and support; and comprehensive, coordinated and continuous care.

Further support for this interpretation of Factor 1 comes from the design of the MPOC-20 questionnaire itself. The first 15 questions of the questionnaire (which initially all loaded as indicators onto Factor 1) were all prefaced with "To what extent do the **people** who work with your child..." (Appendix E). This essentially means that all four domains were explicitly measuring the degree to which the active, interpersonal

interaction between a family and their care providers was family-centred. Thus, Factor 1 was renamed “Family/Care Provider Interaction” in children with epilepsy.

Conversely, the remaining 5 questions of the MPOC-20 (which loaded as indicators onto Factor 2) were prefaced with “To what extent does the **organization** that works with your child...” (Appendix E). This means that all indicators in the “Providing General Information” factor were initially intended to measure family-centred behaviours at an organizational level. This may explain why Factor 2 is a separate, though related construct from that of ‘Family/Care Provider Interaction.’

Thus, FCC does not necessarily have to occur directly through direct family/care provider interaction – it can be provided by any and all staff indirectly. This factor specifically focuses on indirect FCC, where instead of providing care in an interpersonal way, parents are supported by being made aware of important resources. Parents are asked whether they were given information on community or organizational supports (Question 16) or if they were given access to resources like Parent-to-Parent Networking (Question 20). Such information could be made available to parents of children with epilepsy through a clinic coordinator or even the administrative staff, potentially changing outcomes for the parents and how they interact with their care provider(s). This factor therefore measures the extent to which an organization provides family-centred information through latent means. Factor 2 was thus renamed “Providing Information.”

Taken together, the measurement of FCC in children with epilepsy is evaluated by two additive scale scores – “Family/Care Provider Interaction” and “Providing Information.” Individually, these scores will measure the interpersonal or information-giving behaviours of care providers – together, they will measure the extent to which care from neurologists and their organizations were family-centred as a whole.

Figure 4.1 presents the revised MPOC factor structure identified in children with epilepsy. The double-headed arrow shows the correlation between factors and the single-headed arrows represent factor loadings. The far right numbers are measurement errors – the amount of indicator variance not explained by a factor (Harrington, 2008).

The resulting two-factor solution demonstrated an appreciable improvement in model fit over the original factor solution. Though the χ^2 statistic did not confirm a proper model fit ($\chi^2=205.28$, $p<0.0001$), it was less than half the size of the original χ^2 value found in the unrevised model (χ^2 of 427.45). In this respect, there was a significant improvement in model fit. In addition, the χ^2 /degrees of freedom ratio, was now 1.99 – less than the 2.00 borderline. This meant that according to this ‘rough’ indicator of model fit, the revised model fit the data well. The RMSEA estimate was 0.06 (90% confidence interval 0.045-0.068), suggesting that the model had a ‘good’ fit. The CFI statistic was 0.96, which also implied a ‘good’ fit to the data. Finally, the SRMR suggested that the model fit was still ‘good,’ with a value of 0.04, well below the 0.8 cut-off. Taken together, these results satisfied the criteria for a ‘good’ fit. All corresponding goodness-of-fit statistics are presented in Table 4.4 under the column “Final Model.”

Figure 4.1 Revised MPOC-20 Model Identified in Children with Epilepsy

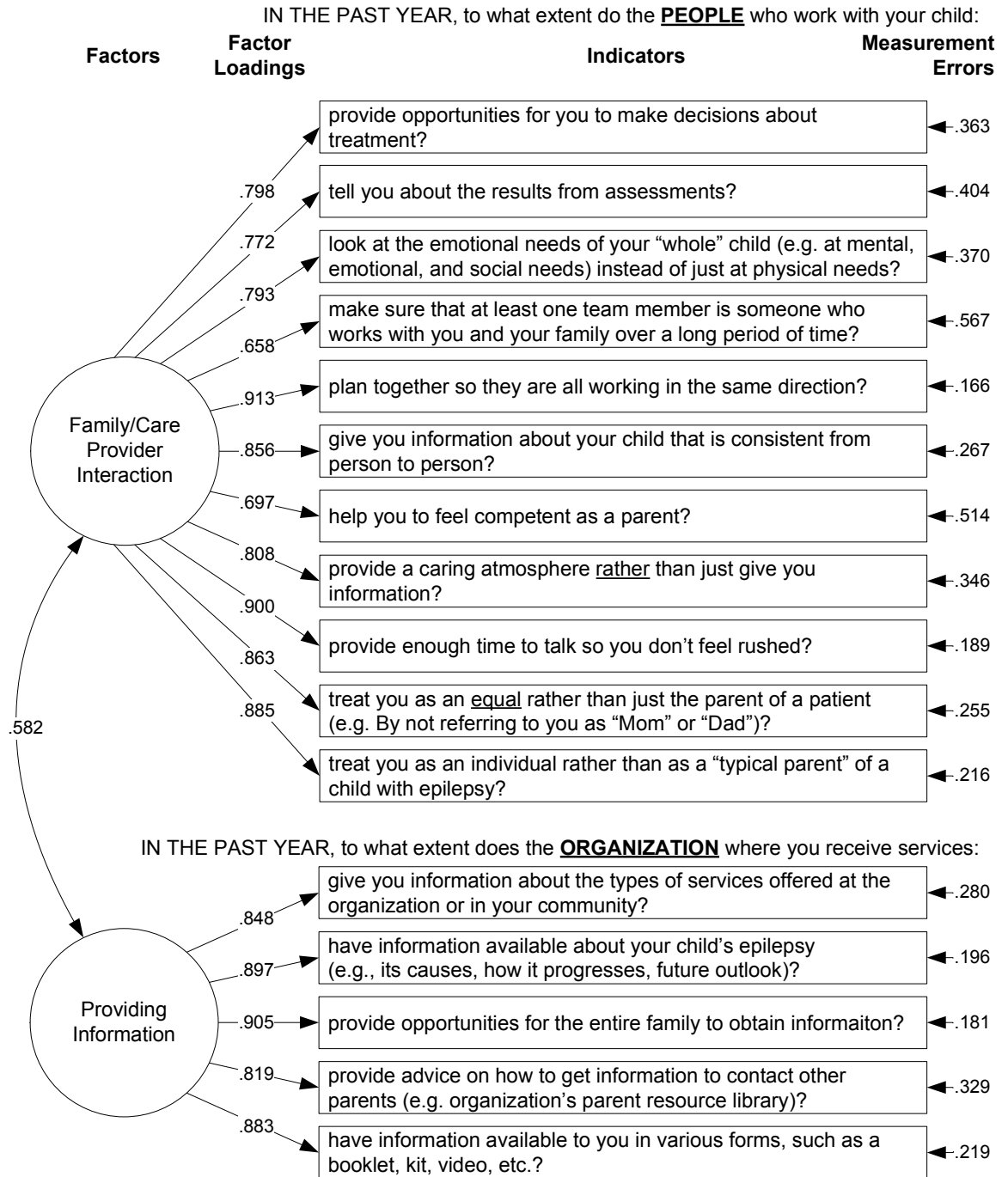


Table 4.1 Demographics of Respondents at HERQULES Time 2

Respondent Characteristics (n=335)	
Mean age in years (SD)	38.4 (5.8)
Age range in years	24 to 61
Gender	
Female	95.2%
Male	4.8%
Relationship to Child	
Biological parent	95.2%
Step parent	0.6%
Foster parent	0.3%
Adoptive parent	2.9%
Guardian	1.0%
Marital Status	
Married	79.3%
Widowed	0.7%
Divorced	3.9%
Separated	7.1%
Remarried	0.3%
Never married	8.7%
Average Household Income	
Less than \$20,000	9.9%
\$20,000-\$39,999	13.3%
\$40,000-\$59,000	19.5%
\$60,000-\$79,000	16.7%
\$80,000 or more	40.6%
Employment Status	
Employed	70.3%
Full-time homemaker	19.6%
Not working	6.2%
Looking for work outside of home	1.6%
Student	2.3%
Education	
Did not complete high school	8.7%
High school	21.7%
Vocational/Technical Training	11.4%
College/University	50.8%
Graduate School	7.4%

Table 4.2 Demographics and Clinical Characteristics of Children at HERQULES Time 2

Respondent Characteristics (n=335)	
Mean age in years (SD)	7.9 (2.4)
Age range in years	4 to 13
Gender	
Male	51.5%
Female	48.5%
Type of Seizures (n=226)	
Focal seizures	59.0%
Generalised seizures	39.9%
Undetermined	1.1%
Severity of Epilepsy (n=326)	
Extremely to Quite Severe	3.6%
Moderately to Somewhat Severe	22.9%
A little Severe	30.6%
Not at all Severe	42.9%
AED Usage Status	
Currently using 1 or more AEDs	80.1%
No Current AED Usage	19.9%

Table 4.3 Summary MPOC-20 Indicator Scores Six Months after Diagnosis of Epilepsy

Indicator	N	Mean	SD	Median
Question 1	297	5.44	1.46	6
Question 2	264	4.30	2.11	5
Question 3	299	5.16	1.62	6
Question 4	274	4.68	1.97	5
Question 5	298	4.97	1.70	5
Question 6	266	4.85	2.00	5
Question 7	298	5.28	1.66	6
Question 8	297	5.16	1.69	6
Question 9	306	5.36	1.70	6
Question 10	284	5.32	1.64	6
Question 11	304	5.12	1.73	6
Question 12	283	5.23	1.67	6
Question 13	301	5.25	1.71	6
Question 14	261	3.49	2.29	3
Question 15	297	5.25	1.74	6
Question 16	277	3.93	2.08	4
Question 17	283	4.38	1.96	5
Question 18	274	4.08	2.04	4
Question 19	280	4.07	2.08	4
Question 20	271	3.61	2.14	4

Table 4.4 Fit Indices for Factor MPOC-20 Models Assessed with HERQULES Time 2 Data (n=326)

Goodness of Fit Statistic	Original Model	Model 1	Model 2	Model 3	Model 4	Final Model
χ^2 (Degrees of Freedom)	427.448 (160)	506.072 (169)	393.877 (151)	341.874 (134)	286.787 (118)	205.277 (103)
<i>p</i> -value	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001
χ^2 /df Ratio	2.672	2.995	2.608	2.555	2.430	1.993
RMSEA (90% C.I.)	0.073 (.065-.082)	0.080 (.072-.088)	0.072 (.063-.081)	0.070 (.061-.080)	0.068 (.058-.078)	0.057 (.045-.068)
Bentler's CFI	0.922	0.902	0.923	0.929	0.939	0.958
SRMR	0.054	0.060	0.052	0.043	0.036	0.036

Table 4.5 MPOC-20 Modification Indices following Collapse of the Original Five-Factor Solution

'BY' Statements (i.e. Indicator Cross-loading)	Modification Indices
'Providing General Information' by Question 2	19.61
'Providing General Information' by Question 4	11.30
'Providing General Information' by Question 14	19.54
'WITH' Statements (i.e. Error Covariance)	
Question 3 with Question 2	24.15
Question 4 with Question 2	21.26
Question 4 with Question 3	19.86
Question 5 with Question 4	12.28
Question 6 with Question 5	11.39
Question 8 with Question 3	12.03
Question 8 with Question 7	57.41
Question 9 with Question 2	17.13
Question 9 with Question 4	10.89
Question 10 with Question 2	10.15
Question 10 with Question 9	14.84
Question 13 with Question 11	23.67
Question 14 with Question 2	38.72
Question 14 with Question 9	13.92
Question 18 with Question 17	10.49
Question 20 with Question 16	12.55

Table 4.6 MPOC-20 Modification Indices following the Removal of Question 2

'BY' Statements (i.e. Indicator Cross-loading)	Modification Indices
'Providing General Information' by Question 4	12.57
'Providing General Information' by Question 14	20.74
'WITH' Statements (i.e. Error Covariance)	
Question 4 with Question 3	22.15
Question 5 with Question 4	13.62
Question 6 with Question 5	11.26
Question 8 with Question 3	10.02
Question 8 with Question 7	54.99
Question 10 with Question 9	10.92
Question 13 with Question 11	22.52
Question 14 with Question 9	11.79
Question 18 with Question 17	10.24
Question 20 with Question 16	12.30

Table 4.7 MPOC-20 Modification Indices following the Removal of Question 14

'BY' Statements (i.e. Indicator Cross-loading)	Modification Indices
'Providing General Information' by Question 4	13.22
'WITH' Statements (i.e. Error Covariance)	
Question 4 with Question 3	22.52
Question 5 with Question 4	14.05
Question 6 with Question 5	10.83
Question 8 with Question 7	53.35
Question 13 with Question 11	22.33
Question 20 with Question 16	11.92

Table 4.8 MPOC-20 Modification Indices following the Removal of Question 4.

'BY' Statements (i.e. Indicator Cross-loading)	Modification Indices
None	
'WITH' Statements (i.e. Error Covariance)	
Question 3 with Question 1	10.82
Question 6 with Question 5	11.86
Question 8 with Question 7	54.30
Question 13 with Question 11	21.29
Question 18 with Question 17	10.11
Question 20 with Question 16	12.18

Table 4.9 MPOC-20 Modification Indices following the Removal of Question 7.

'BY' Statements (i.e. Indicator Cross-loading)	Modification Indices
None	
'WITH' Statements (i.e. Error Covariance)	
Question 6 with Question 5	12.07
Question 9 with Question 8	10.83
Question 13 with Question 11	18.05
Question 20 with Question 16	11.86

Chapter 5 – Discussion

5 Chapter Outline

This chapter summarizes the purpose of this thesis (Section 5.1) and discusses its results within the context of the findings of other studies (Section 5.2). It also describes the strengths and limitations of the study (Section 5.3), discusses the implications of the findings, and makes recommendations for future research (Section 5.4).

5.1 Study Purpose

The main goal of this work was to assess whether the MPOC-20's structural validity – and by extension, construct validity – remains intact when applied within the context of children with epilepsy. If the factor structure was found to be an invalid fit for this population, steps were then taken to re-establish its structural validity. This research built upon previous work by Hunter (2007) that re-established some dimensions of the MPOC's validity (e.g. face validity and concurrent validity) and reliability (e.g. internal consistency and test-retest reliability) within children with epilepsy. Confirmation of the MPOC's psychometric properties in children with epilepsy is required, because without such confirmation, any conclusions derived from its use in this particular population would not be credible.

Data for this work were taken from the Health-Related Quality of Life for Children with Epilepsy Study (HERQULES) – a multi-centre prospective cohort study that included children ages 4-12 with epilepsy. To our knowledge, this work is the first to explicitly focus on the validity of the MPOC's factor structure within this population.

5.2 Summary of Results and Interpretation

5.2.1 Reassessment of the MPOC-20's Factor Structure

The primary goal of this thesis was to assess whether the 20-indicator Measure of Processes of Care (MPOC-20) retained its factor structure in children with epilepsy. This measure ascertains, from the perspective of a parent, the degree to which the care received in the last 6 months was family centered. Family-Centred Care (FCC) is measured through five domains/factors that were identified in children with neurodevelopmental disabilities.

Using Confirmatory Factor Analysis (CFA), the MPOC's factor structure was assessed through interpretation of resulting goodness-of-fit statistics. The hypothesised factor structure was found not to 'fit' the responses of parents of children with epilepsy. The reasons for this poor model fit are likely similar to those described in studies where the MPOC was adopted in new treatment populations or environments.

The psychometric properties of a measure are dependent on the context in which it is being employed. The shifts in the factor structure that occur when the MPOC is moved to a new population or setting are likely due to differences in conditions, treatments, languages, ethnicity, culture, socioeconomics, and service delivery models (Chong et al., 2012; Klassen et al., 2009; McConachie & Logan, 2003; Moore et al., 2009; Saloojee et al., 2009; Siebes et al., 2007). To use the MPOC-20 among children with epilepsy is to move the tool into a population with different characteristics than those of children

with neurodevelopmental disabilities – hence the increased likelihood that the original model will have a poor fit in the new population.

For example, children with cerebral palsy made up 25.3% of the MPOC-20's validation sample. Symptoms of this condition include 'global mental and physical dysfunction or isolated disturbances in gait, cognition, growth, or sensation.' Thus, a feature of care for these patients is the regular use of rehabilitation services such as physical therapy (S. King, Teplicky, et al., 2004; Krigger, 2006). The condition is neither progressive nor curable, which makes the goal of treatment not to achieve normalcy, but to maximise functionality, capability, locomotive abilities, cognitive development, social interaction, and independence (Krigger, 2006).

The clinical presentation of epilepsy, however, is marked by a 'transient' occurrence of seizures (Fisher et al., 2005). Patients experience intermittent and episodic seizures rather than the continuous physical impairment as is seen in patients with cerebral palsy. Treatment is different as well – the primary goal of treatment is not to manage the condition through rehabilitative services such as physical therapy, but rather to attain seizure-free status, or at least reduce the severity of seizures (e.g. frequency, intensity, impact on daily life) through antiepileptic drugs (AEDs) (Goldenberg, 2010).

This suggests that there may be differences in the perceptions of FCC and differences in how it is delivered. Priorities for children and parents are likely to vary by condition. In addition, features of care that may be present in the treatment of one condition may be absent from the treatment of another group. Thus, rather than pursue this ill-fitting

factor solution, an exploratory analysis within a confirmatory factor analysis framework was performed. The goal was to identify a better fitting factor solution for children with epilepsy (T. A. Brown, 2006).

5.2.2 Re-establishment of the MPOC-20's Structural Validity

Further investigation of the goodness-of-fit statistics identified a lack of parsimony in the original five-factor model – there were more indicators and factors than necessary to measure FCC in children with epilepsy. The ensuing exploratory process attained a two factor solution with 16 indicators – a simpler and more interpretable factor solution in this population. This contrasts with the original five-factor solution with 20 indicators identified in children with neurodevelopmental disorders.

Taken together, the ill fit of the original factor structure and the subsequent identification of a two-factor solution in children with epilepsy adds to prior evidence of the MPOC's factor instability in new treatment populations or settings. The MPOC-20 continues to perform well when used in its initial population, but less well when adapted for a different context. These results also underscore the need for steps to ensure that a measurement tool is appropriate for the target population.

In this case, the first step was to identify the optimal number of factors needed to reflect the experiences of care for children with epilepsy. Four of the five factors had poor discriminant validity – their underlying constructs overlapped significantly. For children with epilepsy, only a single overarching construct was needed to explain the phenomenon being collectively measured by these factors. The “Family/Provider

Interaction” factor initially contained all 15 items formerly belonging to the original four factors. All 5 indicators that had loaded onto the “Providing General Information” factor in the original model now loaded definitively onto the new “Providing Information” factor. This new factor remained moderately, rather than strongly correlated with “Family/Provider Interaction” ($r=0.584$) – making it a distinct, though related construct.

The number of indicators in the final model was fewer than in the original model as well. In the search for sources of poor model fit, four indicators were identified as warranting closer investigation. Each of these indicators tapped some aspect of information-provision by care providers. The content of Question 7 (*In the past year, to what extent do the people who work with your child fully explain treatment choices to you?*) was found to be statistically and conceptually redundant with Question 8 (*In the past year, to what extent do the people who work with your child provide opportunities for you to make decisions about treatment?*). Because the content in Question 7 was reasoned to be a necessary precursor for the behaviour in Question 8 to occur, it was identified as a problematic indicator and therefore dropped from the model.

The three remaining indicators that were removed each tapped a clinical information-giving behaviour that was evaluated to not be a central facet of care for children with epilepsy. One question tapped the provision of written information on the child’s progress in general; another question measured the child’s progress in treatment. The final question tapped whether parents were given a choice of what type of information they wished to receive, and when.

There are two potential explanations for this outcome. First, it is possible that the episodic nature of the condition of epilepsy may drive the process of information exchange among stakeholders more so than parent/provider interaction. As mentioned previously, children with epilepsy differ from children with neurodevelopmental disorders in that they tend to experience sporadic, unpredictable episodes of seizure activity, as opposed to a sustained, continual presentation of symptoms. As well, much of the presentation of epilepsy and the effects of treatment tend to occur beyond the purview of the care provider – at home, at school, and within the community.

Information is therefore more likely to exist in the form of a report on the child's health status by the patient and family to the care provider, rather than a formal assessment on the progress of therapy provided by health professionals to families.

Second, it may be that the flow of information is more likely to entail written information when care is delivered within the context of an inter-professional team rather than by a single professional. This behaviour would ensure that all team members – including family members – are up-to-date and all have the same information on the child's progress and health in general. Moreover, a clinical coordinator on such a team, in the form of a nurse or social worker could potentially further the lengths to which information is written, and how and when it is delivered.

5.3 Strengths and Limitations

This work had several strengths. It was the first to explicitly examine the structural validity of the MPOC-20 in a sample of children with epilepsy. Another advantage of this work lay in its methodology, as it performed a confirmatory factor analysis (CFA). This methodology allowed us to make modifications using a statistical basis as well as information on the MPOC's development and information on epilepsy as a condition. This contrasts with the usage of Principal Components Analysis or pure EFA, which assumes that there is no a priori knowledge of the interrelations among indicators.

Another strength of this work was that its analyses were performed on a relatively large sample size of 311 patients – more than ample for a CFA to be performed. In addition, data on the perceptions of the degree to which services were family-centred came from parental self-reports rather than through clinician self-reports – thereby gathering a more representative picture of how families perceive their child's care. Lastly, data came from HERQULES – a multi-centre prospective cohort study that examined children with epilepsy both longitudinally and across the country. This presented an opportunity to study a sample of children being treated at multiple sites over time by a consistent paediatric neurology service.

The main limitation of this work is that the HERQULES questionnaire was not primarily designed to measure health services utilization, or the characteristics of the services received by the child and family. The lack of this type of information made it difficult to draw definite conclusions in a number of areas, including the reasons why parents

answered “Not applicable” to indicators on the questionnaire. This meant that some of our interpretations of the patient and family experiences during the treatment of epilepsy are more speculative than empirical in nature.

Another potential limitation is that the CFA was based on information about FCC in the context of children with neurodevelopmental disorders. By restricting the analysis to what is known about FCC in this population, it is possible that other elements of FCC applicable specifically to patients with epilepsy may not be captured by the revised MPOC-16. To identify these potential elements would require a purely exploratory analysis much like that used in the construction of the original MPOC-56 and MPOC-20. This is a time-consuming and potentially expensive process (Harrington, 2008) that was beyond the scope of this thesis – it still, however, represents an important, subsequent step to be taken.

5.4 Conclusions

The result of this thesis was a revised version of the MPOC-20 with a smaller number of factors and indicators. Further steps should be taken to investigate these results. First and foremost, as the revised model is exploratory rather than confirmatory, these results should be replicated in another sample of children with epilepsy (T. A. Brown, 2006; Harrington, 2008; Streiner & Norman, 2008). These studies should be based on samples with a wide array of characteristics, including the severity of epilepsy and socioeconomic status. It is possible that more disadvantaged patients and families may

have different informational needs than families with lesser clinical or socioeconomic burdens.

It is also recommended that any future investigations into the validity of the MPOC-20 in other contexts and populations include an assessment of its structural validity as was conducted here. This may be an effective means of ensuring that the content of the questionnaire is context-appropriate, and that it measures FCC as experienced by the target population.

Second, additional work should be done to ascertain whether new indicators are needed to replace the four that were removed, or if two scores calculated by 16 indicators is suitable for this population. Replacing the indicators that were removed from the model would likely entail re-wording the questions to account for the impact of intermittent seizure episodes on the information exchange process.

This thesis was the first step in determining whether the delivery of FCC has a quantifiable impact on the trajectory of health-related quality of life (HRQL) for children with epilepsy. The benefit of having a smaller number of factors is that scoring is simpler and that interpretation of the results is easier. In addition, having a two-factor measure of FCC will make it easier to predict and understand the potential impact that FCC may have on the HRQL of children in this population. Despite a smaller number of factors, it is still possible to identify specific areas for improvement by analysing responses on a per-indicator basis.

References

- Aday, L. A., & Cornelius, L. J. (2006). *Designing and Conducting Health Surveys: A Comprehensive Guide* (3 edition.). San Francisco: Jossey-Bass.
- Austin, J., Huster, G. A., Dunn, D. W., & Risinger, M. W. (1996). Adolescents with Active or Inactive Epilepsy or Asthma: A Comparison of Quality of Life. *Epilepsia*, *37*(12), 1228–1238. doi:10.1111/j.1528-1157.1996.tb00558.x
- Austin, J., MacLeod, J., Dunn, D. W., Shen, J., & Perkins, S. M. (2004). Measuring stigma in children with epilepsy and their parents: instrument development and testing. *Epilepsy & Behavior: E&B*, *5*(4), 472–482. doi:10.1016/j.yebeh.2004.04.008
- Austin, J., & McDermott, N. (1988). Parental attitude and coping behaviors in families of children with epilepsy. *The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses*, *20*(3), 174–179.
- Austin, J., Shafer, P. O., & Deering, J. B. (2002). Epilepsy familiarity, knowledge, and perceptions of stigma: report from a survey of adolescents in the general population. *Epilepsy & Behavior: E&B*, *3*(4), 368–375.
- Bailey, D. B. (1992). FOCAS: Family Orientation of Community and Agency Services. In D. B. Bailey, P. J. McWilliam, P. J. Winton, & R. J. Simeonsson (Eds.), *Implementing family-centered services in early intervention: A team-based model for change*. Cambridge, MA: Brookline.
- Bamm, E. L., Rosenbaum, P., & Stratford, P. (2010). Validation of the measure of processes of care for adults: a measure of client-centred care. *International Journal for Quality in Health Care*, *22*(4), 302–309. doi:10.1093/intqhc/mzq031
- Berg, A. T., Berkovic, S. F., Brodie, M. J., Buchhalter, J., Cross, J. H., van Emde Boas, W., ... Scheffer, I. E. (2010). Revised terminology and concepts for organization of seizures and epilepsies: report of the ILAE Commission on Classification and Terminology, 2005-2009. *Epilepsia*, *51*(4), 676–685. doi:10.1111/j.1528-1167.2010.02522.x
- Betz, C. L. (2006). Parent-professional partnerships: bridging the disparate worlds of children, families, and professionals. *Journal of Pediatric Nursing*, *21*(5), 333–336. doi:10.1016/j.pedn.2006.06.002
- Bishop, K. K., Woll, J., & Arango, P. (1993). *Family/Professional Collaboration for Children with Special Health Needs and Their Families*. Burlington, VT: University of Vermont, Department of Social Work. Retrieved from <http://eric.ed.gov/?id=ED381518>
- Bowen, N. K., & Guo, S. (2012). *Structural Equation Modeling*. Oxford University Press.

- Brophy, M., & Barrow, C. (2010). Health problems of the neonate. In E. A. Glasper & J. Richardson (Eds.), *A Textbook of Children's and Young People's Nursing, 2e* (2nd ed., pp. 623–36). Churchill Livingstone.
- Brown, R. T. (2008). Single Parents of Children with Chronic Illness: An Understudied Phenomenon. *Journal of Pediatric Psychology, 33*(4), 408–421.
- Brown, T. A. (2006). *Confirmatory Factor Analysis for Applied Research*. Guilford Press.
- Brown, T. A., & Moore, M. T. (2014). Confirmatory Factor Analysis. In R. H. Hoyle (Ed.), *Handbook of Structural Equation Modeling* (pp. 361–379). Guilford Publications.
- Bury, M. (2005). What is Health? In *Health and Illness* (pp. 1–20). Polity.
- Camfield, P., & Camfield, C. (2010). Idiopathic generalized epilepsy with generalized tonic-clonic seizures (IGE-GTC): a population-based cohort with >20 year follow up for medical and social outcome. *Epilepsy & Behavior: E&B, 18*(1-2), 61–63. doi:10.1016/j.yebeh.2010.02.014
- Campbell, S., & Summersgill, P. (1993). Keeping it in the family: Defining and developing family centred care. *Child Health, 1*(1), 17–20.
- CanChild. (2013, February 5). MPOC-56 & MPOC-20 - CanChild. Retrieved March 12, 2013, from http://www.canchild.ca/en/measures/mpoc56_mpoc20.asp
- Caplan, R., Arbelle, S., Magharious, W., Guthrie, D., Komo, S., Shields, W. D., ... Hansen, R. (1998). Psychopathology in pediatric complex partial and primary generalized epilepsy. *Developmental Medicine & Child Neurology, 40*(12), 805–811. doi:10.1111/j.1469-8749.1998.tb12357.x
- Caplan, R., Siddarth, P., Gurbani, S., Hanson, R., Sankar, R., & Shields, W. D. (2005). Depression and Anxiety Disorders in Pediatric Epilepsy. *Epilepsia, 46*(5), 720–730. doi:10.1111/j.1528-1167.2005.43604.x
- Carpay, H. A., Vermeulen, J., Stroink, H., FBrouwer, O., Peters, A. C. B., & van Donselaar, C. A. (1997). Disability due to restrictions in childhood epilepsy. *Developmental Medicine & Child Neurology, 39*(8), 521–526. doi:10.1111/j.1469-8749.1997.tb07480.x
- Cattell, R. (1978). *The Scientific Use of Factor Analysis in Behavioral and Life Sciences* (1 edition.). New York: Springer.
- CDC/National Center for Health Statistics. (2013, April 17). 2005 – 06 National Survey of Children with Special Health Care Needs. Retrieved December 21, 2013, from <http://www.cdc.gov/nchs/data/slait/NSCSHCNIIEnglishQuest.pdf>
- Centre for Addiction and Mental Health (CAMH). (2004). *Putting Family-Centred Care Philosophy into Practice*. Centre for Addiction and Mental Health. Retrieved from http://www.camh.ca/en/hospital/Documents/www.camh.net/Care_Treatment/Community_and_social_supports/Social_Support/FCCL/FCC_Better_Practices_PD F.pdf

- Cheung, C., & Wirrell, E. (2006). Adolescents' perception of epilepsy compared with other chronic diseases: "through a teenager's eyes." *Journal of Child Neurology*, 21(3), 214–222.
- Chong, W. H., Goh, W., Tang, H. N., Chan, W. P., & Choo, S. (2012). Service Practice Evaluation of the Early Intervention Programs for Infants and Young Children in Singapore. *Children's Health Care*, 41(4), 281–301. doi:10.1080/02739615.2012.721719
- Chu, S., & Reynolds, F. (2007). Occupational Therapy for Children with Attention Deficit Hyperactivity Disorder (ADHD), Part 2: a Multicentre Evaluation of an Assessment and Treatment Package. *The British Journal of Occupational Therapy*, 70(10), 439–448.
- Committee on Hospital Care, & Institute for Patient- and Family-Centered Care. (2012). Patient- and Family-Centered Care and the Pediatrician's Role. *Pediatrics*, 129(2), 394–404. doi:10.1542/peds.2011-3084
- Corlett, J., & Twycross, A. (2006). Negotiation of parental roles within family-centred care: a review of the research. *Journal of Clinical Nursing*, 15(10), 1308–1316. doi:10.1111/j.1365-2702.2006.01407.x
- Cummins, R. A. (2005). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research: JIDR*, 49(Pt 10), 699–706. doi:10.1111/j.1365-2788.2005.00738.x
- Daoud, A. S., Batieha, A., Bashtawi, M., & El-Shanti, H. (2003). Risk factors for childhood epilepsy: a case-control study from Irbid, Jordan. *Seizure*, 12(3), 171–174. doi:10.1016/S1059-1311(02)00194-2
- Darbyshire, P. (1993). Parents, nurses and paediatric nursing: a critical review. *Journal of Advanced Nursing*, 18(11), 1670–1680. doi:10.1046/j.1365-2648.1993.18111670.x
- Dempsey, I., & Keen, D. (2008). A Review of Processes and Outcomes in Family-Centered Services for Children With a Disability. *Topics in Early Childhood Special Education*, 28(1), 42–52. doi:10.1177/0271121408316699
- Dillman, D. A., Smyth, J. D., & Christian, L. M. (2008). *Internet, Mail, and Mixed-Mode Surveys: The Tailored Design Method* (3rd ed.). Wiley.
- Donabedian, A. (1997). Special article: The quality of care: How can it be assessed? *Archives of Pathology & Laboratory Medicine*, 121(11), 1145–50.
- Drazkowski, J., & Sirven, J. (2005). Driving and Social Issues in Epilepsy. In E. Wyllie, A. Gupta, & D. K. Lachhwani (Eds.), *The Treatment of Epilepsy: Principles and Practice* (Fourth., pp. 1202–1209). Lippincott Williams & Wilkins.
- Dunn, D. W. (1999). Symptoms of Depression in Adolescents With Epilepsy. *Journal of the American Academy of Child & Adolescent Psychiatry*, 38(9), 1132–1138.

- Dunn, D. W., & Kronenberger, W. G. (2005). Childhood epilepsy, attention problems, and ADHD: review and practical considerations. *Seminars in Pediatric Neurology*, 12(4), 222–228. doi:10.1016/j.spn.2005.12.004
- Dunst, C. J., Boyd, K., Trivette, C. M., & Hamby, D. W. (2002). Family-Oriented Program Models and Professional Helppgiving Practices*. *Family Relations*, 51(3), 221–229. doi:10.1111/j.1741-3729.2002.00221.x
- Dunst, C. J., Johanson, C., & al, et. (1991). Family-Oriented Early Intervention Policies and Practices: Family-Centered or Not? *Exceptional Children*, 58(2), 115.
- Elliot, I., Lach, L. M., & Smith, M. L. (2005, October 31). Epilepsy: Impact on the Life of the Child. Retrieved October 26, 2013, from http://www.epilepsy.com/articles/ar_1130770266
- Elliott, R. E., Rodgers, S. D., Bassani, L., Morsi, A., Geller, E. B., Carlson, C., ... Doyle, W. K. (2011). Vagus nerve stimulation for children with treatment-resistant epilepsy: a consecutive series of 141 cases. *Journal of Neurosurgery. Pediatrics*, 7(5), 491–500. doi:10.3171/2011.2.PEDS10505
- Ellis, N., Upton, D., & Thompson, P. (2000). Epilepsy and the family: a review of current literature. *Seizure*, 9(1), 22–30. doi:10.1053/seiz.1999.0353
- Epilepsy Canada. (2005a). Epidemiology: Prevalence and Incidence. Retrieved April 28, 2012, from <http://www.epilepsy.ca/en-CA/Facts/Epidemiology.html>
- Epilepsy Canada. (2005b). Epilepsy Facts - Did You Know? Retrieved April 28, 2012, from <http://www.epilepsy.ca/en-CA/Facts/Epilepsy-Facts.html>
- Espe-Sherwindt, M. (2008). Family-Centred Practice: Collaboration, Competency and Evidence. *Support for Learning*, 23(3), 136–143.
- Ettinger, A. B., Weisbrot, D. M., Nolan, E. E., Gadow, K. D., Vitale, S. A., Andriola, M. R., ... Hermann, B. P. (1998). Symptoms of Depression and Anxiety in Pediatric Epilepsy Patients. *Epilepsia*, 39(6), 595–599. doi:10.1111/j.1528-1157.1998.tb01427.x
- Family Voices. (2008). The Family-Centered Care Self-Assessment Tools. Retrieved December 7, 2013, from https://org2.salsalabs.com/o/6739/t/11331/shop/item.jsp?storefront_KEY=347&t=&store_item_KEY=1469
- Family Voices. (2013, Winter). Family Driven Quality Measurement to Promot Family-Centered Care'. Retrieved December 7, 2013, from <http://www.fv-ncfpp.org/activities/fcc-tool-validation/>
- Ferro, M. A., Avison, W. R., Campbell, K. M., & Speechley, K. N. (2011). The impact of maternal depressive symptoms on health-related quality of life in children with epilepsy: A prospective study of family environment as mediators and moderators. *Epilepsia*, 52(2), 316–325. doi:10.1111/j.1528-1167.2010.02769.x

- Fessler, A. J., & Treiman, D. M. (2009). Epilepsy and aggression Proceed with caution. *Neurology*, *73*(21), 1720–1721. doi:10.1212/WNL.0b013e3181c467af
- Finney, S. J., & DiStefano, C. (2013). Nonnormal and categorical data in structural equation models. In G. R. Hancock & R. O. Mueller (Eds.), *Structural Equation Modeling: A Second Course* (2nd ed., pp. 439–492). Charlotte, NC: IAP.
- Fisher, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, J. H., Elger, C. E., ... Wiebe, S. (2014). ILAE Official Report: A practical clinical definition of epilepsy. *Epilepsia*, *55*(4), 475–482. doi:10.1111/epi.12550
- Fisher, R. S., Boas, W. van E., Blume, W., Elger, C., Genton, P., Lee, P., & Engel, J. (2005). Epileptic Seizures and Epilepsy: Definitions Proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia*, *46*(4), 470–472. doi:10.1111/j.0013-9580.2005.66104.x
- Franck, L. S., & Callery, P. (2004). Re-thinking family-centred care across the continuum of children's healthcare. *Child: Care, Health and Development*, *30*(3), 265–277. doi:10.1111/j.1365-2214.2004.00412.x
- Freilinger, M., Reisel, B., Reiter, E., Zelenko, M., Hauser, E., & Seidl, R. (2006). Behavioral and emotional problems in children with epilepsy. *Journal of Child Neurology*, *21*(11), 939–945.
- Furr, R. M. (2011). Confirmatory Factor Analysis as a Psychometric tool. In *Scale Construction and Psychometrics for Social and Personality Psychology* (pp. 91–109). SAGE Publications.
- Garwick, A., Kohrman C, Wolman C, & Blum RW. (1998). Families' recommendations for improving services for children with chronic conditions. *Archives of Pediatrics & Adolescent Medicine*, *152*(5), 440–448. doi:10.1001/archpedi.152.5.440
- Geerts, A., Arts, W. F., Stroink, H., Peeters, E., Brouwer, O., Peters, B., ... Van Donselaar, C. (2010). Course and outcome of childhood epilepsy: A 15-year follow-up of the Dutch Study of Epilepsy in Childhood. *Epilepsia*, *51*(7), 1189–1197. doi:10.1111/j.1528-1167.2010.02546.x
- Goetz, A. L., Gavin, W., & Lane, S. J. (2000). Measuring parent/professional interaction in early intervention: Validity and reliability. *The Occupational Therapy Journal of Research*, *20*(4), 222–240.
- Goldenberg, M. M. (2010). Overview of Drugs Used For Epilepsy and Seizures. *Pharmacy and Therapeutics*, *35*(7), 392–415.
- Harrington, D. (2008). *Confirmatory Factor Analysis*. Oxford University Press.
- Hoare, P., Mann, H., & Dunn, S. (2000). Parental perception of the quality of life among children with epilepsy or diabetes with a new assessment questionnaire. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *9*(6), 637–644.

- Hobbs, N. (1985). *Chronically ill children and their families* (1st ed. --). San Francisco: Jossey-Bass.
- Høie, B., Sommerfelt, K., Waaler, P. E., Alsaker, F. D., Skeidsvoll, H., & Mykletun, A. (2006). Psychosocial problems and seizure-related factors in children with epilepsy. *Developmental Medicine and Child Neurology, 48*(3), 213–219. doi:10.1017/S0012162206000454
- Hoyle, R. H. (2014). Introduction and Overview. In R. H. Hoyle (Ed.), *Handbook of Structural Equation Modeling* (pp. 361–379). Guilford Publications.
- Hunter, E. (2007). *Psychometric Properties of the Measure of Processes of Care (MPOC-20) in Children with Epilepsy*. University of Western Ontario, London, Ontario.
- Hutchfield, K. (1999). Family-centred care: a concept analysis. *Journal of Advanced Nursing, 29*(5), 1178–1187. doi:10.1046/j.1365-2648.1999.00987.x
- Institute for Patient- and Family-Centered Care. (2010, December 29). Frequently Asked Questions. Retrieved January 16, 2013, from <http://www.ipfcc.org/faq.html>
- Jalava, M., Sillanpää, M., Camfield, C., & Camfield, P. (1997). Social Adjustment and Competence 35 Years After Onset of Childhood Epilepsy: A Prospective Controlled Study. *Epilepsia, 38*(6), 708–715. doi:10.1111/j.1528-1157.1997.tb01241.x
- Judge, S. L. (1997). Parental Perceptions of Help-Giving Practices and Control Appraisals in Early Intervention Programs. *Topics in Early Childhood Special Education, 17*(4), 457–476. doi:10.1177/027112149701700406
- Keene, D. L. (2006). A systematic review of the use of the ketogenic diet in childhood epilepsy. *Pediatric Neurology, 35*(1), 1–5. doi:10.1016/j.pediatrneurol.2006.01.005
- Kenny, D. A., Milan, S., & Hoyle, R. H. (2014). Identification. In *Handbook of Structural Equation Modeling* (pp. 361–379). Guilford Publications.
- King, G., King, S., & Rosenbaum, P. (1996). Interpersonal aspects of care-giving and client outcomes: A review of the literature. *Ambulatory Child Health, 2*, 151–160.
- King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Pediatric Psychology, 24*(1), 41–53. doi:10.1093/jpepsy/24.1.41
- King, G., Rosenbaum, P., & King, S. (1997). Evaluating family-centred service using a measure of parents' perceptions. *Child: Care, Health and Development, 23*(1), 47–62.
- King, S., King, G., & Rosenbaum, P. (2004). Evaluating Health Service Delivery to Children With Chronic Conditions and Their Families: Development of a Refined Measure of Processes of Care (MPOC–20). *Children's Health Care, 33*(1), 35–57. doi:10.1207/s15326888chc3301_3

- King, S., Rosenbaum, P., & King, G. (1995). *The Measure of Processes of Care: A Means to Assess Family-centred Behaviours of Health Care Providers*. Neurodevelopmental Clinical Research Unit, McMaster University.
- King, S., Rosenbaum, P., & King, G. (1996). Parents' perceptions of caregiving: development and validation of a measure of processes. *Developmental Medicine and Child Neurology*, 38(9), 757–772.
- King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-Centered Service for Children With Cerebral Palsy and Their Families: A Review of the Literature. *Seminars in Pediatric Neurology*, 11(1), 78–86. doi:10.1016/j.spn.2004.01.009
- Klassen, A. F., Dix, D., Cano, S. J., Papsdorf, M., Sung, L., & Klaassen, R. J. (2009). Evaluating family-centred service in paediatric oncology with the measure of processes of care (MPOC-20). *Child: Care, Health and Development*, 35(1), 16–22. doi:10.1111/j.1365-2214.2008.00887.x
- Klassen, A. F., Raina, P., McIntosh, C., Sung, L., Klaassen, R. J., O'Donnell, M., ... Dix, D. (2011). Parents of children with cancer: Which factors explain differences in health-related quality of life. *International Journal of Cancer*, 129(5), 1190–1198. doi:10.1002/ijc.25737
- Kline, R. B. (2011). *Principles and Practice of Structural Equation Modeling*. Guilford Press.
- Kokkonen, J., Kokkonen, E. R., Saukkonen, A. L., & Pennanen, P. (1997). Psychosocial outcome of young adults with epilepsy in childhood. *Journal of Neurology, Neurosurgery & Psychiatry*, 62(3), 265–268. doi:10.1136/jnnp.62.3.265
- Kotsopoulos, I. A. W., van Merode, T., Kessels, F. G. H., de Krom, M. C. T. F. M., & Knottnerus, J. A. (2002). Systematic review and meta-analysis of incidence studies of epilepsy and unprovoked seizures. *Epilepsia*, 43(11), 1402–1409.
- Krigger, K. W. (2006). Cerebral palsy: an overview. *American Family Physician*, 73(1), 91–100.
- Kuo, D. Z., Bird, T. M., & Tilford, J. M. (2011). Associations of family-centered care with health care outcomes for children with special health care needs. *Maternal and Child Health Journal*, 15(6), 794–805. doi:10.1007/s10995-010-0648-x
- Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-Centered Care: Current Applications and Future Directions in Pediatric Health Care. *Maternal and Child Health Journal*, 16(2), 297–305. doi:10.1007/s10995-011-0751-7
- Lefevre, F., & Aronson, N. (2000). Ketogenic diet for the treatment of refractory epilepsy in children: A systematic review of efficacy. *Pediatrics*, 105(4), E46.
- Lehne, R. A. (2012). Drugs for Epilepsy. In *Pharmacology for Nursing Care* (Eighth ed.). St. Louis, USA: Elsevier Health Sciences.

- Lindeke, L. L., Leonard, B. J., Presler, B., & Garwick, A. (2002). Family-centered care coordination for children with special needs across multiple settings. *Journal of Pediatric Health Care: Official Publication of National Association of Pediatric Nurse Associates & Practitioners*, 16(6), 290–297.
- Lovat, A., Mayes, R., McConnell, D., & Clemson, L. (2010). Family caregivers' perceptions of hospital-based allied health services post-stroke: Use of the Measure of Processes of Care to investigate processes of care. *Australian Occupational Therapy Journal*, 57(3), 167–173. doi:10.1111/j.1440-1630.2009.00828.x
- MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 8(1), 74–85. doi:10.1111/j.1369-7625.2005.00319.x
- Maguire, M., Marson, A. G., & Ramaratnam, S. (2012). Epilepsy (generalised). *Clinical Evidence*, 2012.
- Mah, J. K., Tough, S., Fung, T., Douglas-England, K., & Verhoef, M. (2006). Adolescent quality of life and satisfaction with care. *Journal of Adolescent Health*, 38(5), 607.e1–607.e7. doi:10.1016/j.jadohealth.2005.08.004
- Mardia, K. V., Kent, J. T., & Bibby, J. M. (1980). *Multivariate Analysis* (1 edition.). London; New York: Academic Press.
- Maternal and Child Health Bureau. (2005). *Definition of Family-Centered Care*. Retrieved from http://www.familyvoices.org/admin/work_family_centered/files/FCCare.pdf
- McConachie, H., & Logan, S. (2003). Validation of the measure of processes of care for use when there is no Child Development Centre. *Child: Care, Health and Development*, 29(1), 35–45. doi:10.1046/j.1365-2214.2003.00314.x
- McKean, K., Phillips, B., & Thompson, A. (2012). A family-centred model of care in paediatric speech-language pathology. *International Journal of Speech-Language Pathology*, 14(3), 235–246. doi:10.3109/17549507.2011.604792
- Meador, K. (2011). Cognitive Effects of Epilepsy and of Antiepileptic Medications. In E. Wyllie, G. Cascino, B. Gidal, & H. Goodkin (Eds.), *Wyllie's Treatment of Epilepsy: Principles and Practice*. Philadelphia: Wolters Kluwer/Lippincott Williams & Wilkins. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&NEWS=n&CSC=Y&PAGE=booktext&D=books&SC=01437582>
- Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2002). The Medical Home. *Pediatrics*, 110(1), 184–186.
- Miller, A. R., Recsky, M. A., & Armstrong, R. W. (2004). Responding to the needs of children with chronic health conditions in an era of health services reform.

- CMAJ: Canadian Medical Association Journal*, 171(11), 1366–1367.
doi:10.1503/cmaj.1040019
- Modi, A. C., Ingerski, L. M., Rausch, J. R., & Glauser, T. A. (2011). Treatment Factors Affecting Longitudinal Quality of Life in New Onset Pediatric Epilepsy. *Journal of Pediatric Psychology*, 36(4), 466–475. doi:10.1093/jpepsy/jsq114
- Mokkink, L. B., Terwee, C. B., Patrick, D. L., Alonso, J., Stratford, P. W., Knol, D. L., ... de Vet, H. C. W. (2010). The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *Journal of Clinical Epidemiology*, 63(7), 737–745. doi:10.1016/j.jclinepi.2010.02.006
- Moore, M. H., Mah, J. K., & Trute, B. (2009). Family-centred care and health-related quality of life of patients in paediatric neurosciences. *Child: Care, Health and Development*, 35(4), 454–461. doi:10.1111/j.1365-2214.2008.00902.x
- Murphy, D. L., Lee, I. M., Turnbull, A. P., & Turbiville, V. (1995). The Family-Centered Program Rating Scale An Instrument for Program Evaluation and Change. *Journal of Early Intervention*, 19(1), 24–42. doi:10.1177/105381519501900104
- Muthén, L. K., & Muthén, B. O. (2012). *Mplus User's Guide* (Seventh Edition.). Los Angeles, CA: Muthén & Muthén.
- National Institutes of Health. (2012, February 16). Epilepsy: MedlinePlus Medical Encyclopedia. Retrieved October 25, 2013, from <http://www.nlm.nih.gov/medlineplus/ency/article/000694.htm>
- Norman, G. R., & Streiner, D. L. (2008). *Biostatistics: The Bare Essentials*. PMPH-USA.
- O'Neil, M. E., Palisano, R. J., & Westcott, S. L. (2001). Relationship of Therapists' Attitudes, Children's Motor Ability, and Parenting Stress to Mothers' Perceptions of Therapists' Behaviors During Early Intervention. *Physical Therapy*, 81(8), 1412–1424.
- Palisano, R. J., Chiarello, L. A., Orlin, M., Oeffinger, D., Polansky, M., Maggs, J., ... Children's Activity and Participation Group. (2011). Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy. *Developmental Medicine and Child Neurology*, 53(2), 142–149. doi:10.1111/j.1469-8749.2010.03819.x
- Plioplys, S., Dunn, D. W., & Caplan, R. (2007). 10-Year Research Update Review: Psychiatric Problems in Children With Epilepsy. *Journal of the American Academy of Child & Adolescent Psychiatry*, 46(11), 1389–1402.
- Poenaru, D., Roblin, N., Bird, M., Duce, S., Groll, A., Pietak, D., ... Thompson, J. (1997). The pediatric bowel management clinic: Initial results of a multidisciplinary approach to functional constipation in children. *Journal of Pediatric Surgery*, 32(6), 843–848. doi:10.1016/S0022-3468(97)90633-3

- Prasad, A., Sang, X., Corbett, B., & Burneo, J. (2011). Prevalence of childhood epilepsy in Canada. *Canadian Journal of Neurological Sciences*, *38*(5), 719–722.
- Purnell, L. D. (2012). *Transcultural Health Care: A Culturally Competent Approach*. F.A. Davis.
- Räty, L. K. A., Larsson, B. M. W., & Söderfeldt, B. A. (2003). Health-related quality of life in youth: a comparison between adolescents and young adults with uncomplicated epilepsy and healthy controls. *Journal of Adolescent Health*, *33*(4), 252–258.
- Raykov, T., & Marcoulides, G. A. (2012). *An Introduction to Applied Multivariate Analysis*. Routledge.
- Reid, A. Y., Metcalfe, A., Patten, S. B., Wiebe, S., Macrodimitris, S., & Jetté, N. (2012). Epilepsy is associated with unmet health care needs compared to the general population despite higher health resource utilization—A Canadian population-based study. *Epilepsia*, *53*(2), 291–300. doi:10.1111/j.1528-1167.2011.03353.x
- Rhemtulla, M., Brosseau-Liard, P. É., & Savalei, V. (2012). When can categorical variables be treated as continuous? A comparison of robust continuous and categorical SEM estimation methods under suboptimal conditions. *Psychological Methods*, *17*(3), 354–373. doi:10.1037/a0029315
- Robson, C. (2006). *Examining the social stigma of epilepsy: a qualitative analysis of attitudes, perceptions and understanding towards epilepsy and people with epilepsy among young adults in the undergraduate population* (MSc Thesis). University of York, UK, Dept of Health Sciences.
- Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-Centred Service. *Physical & Occupational Therapy in Pediatrics*, *18*(1), 1–20. doi:10.1080/J006v18n01_01
- Rosenbaum, P., Russell, D. J., Cadman, D. T., Gowland, C., Jarvis, S., & Hardy, S. (1990). Issues in Measuring Change in Motor Function in Children with Cerebral Palsy: A Special Communication. *Physical Therapy*, *70*(2), 125–131.
- Ryan, E., & Steinmiller, E. (2004). Modeling Family-Centered Pediatric Nursing Care: Strategies for Shift Report. *Journal for Specialists in Pediatric Nursing*, *9*(4), 123–134. doi:10.1111/j.1547-5069.2004.00123.x
- Sabaz, M., Cairns, D. R., Lawson, J. A., Bleasel, A. F., & Bye, A. M. E. (2001). The Health-Related Quality of Life of Children with Refractory Epilepsy: A Comparison of Those With and Without Intellectual Disability. *Epilepsia*, *42*(5), 621–628. doi:10.1046/j.1528-1157.2001.25200.x
- Saloojee, G. M., Rosenbaum, P. R., Westaway, M. S., & Stewart, A. V. (2009). Development of a measure of family-centred care for resource-poor South African settings: the experience of using a modified version of the MPOC-20.

- Child: Care, Health and Development*, 35(1), 23–32. doi:10.1111/j.1365-2214.2008.00914.x
- Sánchez-Carpintero, R., & Neville, B. G. R. (2003). Attentional ability in children with epilepsy. *Epilepsia*, 44(10), 1340–1349.
- Schmitt, T. A. (2011). Current Methodological Considerations in Exploratory and Confirmatory Factor Analysis. *Journal of Psychoeducational Assessment*, 29(4), 304–321. doi:10.1177/0734282911406653
- Shaller, D. (2007). *Patient-Centered Care: What Does It Take?*. The Commonwealth Fund. Retrieved from http://www.commonwealthfund.org/~media/files/publications/fund-report/2007/oct/patient-centered-care--what-does-it-take/shaller_patient-centeredcarewhatdoesittake_1067-pdf.pdf
- Sheeran, T., Marvin, R. S., & Pianta, R. (1997). Mothers' Resolution of Their Child's Diagnosis and Self-Reported Measures of Parenting Stress, Marital Relations, and Social Support. *Journal of Pediatric Psychology*, 22(2), 197–212. doi:10.1093/jpepsy/22.2.197
- Shelton, T. L., & Stepanek, J. S. (1994). *Family-Centered Care for Children Needing Specialized Health and Developmental Services. Third Edition*. Association for the Care of Children's Health, 7910 Woodmont Ave., Suite 300, Bethesda, MD 20814 (\$15, non-members, Order No. 3233N; \$12, members, Order No. 3223M; plus \$3.50 shipping and handling; quantity discounts available). Retrieved from <http://eric.ed.gov/?id=ED381926>
- Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: a review of qualitative studies. *Journal of Clinical Nursing*, 15(10), 1317–1323. doi:10.1111/j.1365-2702.2006.01433.x
- Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J., & Pascoe, E. (2012). Family-centred care for hospitalised children aged 0-12 years. *Cochrane Database of Systematic Reviews*, (10). doi:10.1002/14651858.CD004811.pub3.
- Siebes, R. C., Maassen, G. H., Wijnroks, L., Ketelaar, M., van Schie, P. E. M., Gorter, J. W., & Vermeer, A. (2007). Quality of paediatric rehabilitation from the parent perspective: validation of the short Measure of Processes of Care (MPOC-20) in the Netherlands. *Clinical Rehabilitation*, 21(1), 62–72. doi:10.1177/0269215506071280
- Sillanpää, M., Jalava, M., Kaleva, O., & Shinnar, S. (1998). Long-term prognosis of seizures with onset in childhood. *The New England Journal of Medicine*, 338(24), 1715–1722. doi:10.1056/NEJM199806113382402
- Speechley, K. N., Ferro, M. A., Camfield, C. S., Huang, W., Levin, S. D., Smith, M. L., ... Zou, G. (2012). Quality of life in children with new-onset epilepsy: a 2-year prospective cohort study. *Neurology*, 79(15), 1548–1555. doi:10.1212/WNL.0b013e31826e25aa

- Spencer, S., & Huh, L. (2008). Outcomes of epilepsy surgery in adults and children. *The Lancet Neurology*, 7(6), 525–537. doi:10.1016/S1474-4422(08)70109-1
- Spieth, L. E., & Harris, C. V. (1996). Assessment of Health-Related Quality of Life in Children and Adolescents: An Integrative Review. *Journal of Pediatric Psychology*, 21(2), 175–193. doi:10.1093/jpepsy/21.2.175
- Spilker, B., Schipper, H., Clinch, J., & Olweny, C. (Eds.). (1996). Quality of life studies: definitions and conceptual issues. In *Quality of life and pharmacoeconomics in clinical trials* (2nd Edition., pp. 11–23). Philadelphia: Lippincott-Raven.
- Stein, R. (1998). Children with chronic conditions in the 21st century. *Journal of Urban Health*, 75(4), 732–738. doi:10.1007/BF02344503
- Stevens, G. D., Pickering, T. A., & Laqui, S. A. (2010). Relationship of medical home quality with school engagement and after-school participation among children with asthma. *The Journal of Asthma: Official Journal of the Association for the Care of Asthma*, 47(9), 1001–1010. doi:10.1080/02770903.2010.514636
- Stewart, M., Brown, J. B., McWhinney, I. R., Freeman, T., Weston, W., & McWilliam, C. (2014). *Patient-Centered Medicine: Transforming the Clinical Method* (3rd Revised Edition.). Oxford: Radcliffe Publishing Ltd.
- Stone, B. L., Murphy, N. A., Mundorff, M. B., Parker, H. B., Peterson, P. R., & Srivastava, R. (2008). Children with chronic complex medical illnesses: Is inpatient care family-centered? *Journal of Pediatric Rehabilitation Medicine*, 1(3), 237–243.
- Streiner, D. L., & Norman, G. R. (2008). *Health Measurement Scales: A practical guide to their development and use*. Oxford University Press.
- Sunde, E. R., Mabe, P. A., & Josephson, A. (1993). Difficult parents. From adversaries to partners. *Clinical Pediatrics*, 32(4), 213–219.
- Swaine, B. R., Pless, I. B., Friedman, D. S., & Montes, J. L. (1999). Using the measure of processes of care with parents of children hospitalized for head injury. *American Journal of Physical Medicine & Rehabilitation / Association of Academic Physiatrists*, 78(4), 323–329.
- Tabachnick, B. G., & Fidell, L. S. (2012). *Using Multivariate Statistics* (6 edition.). Boston: Pearson.
- Tellez-Zenteno, J. F., Pondal-Sordo, M., Matijevic, S., & Wiebe, S. (2004). National and Regional Prevalence of Self-reported Epilepsy in Canada. *Epilepsia*, 45(12), 1623–1629. doi:10.1111/j.0013-9580.2004.24904.x
- Thurstone, L. L. (1947). *Multiple-factor analysis; a development and expansion of The Vectors of Mind* (Vol. xix). Chicago, IL, US: University of Chicago Press.
- Tse, E., Hamiwka, L., Sherman, E. M. S., & Wirrell, E. (2007). Social skills problems in children with epilepsy: Prevalence, nature and predictors. *Epilepsy & Behavior*, 11(4), 499–505. doi:10.1016/j.yebeh.2007.08.008

- Turchi, R. M., Antonelli, R. C., Norwood, K. W., Adams, R. C., Brei, T. J., Burke, R. T., ... Sia, C. (2014). Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems. *Pediatrics*, *133*(5), e1451–e1460. doi:10.1542/peds.2014-0318
- Wakamoto, H., Nagao, H., Hayashi, M., & Morimoto, T. (2000). Long-term medical, educational, and social prognoses of childhood-onset epilepsy: a population-based study in a rural district of Japan. *Brain & Development*, *22*(4), 246–255.
- Webster, P. D., Johnson, B. H., & Institute for Family-Centered Care. (1999). *Developing family-centered vision, mission, and philosophy of care statements*. Bethesda, Md.: Institute for Family-Centered Care.
- Wheless, J. W., Clarke, D. F., McGregor, A. L., Pearl, P. L., & Ng, Y.-T. (2012). *Epilepsy in Children and Adolescents*. John Wiley & Sons.
- Wiebe, S., Matijevic, S., Eliasziw, M., & Derry, P. (2002). Clinically important change in quality of life in epilepsy. *Journal of Neurology, Neurosurgery, and Psychiatry*, *73*(2), 116–120. doi:10.1136/jnnp.73.2.116
- Williams, J. (2003). Learning and behavior in children with epilepsy. *Epilepsy & Behavior: E&B*, *4*(2), 107–111.
- Willmore, L., Pickens, I. A., & Pellock, J. (2011). Monitoring for Adverse Effects of Antiepileptic Drugs. In E. Wyllie, G. Cascino, B. Gidal, & H. Goodkin (Eds.), *Wyllie's Treatment of Epilepsy: Principles and Practice*. Philadelphia: Wolters Kluwer/Lippincott Williams & Wilkins. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&NEWS=n&CSC=Y&PAGE=booktext&D=books&SC=01437582>
- Woodside, J. M., Rosenbaum, P., King, S., & King, G. (2001). Family-Centered Service: Developing and Validating a Self-Assessment Tool for Pediatric Service Providers. *Children's Health Care*, *30*(3), 237–252. doi:10.1207/S15326888CHC3003_5
- World Health Organization. (2005). *Atlas: Epilepsy Care in the World*. Geneva: WHO.
- Wyllie, E. (1998). Surgical treatment of epilepsy in children. *Pediatric Neurology*, *19*(3), 179–188. doi:10.1016/S0887-8994(98)00062-9

Appendices

Appendix A: Literature Search Strategy

The objective of our search strategy was to probe the literature for papers that address potential linkages between FCC as defined by our working definition and any form of health-related outcomes. This thesis focuses on FCC as applied in a population of children with epilepsy – therefore the focus of this literature review will be on children with chronic illnesses between birth and age 18.

Methodology. A search strategy was created to identify all published literature regarding the effects of clinic-based Family-Centred Care (FCC) on health outcomes of children with chronic illness. To characterise any potential effects of FCC, only papers that included a form of epidemiological study design or quantitative analysis were included in this literature search.

In April of 2013, a literature search of peer-reviewed studies was performed. This search included five databases: MEDLINE, EMBASE, CINAHL, PsycINFO, and Web of Science. MEDLINE and EMBASE were searched using the OVID search interface, while CINAHL, PsycINFO and Web of Science were searched using EBSCOhost, ProQuest, and Web of Knowledge respectively. Each interface differs in the availability of major subject headings, options available for modifying and sorting search results, as well as the way in which search parameters are entered. To compensate, a single search pattern was created and utilized across each database to ensure consistency in results.

Major subject headings were exploded for MEDLINE and EMBASE (i.e. Medical Subject Headings, or MeSH), CINAHL (i.e. CINAHL Subject Headings), and PsycINFO (i.e. Subject

Index Headings). The Web of Science database did not include any form of subject headings.

Family-Centred Care is used interchangeably with other terms and phrases, such as Family-Centred Practice or Family-Focused Care. Additionally, differences between British and American English spelling conventions require our search strategy to capture both 'centred' and 'centered.' Therefore, Step 1 of the search process was to capture as many of the alternate phrases and spellings of FCC in the literature as possible. Step 2 was to collect papers that employed any number of instruments known to measure Family-Centred Care, such as the Measures of Processes of Care (MPOC) and un-named assessment tools created by the Institute of Patient- and Family-Centered Care. These results were then pooled (Step 3).

A succession of steps was then used to limit results to the population outlined in our objective. Steps 4 & 5 limited the papers in each successive database to infants, children and adolescents, as well as papers with a paediatric medicine and paediatric nursing background. Steps 6 & 7 were added to ensure that only papers that relied on predominantly quantitative methodology would be included. The next steps, (8 & 9) limited the environments where FCC was being practiced to clinical settings; particularly the hospital and private healthcare office. Finally, Steps 10 and 11 limited papers to English articles with a human population, and articles published in journals only.

Table A-1 Steps in search strategy example using the OVID MEDLINE database

1. (family cent?red care or family cent?red service or family cent?red* or family focused*)
2. ("Family-Centered Care Self Assessment Tool" or "Institute for Family Centered Care" or "Institute for Patient and Family Centered Care" or IFCC or IPFCC or "Patient-Family-Centered Care Survey" or "measures of processes of care" or MPOC* or "Family-Centred Care Survey" or FCCS or "Give Youth a Voice" or "goals of care conversation")
3. 1 or 2
4. exp child/ or exp adolescence/ or exp infant/ or exp pediatrics/ or exp pediatric nursing/ or child*.mp. or infant*.mp. or adolescen*.mp. or teen*.mp. or p?ediatric*.mp. or "school age".mp. or schoolage.mp.
5. 3 and 4
6. exp epidemiologic study characteristics as topic/ or epidemiologic method or ((clinic* or eval* or prospective or retrospective or comparative or quantitative or experiment* or random* control* or observation* or cohort or case control or cross sectional or crossover or cross over or ecological or factorial or intervention or impact or outcome or survey) adj5 (study or studies or instrument* or measure* or design or trial))
7. 5 and 6
8. (practice or urgent care or medical centre or medical center or office* or hospital* or clinic* or intensive care unit or icu or in-patient or out-patient or inpatient or outpatient or tertiary care or primary care or ambulatory* or "health centre" or "health center" or rehabilita* or medical home)
9. 7 and 8
10. limit 9 to (english language and humans)
11. limit 10 to journal

Inclusion and Exclusion Criteria. The criteria for inclusion in this literature review were as follows. A study must: 1) characterise the impact of a family-centred intervention or policy on health outcomes; 2) focus on the impact of FCC in children with chronic illness up to the age of 18 years; 3) observe FCC within clinical care settings; 4) utilise an epidemiological study design or a form of quantitative analysis.

Neonates born prematurely and those in Neonatal Intensive Care Units (or other special care nurseries) were excluded for two reasons: 1. FCC provided in the NICU is different from that provided to paediatric patients beyond the neonatal stage (Brophy & Barrow, 2010); 2. studies that focus on neonates needing special care do not always make a distinction whether the reason for admittance is due to a chronic or an acute condition. Without the ability to separate the effects of FCC on children with acute illness from children with chronic illness, these studies are considered ineligible for inclusion in this literature review.

Grey literature, (conference proceedings, poster presentations, and abstracts) were captured in the search process. While published in a peer-reviewed journal, they often do not provide sufficient information to meet the parameters of the search strategy. As a result, they were removed in the 'manual removal' stage.

Manual Removal of Ineligible Papers. The initial inspection of the search strategy results revealed that many of the resulting articles did not meet the inclusion or exclusion criteria. By capturing as many journal articles as possible on FCC, the search strategy returned a set of papers that were only slightly related to FCC or focussed on single

components of FCC. A number of ineligible papers resulted from incorrectly classified articles in each of the databases (i.e. keywords and abstracts). Finally, limitations in each of the database search engines made it difficult to limit results without removing potentially eligible studies.

To remove ineligible papers, a screening process by way of manual removal was undertaken. In total, 1443 articles were manually removed in a screening process utilizing the titles of the articles, the abstracts, as well as keywords assigned by their source database. When not enough information was available to determine the potential eligibility of a study, a brief scan of the full-text document for key words and phrases would determine their eligibility.

The next stage of the literature review was to review all remaining articles in-depth to determine their eligibility for inclusion (n = 52). Through this process, it became clear that some papers purporting to discuss FCC were actually discussing a few specific components of FCC, or specific interventions that lacked one or more of the defining elements of FCC. Alternatively, there were papers that explicitly stated an emphasis on a different form of care, such as family-focused care; when in fact, the characteristics of the care delivered were family-centred instead.

To differentiate between FCC and these other family 'oriented' forms of care; a methodological classification system is required. For this literature review, we relied on the classification system of Dunst, Johanson, & al, (1991) introduced in Section 2.4.2.

Each paper was read thoroughly to determine the intensity of collaborative behaviour and partnership between care providers and parents. Depending on their degree of family-orientation, they were organized in the appropriate category (Table 2).

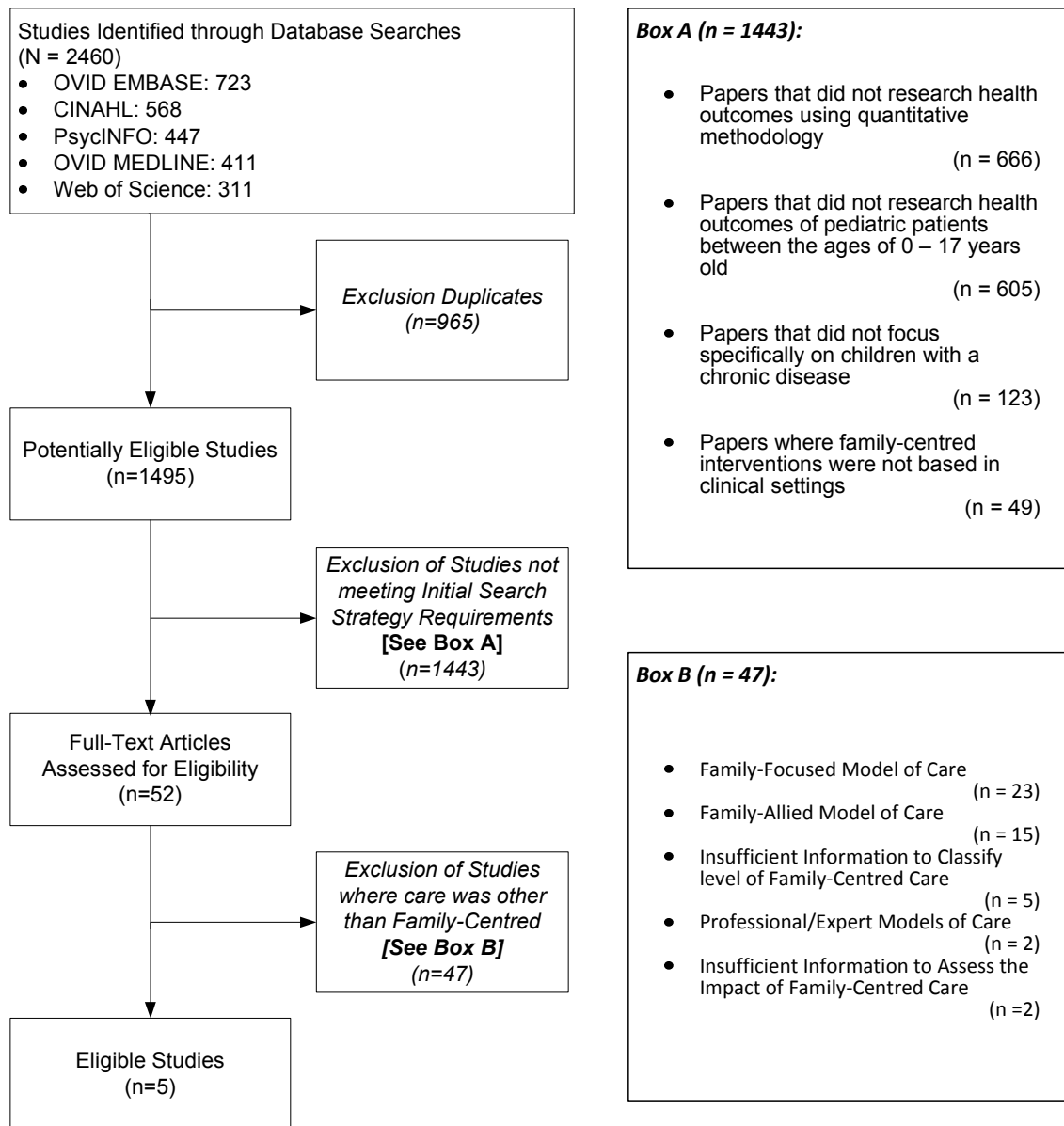
Table A-2 Types of Family-Oriented Care (Dunst, Boyd, Trivette, & Hamby, 2002)

Model	Criteria
Professionally Centered	Families are seen mostly as deficient and incapable of healthy functioning without professional interventions. Professionals see themselves as experts who determine family needs. Families' views and opinions are given little time or no credence. Interventions are implemented by professionals with families being passive participants in the intervention process.
Family Allied	Families are seen as minimally capable of independently effecting changes in their lives. Families are viewed as agents of professionals for carrying out professionally prescribed recommendations and courses of action. Professionals enlist families to implement intervention under the guidance and tutelage of the professionals.
Family Focused	Families are seen as capable of making choices among options professionals deem important for healthy functioning. Professionals provide advice and encouragement to families on the basis of their choices and decisions. Interventions focus on monitoring family use of professionally valued services.
Family Centered	Families are viewed as fully capable of making informed choices and acting on their choices. Professionals view themselves as agents of families who strengthen existing and promote acquisition of new skills. Interventions emphasize capacity building and resource and support mobilization by families.

The result of this stage of sorting was a number of papers that met the first criterion (i.e. characterisation of the impact of FCC on health outcomes). Specifically, five articles were found to be relevant to the review objectives, and were thus included in this literature review. Immediately following the search, the ancestry method was employed in searching each of the bibliographies of the articles that were relevant to our

objective. No new papers were found. The following diagram (Figure 1) displays the result at each stage of the search and categorization processes in this literature review.

Figure A-1 Refinement Process used to Arrive at the Final Number of Studies



Appendix B: Ethics Approval Notice



Office of Research Ethics

The University of Western Ontario

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. K.N. Speechley

Review Number: 10069E

Revision Number:

Protocol Title: Health-Related Quality of Life in Children with Epilepsy: The First Two Years After Diagnosis Through Parents' Eyes

Department and Institution: Paediatrics, Children's Hospital of Western Ontario

Sponsor: CIHR

Approval Date: 18-Nov-03

End Date: 31-Mar-08

Documents Reviewed and Approved: UWO Protocol, Letters of Information & Consent

Documents Received for Information:

This is to notify you that the University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement and the Health Canada/CH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has received and granted expedited approval to the above named research study on the date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

This approval shall remain valid until end date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB (Expedited): Dr. Paul Harding

Karen Kueneman, BA (Hons), Ethics Officer HSREB (Expedited)

Faxed: N
Date: Nov. 19/03
VK.

This is an official document. Please retain the original in your files.



Office of Research Ethics

The University of Western Ontario

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. K.N. Speechley

Review Number: 10069E

Revision Number: 3

Protocol Title: Health-Related Quality of Life in Children with Epilepsy: The First Two Years After Diagnosis Through Parents' Eyes

Department and Institution: Paediatrics, Children's Hospital of Western Ontario

Sponsor: CIHR

Ethics Approval Date: March 7, 2006

Expiry Date: March 31, 2008

Documents Reviewed and Approved: Revised Study Method - Sub-study, Telephone Script for Sub-study, Letter of Information for Sub-study

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted expedited approval to the above named research study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

This approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

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- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. John W. McDonald

Deputy Chair: Susan Hoddinott

Ethics Officer to Contact for Further Information		
<input checked="" type="checkbox"/> Karen Kueneman	<input type="checkbox"/> Janice Sutherland	<input type="checkbox"/> Jennifer McEwen

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Appendix C: HERQULES Physician Form

Q__ __ Months

PHYSICIAN FORM

Study ID __ __ __ __

Health Related Quality of Life in Children with Epilepsy: The First Two Years After Diagnosis Through Parents' Eyes

Patient's Date of Birth (dd/mm/yy): _____ Site #: _____

Please answer the following questions based on information from this patient's most recent visit and return upon completion

1. Date of patient's last visit (dd/mm/yy): _____ or Date of Telephone F/U (dd/mm/yy) _____
2. Date form completed (dd/mm/yy): _____

If information for 3 thru 7 is unchanged from baseline (diagnosis) visit, please check here and proceed to 8.

3. Seizure type(s): 1) _____ 2) _____
3) _____ 4) _____
4. Epilepsy syndrome: _____
5. Convulsive status epilepticus:
 No
 Yes
6. Exclusive nocturnal seizures:
 No
 Yes
7. Age of first seizure (excluding febrile seizure): _____ yrs

8. Does this patient have any family with epilepsy?
 No
 Yes
9. Number of AEDs currently: _____
10. Number of AEDs total: _____
11. Is this patient of school age?
 No
 Yes → Grade: ___ regular class regular class with resource special class

PLEASE TURN OVER TO COMPLETE

Study ID _____

12. Does the patient have behavioural problems?

- No (normal)
 Yes → Please check one: mild moderate severe

Diagnosis: _____

13. Does the patient have cognitive problems?

- No (normal)
 Yes → Please check one: borderline mild moderate severe

Diagnosis: _____

14. Does this patient have motor problems?

- No
 Yes → Please check one: mild moderate severe

Diagnosis: _____

15. Other neurological deficits? Please specify: _____

16. Taking into account all aspects of this patient's epilepsy, how would you rate its severity at his/her last visit? Please check one answer.

- Extremely severe
 Very severe
 Quite severe
 Moderately severe
 Somewhat severe
 A little severe
 Not at all severe

17. Rate the following aspects of this patient's epilepsy at his/her last visit.

Check one box using the following 7-point scale:

1 = none or never
7 = extremely frequent, severe or high

	1	2	3	4	5	6	7
Frequency of seizures							
Intensity of seizures							
Falls or injuries during seizures							
Severity of post-ictal period							
Amount of antiepileptic drugs							
Side effects of antiepileptic drugs							
Interference of epilepsy or drugs with daily activities							

Appendix D: Letter of Information



<Date>

Dear Ms.;

We are conducting a study entitled: **“Health-related quality of life in children with epilepsy: The first two years after diagnosis through parents’ eyes”** in cooperation with a group of child neurologists from across Canada, including your child’s neurologist. This study will help us better understand the experiences of children living with epilepsy and their families to learn how we can best support children with epilepsy.

We are writing to invite you to participate in this project. If you agree to participate you will be asked to complete a survey about your child’s health and well being and how your child’s health may be affecting your family. A questionnaire will be mailed to you to complete at a time convenient for you. Three more questionnaires will be sent to you approximately 6, 12 and 24 months after the first one. Each survey will take about one hour to complete. You will also be asked to sign a consent form giving your child’s neurologist permission to provide us with information about your child’s epilepsy such as type, frequency and severity of seizures, medication information and whether your child has any other medical conditions. The neurologist will be reimbursed for his/her time in completing the medical forms. As a token of appreciation for your participation, we will send you \$5.00 with each questionnaire you complete. Your participation in this study will not result in any extra visits to your child’s doctor.

All information will be kept strictly confidential. Only a study number will identify information you give us. No personal information that could identify you or your child will be left on the questionnaires once they are returned to the research office. To ensure confidentiality, all names and identification numbers will be kept in a locked cabinet with access limited to the research staff. If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published. Your involvement with this project is entirely voluntary. If you choose not to participate, discontinue participation or do not wish to answer some questions in the surveys, it will not affect your child’s care in any way. There are no known risks to participating in this study.

In a few days, our study coordinator will contact you by telephone to answer any questions you may have and request your participation in the study. Please feel free to contact me at (519) 685-8500 Ext. 52182 if you have any questions. If you are calling long distance, please call collect. If you have questions about how this study is being conducted or your rights as a research subject you may contact the Director, Office of Research Ethics, The University of Western Ontario at (519) 661-3036 or email at ethics@uwo.ca. This letter is yours to keep.

Yours sincerely,

Kathy Nixon Speechley, Ph.D.
Associate Professor
Department of Paediatrics
University of Western Ontario

Department of Paediatrics • Schulich School of Medicine & Dentistry • The University of Western Ontario

Appendix E: MPOC-20 Excerpt from HERQULES Parent Questionnaire

SECTION 7:

We would like to understand and measure the experiences of parents who have a child with epilepsy. In particular we wish to know about your perceptions of the care you have been receiving over the past year from the health care institution(s) that provide(s) services to your child for his/her epilepsy.

The care that you and your child receive from this organization may bring you into contact with many individuals. The questions on this form are grouped by who these contacts are, as described below.

PEOPLE:

refers to those individuals who work directly with you or your child. These **may include** doctors, nurses, psychologists, therapists, social workers, etc.

ORGANIZATION:

refers to all staff from the health care institution(s), whether involved directly with your child or not. In addition to health care people they **may include** support staff such as office staff, housekeepers, administrative personnel, etc.

The questions are based on what parents, like yourself, have told us about the way care is sometimes offered. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own without discussing it with anyone.

7.1. For each question, please indicate how much the event or situation happens to you. You are asked to respond by circling **one** number from 1 (Not at All) to 7 (To a Very Great Extent) that you feel best fits your experience. Please note that the zero value (0) is used only if the situation described does not apply to you.

- 7. To a Very Great Extent
- 6. To a Great Extent
- 5. To a Fairly Great Extent
- 4. To a Moderate Extent
- 3. To a Small Extent
- 2. To a Very Small Extent
- 1. Not at All
- 0. Not Applicable

Indicate how much this event or situation happens to you.

IN THE PAST YEAR

TO WHAT EXTENT DO THE **PEOPLE**
WHO WORK WITH YOUR CHILD

	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
a. help you to feel competent as a parent?	7	6	5	4	3	2	1	0
b. provide you with written information about what your child is doing in <u>treatment</u> ?	7	6	5	4	3	2	1	0
c. provide a caring atmosphere <u>rather</u> than just give you information?	7	6	5	4	3	2	1	0
d. let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0

IN THE PAST YEAR

TO WHAT EXTENT DO THE **PEOPLE**
WHO WORK WITH YOUR CHILD

	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
e. look at the needs of your "whole" child (e.g., at mental, emotional, and social needs) instead of just at physical needs?	7	6	5	4	3	2	1	0
f. make sure that at least one team member is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0
g. fully explain treatment choices to you?	7	6	5	4	3	2	1	0
h. provide opportunities for you to make decisions about treatment?	7	6	5	4	3	2	1	0
i. provide enough time to talk so you don't feel rushed?	7	6	5	4	3	2	1	0
j. plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0
k. treat you as an <u>equal</u> rather than just as the parent of a patient (e.g. by not referring to you as "Mom" or "Dad")?	7	6	5	4	3	2	1	0
l. give you information about your child that is consistent from person to person?	7	6	5	4	3	2	1	0
m. treat you as an individual rather than as a "typical parent" of a child with epilepsy?	7	6	5	4	3	2	1	0
n. provide you with written information about your child's progress?	7	6	5	4	3	2	1	0
o. tell you about the results from assessments?	7	6	5	4	3	2	1	0

IN THE PAST YEAR

TO WHAT EXTENT DOES THE **ORGANIZATION**
WHERE YOU RECEIVE SERVICES

	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
p. give you information about the types of services offered at the organization or in your community?	7	6	5	4	3	2	1	0
q. have information available about your child's epilepsy (e.g., its causes, how it progresses, future outlook)?	7	6	5	4	3	2	1	0
r. provide opportunities for the entire family to obtain information?	7	6	5	4	3	2	1	0
s. have information available to you in various forms, such as a booklet, kit, video, etc.?	7	6	5	4	3	2	1	0
t. provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?	7	6	5	4	3	2	1	0

Appendix F: Diagnostic Tests in Preparation for Confirmatory Factor Analysis

Level of Measurement. Since the MPOC-20 uses Likert scaling, researchers can assume that the indicators are measured on either categorical or continuous scales. Following Rhemtulla, Brosseau-Liard, & Savalei (2012) and S. S. Stevens (1946) the MPOC was treated here as continuous because it has features of both interval and ratio scaling and because each indicator had more than the recommended 5 response categories.

Missing Data. Each indicator of the MPOC-20 is rated on a scale of 1 through 7, with an additional “Not Applicable” option. The developers of the instrument proposed that i) non-responses (i.e. incomplete or unanswered) and ii) responses marked as “Not Applicable” be treated as missing data points (King et al., 1995). They also stated that questionnaires should not be analysed if; i) more than 50% of the indicators are non-responses, ii) more than 50% of the indicators are marked “Not Applicable,” or iii) a combination of non-responses and “Not Applicable” indicators totals more than 50% of all indicators in the questionnaire (King et al., 1995).

In our sample, eight respondents had >50% non-responses, fifteen had >50% marked as “Not Applicable,” and one had >50% nonresponses and/or “Not Applicable.” Another respondent was found to be not eligible for inclusion in the analysis after data collection had concluded. Thus, 25 respondents were omitted, leaving a total of 311 respondents with analyzable data.

Table F-1 presents the pattern of non-response/"Not Applicable" data for the eligible 311 respondents. The amount of non-response was very small, accounting for 0.32% to 0.96% of the responses in each indicator. Thus, the percentage of nonresponses per indicator was well below 5% – meaning that its impact on subsequent analyses would be minimal. Therefore, there was no need to investigate missing data patterns further (Brown, 2006).

With respect to "Not Applicable" responses, percentages ranged from 0.96% to 15.43% per indicator. This is not problematic, however, because the nature of their missingness is known. Respondents answered "Not Applicable" because the content described in the questions did not apply to them within the previous 6 months. It is not possible to investigate why parents did not perceive the receipt of these services, as it was not a goal of the MPOC-20 or the HERQULES survey to identify the determinants of FCC.

The final missing data issue to be addressed was how missing data would be handled by both the diagnostic tests and the CFA itself. Many analyses perform list-wise deletion – respondents with at least 1 missing data point are removed from the analysis. Of the diagnostics described in this section, three use list-wise deletion: the test for multivariate outliers; the test for univariate normality; and the test for multivariate normality. Because 168 respondents had a missing data point for at least one indicator, the results of these tests were based on a sample size of 143. The tests for multicollinearity and singularity were able to use data from all 311 respondents.

To determine whether there was a difference between respondents with missing data points and those with complete data, each group was assigned a dummy variable in SAS. The student's t-test was used to identify whether there was a difference in mean indicator scores across groups. Fourteen of twenty indicators indicated that there was no statistical difference in scores between respondents with complete and incomplete questionnaires. The remaining six indicators had relatively small observed differences (i.e. a maximum percentage difference of 10.8% between the mean scores of either group). Given that there were no large differences between the two groups, we believe the results of the diagnostic tests are generalizable to the sample as a whole. The results of these tests are displayed in Table F-2.

With regard to the CFA itself, there are two recommended ways to handle missing data. The first is multiple imputation, where data from completed questionnaires are used to predict missing scores. The second is the usage of the full-information maximum likelihood estimator (FIML). Methodologists generally use the latter when attaining statistical estimates of a model's fit while accounting for missing data (Brown, 2006). Thus, a type of FIML was used here to handle missing data.

Detection of Potential Outliers. Checking for outliers – unique respondents with unusual or extreme values on one or more indicators – is also customary before performing a CFA. There are two kinds of outliers. The first is a univariate outlier – this occurs when there is an extreme score on a single indicator. Due to the limited range of available responses to each question, it was decided that univariate outliers were not likely, so

they were not pursued. The second is a multivariate outlier – a cluster of unusual or extreme scores across multiple indicators.

Finding potential multivariate outliers began by calculating Mahalanobis Distances (MDs) for each of the eligible respondents with complete data (n=143). The MD represents the relation of a respondent's answers to the mean of all answers within the sample. Next, the individual's MD was compared against the critical value for the sample (i.e. 45.315 at a conservative $\alpha=0.001$). If a respondent's MD exceeded the critical value, their questionnaire was investigated further, to determine whether responses reflected 'legitimate variability,' or were in fact, anomalous responses (Harrington, 2008; Raykov & Marcoulides, 2012).

Potentially anomalous questionnaires were examined and assessed on a case-by case basis. For example, the respondent with the highest MD answered 'To a very great extent' on 14 of 20 questions – which implied a perception of receiving a high degree of FCC. This respondent also replied 'Not at all' on 2 questions – which suggested that they did not feel like a partner in care, and that they had not received advice on how to get more information or get in contact with other parents. It is possible that a parent could receive many of the features of FCC, but still feel that their child's care was lacking in key areas. As a result, this respondent was kept in the analysis.

Of the 143 respondents with complete data, sixteen were identified as potential multivariate outliers through a SAS macro created by Raykov & Marcoulides (2012). All of the respondents' questionnaires were examined in the manner described above,

leading to the conclusion that the variations in scores were both valid and representative of potential parental experiences. They were all therefore retained in the analysis.

Adequacy of Sample Size. Because the search for multivariate outliers did not yield any additional omission of respondents, the number of eligible respondents remained 311. The size of a sample has an effect on the results of a CFA, as the results of the CFA are sensitive to how large or small a sample is (Tabachnick & Fidell, 2012). A 'rule of thumb' is that total sample sizes between 100 and 200 are considered 'medium' sized, while sizes above 200 are considered 'large' and acceptable for most models (Kline, 2011; MacCallum, Widaman, Zhang, & Hong, 1999). Assuming that a sample size of over 200 is ideal, the available sample size of 311 was considered adequate for a CFA to be performed.

Multivariate Normality. Another requirement for CFA is multivariate normality. This is the assumption that all possible combinations of indicators are normally distributed (Raykov & Marcoulides, 2012; Tabachnick & Fidell, 2012). Univariate normality is a necessary but not sufficient condition for multivariate normality to occur. If there are signs of univariate non-normality, however, it is very likely that there is multivariate non-normality as well (Brown, 2006).

The assumptions of univariate and multivariate normality were tested through statistics generated by the SAS MULTNORM macro (SAS Institute Inc., 2007, 2010). The results were based on a sample of 143 completed questionnaires. These statistics are generally

sensitive to sample size, so visual assessment of corresponding graphs using frequency histograms or normal P-P plots is needed to correctly assess normality (SAS Institute Inc., 2007; Tabachnick & Fidell, 2012).

The results of the statistical tests are displayed in Table F-3. They are accompanied by frequency histograms with a normal distribution overlay in Figure F-1 and a Q-Q Plot to examine multivariate normality in Figure F-2. According to the Shapiro-Wilk test statistics generated for each indicator, the assumption of univariate normality did not hold for all indicators in the model ($p < 0.0001$). The corresponding Q-Q plots confirmed this conclusion. As suggested by the consistent presence of univariate non-normality, the sample was found to be multivariate non-normal as well. This was identified using Mardia Skewness, Mardia Kurtosis, and Henze-Zirkler T-test statistics ($p < 0.0001$) and the corresponding P-P plot (Mardia, 1974). Taken together, this meant that our CFA methodology needed to take the non-normality of the data into account.

Identifying Multicollinearity and Singularity. Multicollinearity occurs when two or more indicators are highly correlated ($0.90 \leq r < 1.00$), while singularity occurs when two or more indicators have a perfect correlation ($r=1.00$). When performing CFA, the existence of either would cause statistical issues – namely that as the correlation between two indicators increases, the denominator for certain calculations approaches zero. Thus, calculations involving multicollinear indicators would result in large and unstable parameter estimates, whereas singularity would prohibit the calculations from taking place altogether (Tabachnick & Fidell, 2012).

Screening for multivariate multicollinearity and singularity involved calculating squared multiple correlation (SMC) values for each of the indicators in relation to the group of indicators as a whole (Tabachnick & Fidell, 2012). These statistics (Table F-4) show the relation of an indicator to the others in the set. If the SMC value is ≥ 0.90 , the indicator is highly related to others in the set, and thus there is multicollinearity; if the value is extremely close to 1, there is singularity. Among MPOC indicators, the highest SMC value was 0.860; therefore, neither singularity nor multicollinearity was a threat in this data set (Norman & Streiner, 2008; Tabachnick & Fidell, 2012).

The correlation matrix was also examined for evidence of bivariate collinearity and singularity (Table F-5). The highest correlation ($r=0.856$) was found between two indicators related to Question 7 (*In the past year, to what extent do the people who work with your child fully explain treatment choices to you?*) and Question 8 (*In the past year, to what extent do the people who work with your child provide opportunities for you to make decisions about treatment?*). Keeping indicators with a bivariate correlation of 0.70 and higher is not recommended, except in situations where structural analyses or repeated measures testing are being done (Tabachnick & Fidell, 2012). Thus, these two indicators were flagged for potential removal during later stages of the analysis.

Table F-1 Amount of ‘Missing’ Responses Six Months after Diagnosis of Epilepsy

Indicator	Non-Responses		“Not Applicable”	
	N	Percentage	N	Percentage
Question 1	1	0.32%	13	4.18%
Question 2	3	0.96%	44	14.15%
Question 3	1	0.32%	11	3.54%
Question 4	2	0.64%	35	11.25%
Question 5	1	0.32%	12	3.86%
Question 6	1	0.32%	44	14.15%
Question 7	2	0.64%	12	3.86%
Question 8	3	0.96%	11	3.54%
Question 9	2	0.64%	3	0.96%
Question 10	1	0.32%	26	8.36%
Question 11	2	0.64%	5	1.61%
Question 12	3	0.96%	25	8.04%
Question 13	2	0.64%	8	2.57%
Question 14	2	0.64%	48	15.43%
Question 15	1	0.32%	13	4.18%
Question 16	2	0.64%	32	10.29%
Question 17	1	0.32%	27	8.68%
Question 18	2	0.64%	35	11.25%
Question 19	2	0.64%	29	9.32%
Question 20	1	0.32%	39	12.54%

Table F-2 Test Statistics for Univariate and Multivariate Normality

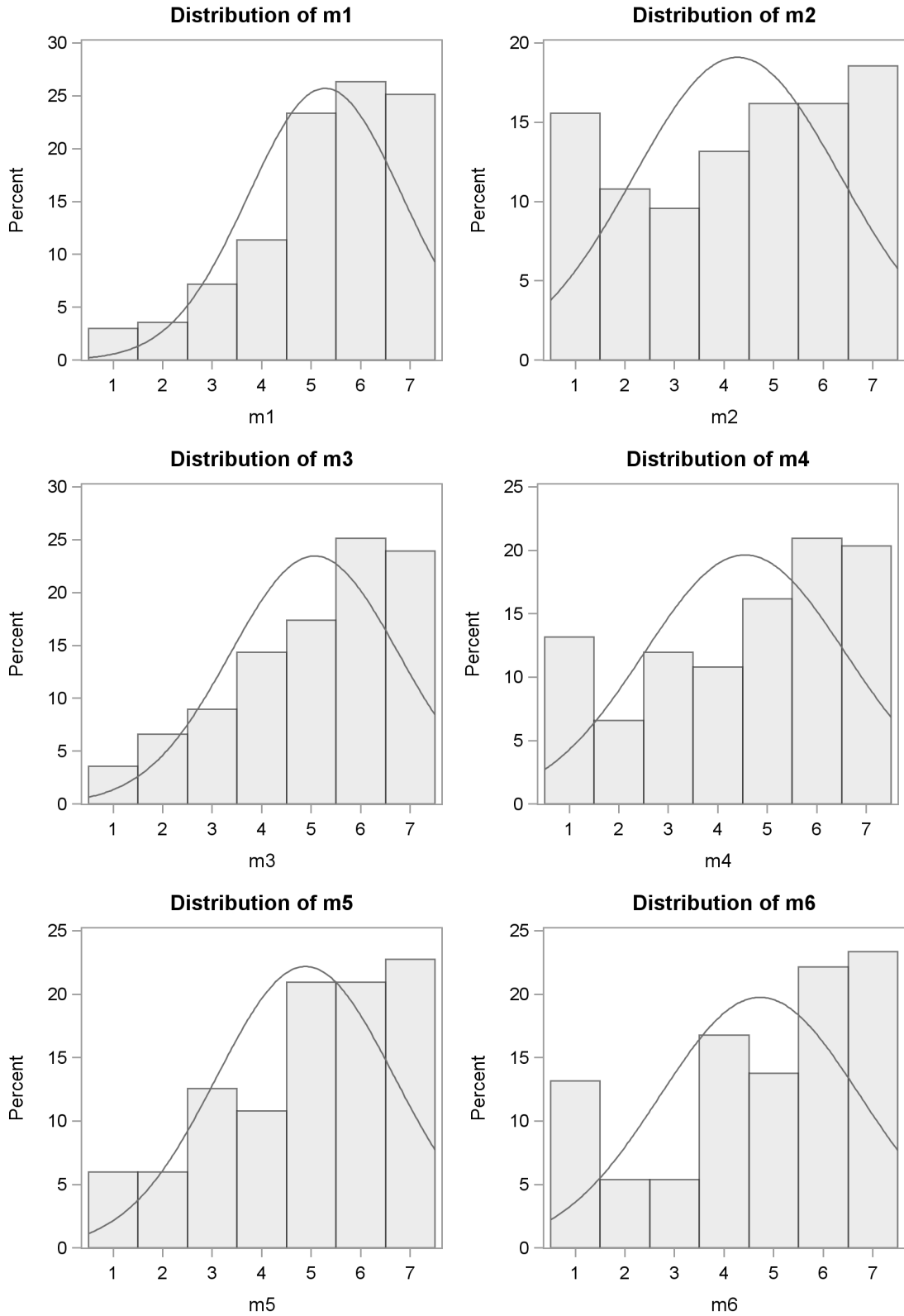
Tests for Univariate Normality	Test Statistic	Value	Probability
Question 1	Shapiro-Wilk W	0.88	<.0001
Question 2	Shapiro-Wilk W	0.90	<.0001
Question 3	Shapiro-Wilk W	0.89	<.0001
Question 4	Shapiro-Wilk W	0.89	<.0001
Question 5	Shapiro-Wilk W	0.90	<.0001
Question 6	Shapiro-Wilk W	0.87	<.0001
Question 7	Shapiro-Wilk W	0.87	<.0001
Question 8	Shapiro-Wilk W	0.89	<.0001
Question 9	Shapiro-Wilk W	0.87	<.0001
Question 10	Shapiro-Wilk W	0.88	<.0001
Question 11	Shapiro-Wilk W	0.89	<.0001
Question 12	Shapiro-Wilk W	0.88	<.0001
Question 13	Shapiro-Wilk W	0.87	<.0001
Question 14	Shapiro-Wilk W	0.87	<.0001
Question 15	Shapiro-Wilk W	0.88	<.0001
Question 16	Shapiro-Wilk W	0.90	<.0001
Question 17	Shapiro-Wilk W	0.91	<.0001
Question 18	Shapiro-Wilk W	0.91	<.0001
Question 19	Shapiro-Wilk W	0.90	<.0001
Question 20	Shapiro-Wilk W	0.89	<.0001
Tests for Multivariate Normality	Test Statistic	Value	Probability
System Level	Mardia Skewness	4524	<.0001
	Mardia Kurtosis	41.03	<.0001
	Henze-Zirkler T	1.72	<.0001

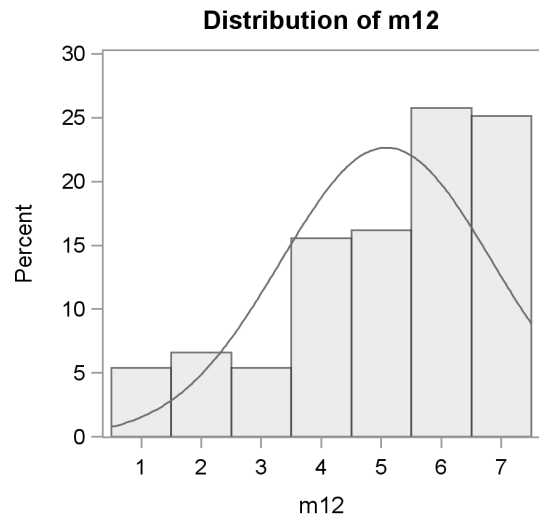
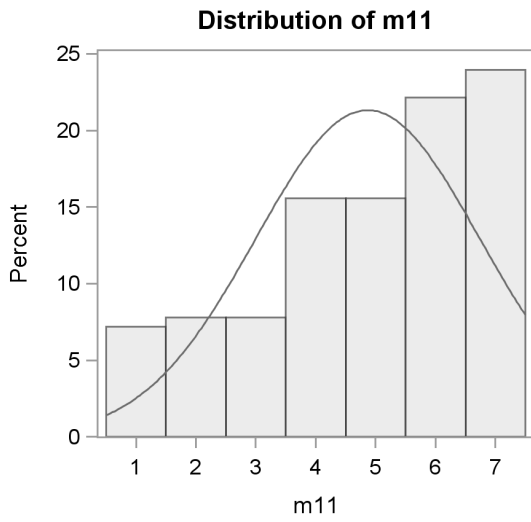
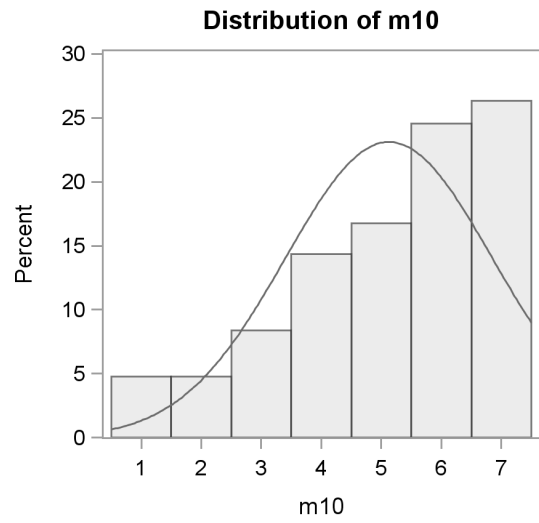
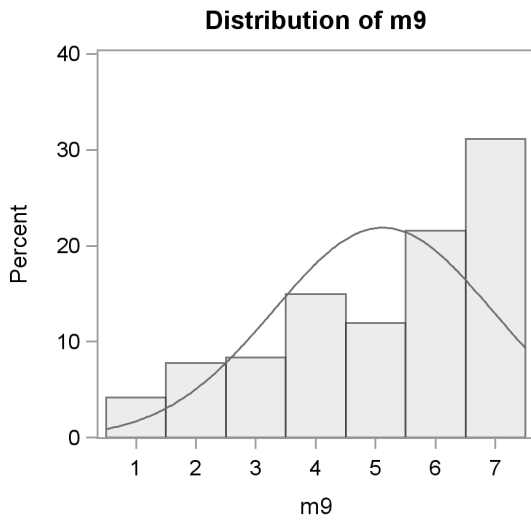
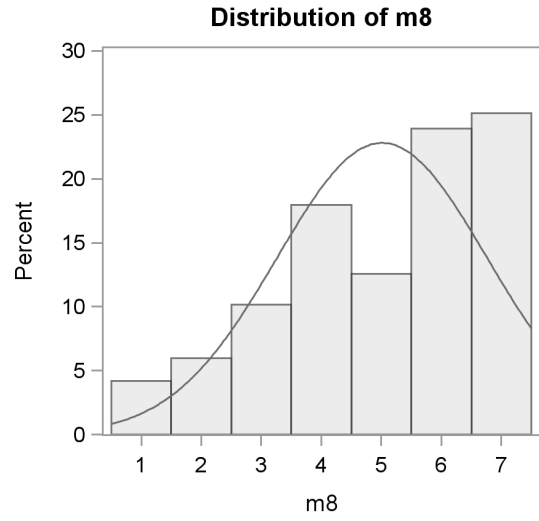
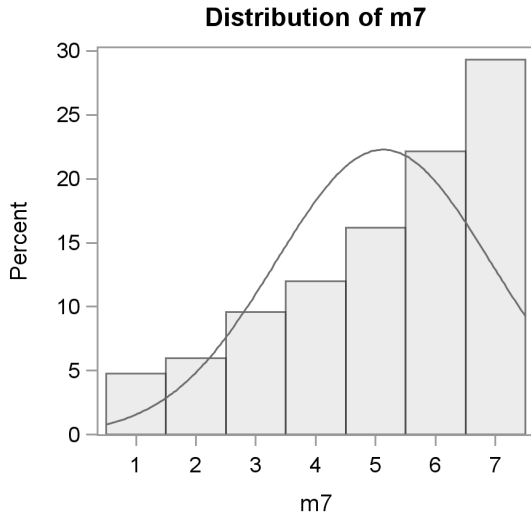
Table F-3 Results of T-Test comparing Respondents with Missing Data to those with Complete Data

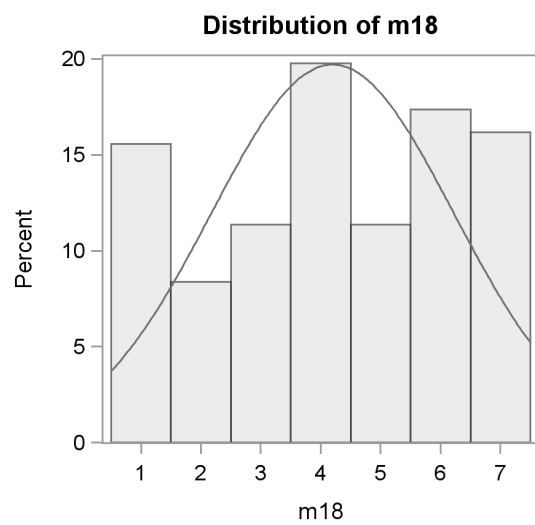
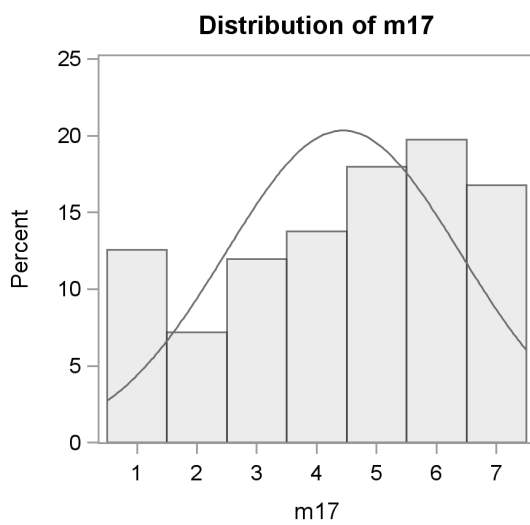
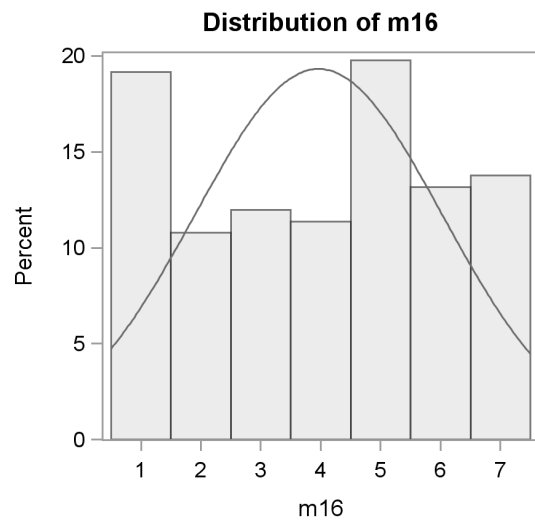
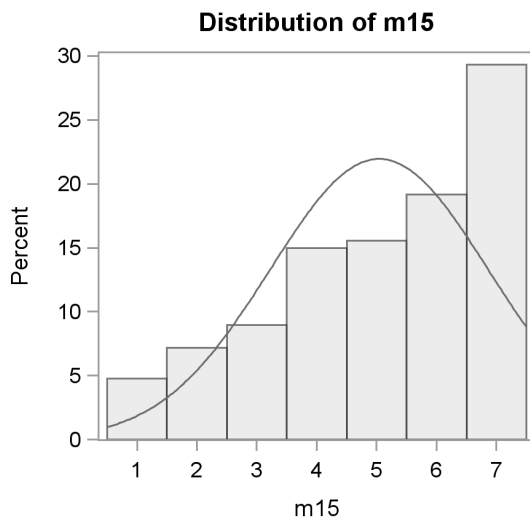
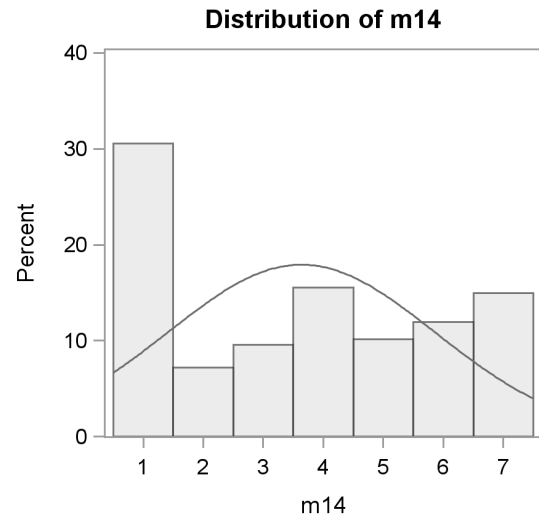
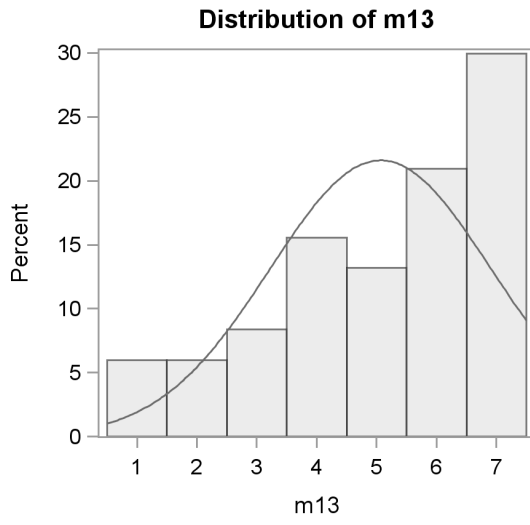
Tests for Univariate Normality	t-value	p-value	Difference in Means
Question 1	-2.16	0.0319*	-0.3570
Question 2	-0.36	0.7179	-0.0974
Question 3	-1.12	0.2652	-0.2069
Question 4	-1.44	0.1425	-0.3523
Question 5	-0.97	0.3324	-0.1901
Question 6	-1.38	0.1694	-0.3462
Question 7	-1.89	0.0594	-0.3552
Question 8	-1.80	0.0726	-0.3496
Question 9	-2.83	0.0050*	-0.5349
Question 10	-2.52	0.0124*	-0.4811
Question 11	-2.87	0.0044*	-0.5551
Question 12	-1.86	0.0646	-0.3644
Question 13	-2.09	0.0375*	-0.4043
Question 14	1.34	0.1832	0.4007
Question 15	-2.39	0.0177*	-0.4735
Question 16	0.35	0.7233	0.0913
Question 17	0.61	0.5456	0.1440
Question 18	1.18	0.2377	0.3004
Question 19	0.80	0.4266	0.2028
Question 20	1.01	0.3144	0.2703

* Statically Significant p-value ($p < 0.05$)

Figure F-1 Frequency Histograms for the Tests for Univariate Normality







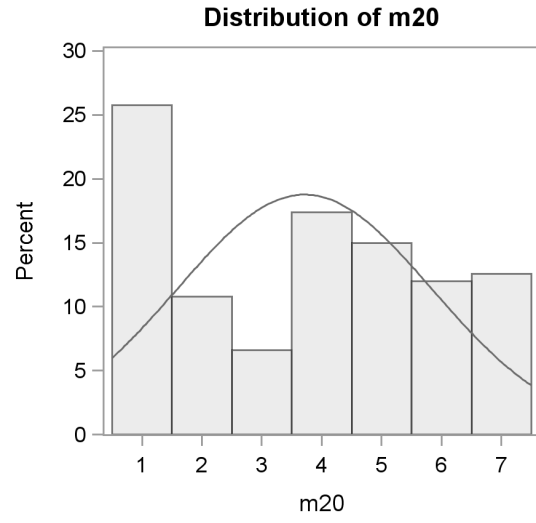
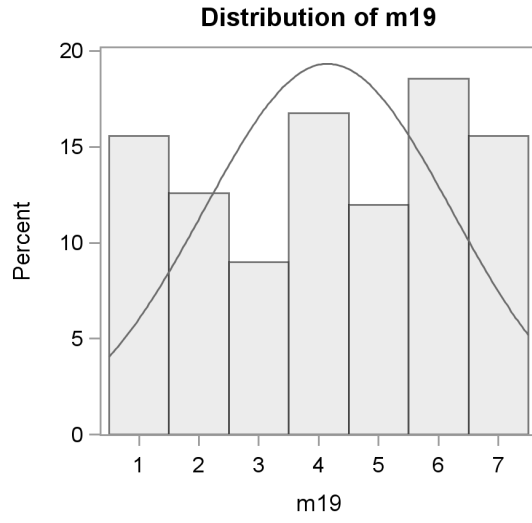


Figure F-2 Q-Q Plot for the Test for Multivariate Normality

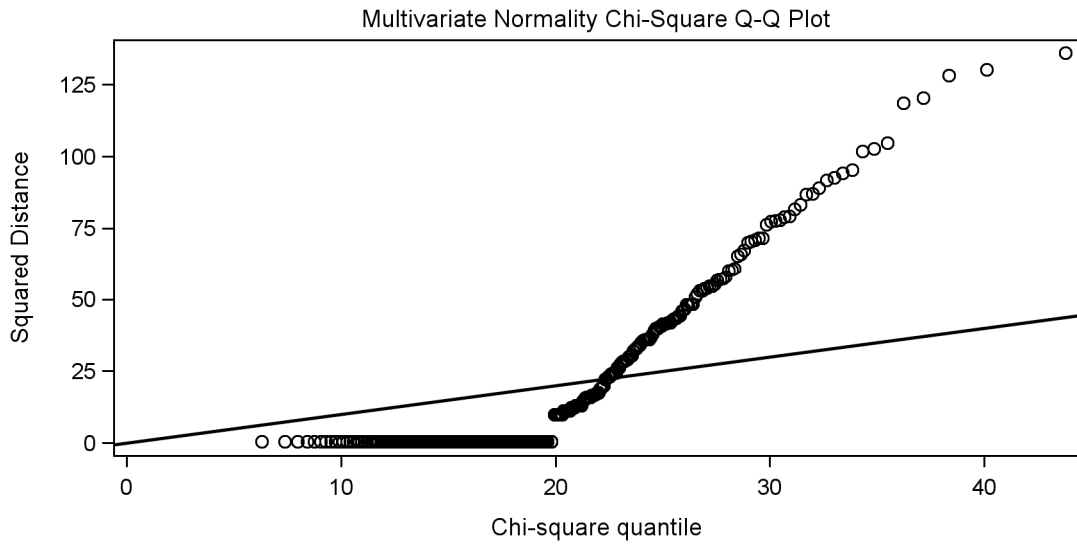


Table F-4 Square Multiple Correlations (SMCs) Six Months after Diagnosis of Epilepsy

SMC	Value
Question 1	0.596
Question 2	0.749
Question 3	0.792
Question 4	0.780
Question 5	0.720
Question 6	0.600
Question 7	0.856
Question 8	0.786
Question 9	0.855
Question 10	0.860
Question 11	0.812
Question 12	0.833
Question 13	0.849
Question 14	0.661
Question 15	0.686
Question 16	0.757
Question 17	0.841
Question 18	0.855
Question 19	0.855
Question 20	0.798

Table F-5 Correlation Matrix for the MPOC-20 Indicator Variables

		Indicators																			
		Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20
Indicators	Q1	---																			
	Q2	.502	---																		
	Q3	.665	.695	---																	
	Q4	.599	.690	.741	---																
	Q5	.617	.568	.716	.709	---															
	Q6	.484	.438	.580	.532	.644	---														
	Q7	.595	.563	.678	.649	.705	.590	---													
	Q8	.556	.527	.593	.620	.637	.549	<u>.856*</u>	---												
	Q9	.602	.504	.685	.602	.703	.586	.787	.768	---											
	Q10	.636	.553	.734	.662	.763	.644	.796	.701	.848	---										
	Q11	.608	.560	.668	.607	.636	.482	.720	.699	.786	.777	---									
	Q12	.598	.530	.660	.592	.626	.554	.716	.655	.787	.777	.736	---								
	Q13	.592	.569	.716	.613	.663	.532	.768	.701	.775	.780	.825	.793	---							
	Q14	.386	.686	.524	.571	.495	.373	.490	.474	.437	.468	.522	.510	.536	---						
	Q15	.453	.574	.625	.552	.628	.501	.708	.609	.661	.713	.644	.697	.697	.515	---					
	Q16	.316	.583	.495	.550	.443	.353	.430	.385	.374	.415	.398	.407	.464	.487	.454	---				
	Q17	.368	.559	.480	.528	.455	.327	.459	.418	.418	.410	.451	.461	.479	.512	.481	.747	---			
	Q18	.367	.533	.497	.533	.434	.317	.473	.460	.465	.475	.465	.491	.538	.549	.469	.742	.838	---		
	Q19	.335	.528	.460	.520	.441	.311	.439	.368	.401	.427	.419	.453	.485	.513	.448	.753	.789	.797	---	
	Q20	.271	.440	.429	.456	.396	.254	.395	.372	.380	.384	.446	.389	.444	.460	.431	.760	.703	.716	.737	---

References

- Brown, T. A. (2006). *Confirmatory Factor Analysis for Applied Research*. Guilford Press.
- Harrington, D. (2008). *Confirmatory Factor Analysis*. Oxford University Press.
- King, S., Rosenbaum, P., & King, G. (1995). *The Measure of Processes of Care: A Means to Assess Family-centred Behaviours of Health Care Providers*. Neurodevelopmental Clinical Research Unit, McMaster University.
- Kline, R. B. (2011). *Principles and Practice of Structural Equation Modeling*. Guilford Press.
- MacCallum, R. C., Widaman, K. F., Zhang, S., & Hong, S. (1999). Sample Size in Factor Analysis. *Psychological Methods*, 4(1), 84–99. doi:10.1037/1082-989X.4.1.84
- Mardia, K. V. (1974). Applications of Some Measures of Multivariate Skewness and Kurtosis in Testing Normality and Robustness Studies. *Sankhyā: The Indian Journal of Statistics, Series B (1960-2002)*, 36(2), 115–128.
- Norman, G. R., & Streiner, D. L. (2008). *Biostatistics: The Bare Essentials*. PMPH-USA.
- Raykov, T., & Marcoulides, G. A. (2012). *An Introduction to Applied Multivariate Analysis*. Routledge.
- Rhemtulla, M., Brosseau-Liard, P. É., & Savalei, V. (2012). When can categorical variables be treated as continuous? A comparison of robust continuous and categorical SEM estimation methods under suboptimal conditions. *Psychological Methods*, 17(3), 354–373. doi:10.1037/a0029315
- SAS Institute Inc. (2007). *Macro to test multivariate normality (Version 1.4)*. Cary, NC: SAS Institute Inc. Retrieved from <http://support.sas.com/kb/24/983.html>
- SAS Institute Inc. (2010). *Base SAS® 9.2 Procedures Guide: Statistical Procedures (Third Edition)*. Cary, NC: SAS Institute Inc.
- Stevens, S. S. (1946). On the Theory of Scales of Measurement. *Science*, 103(2684), 677–680. doi:10.1126/science.103.2684.677
- Tabachnick, B. G., & Fidell, L. S. (2012). *Using Multivariate Statistics (6 edition)*. Boston: Pearson.

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