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EFFECTIVENESS OF FAMILY-MANAGEMENT INTERVENTION ON IMPROVING QUALITY OF LIFE AND BURDEN OF FAMILY WITH AUTISTIC CHILDREN IN VIETNAM

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Burapha University

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EFFECTIVENESS OF FAMILY-MANAGEMENT INTERVENTION ON IMPROVING QUALITY OF LIFE AND BURDEN OF FAMILY WITH AUTISTIC CHILDREN IN VIETNAM

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Families of children with autism play a critical role in their child's ability to adapt and live in daily life as well as receiving treatment. By taking of various roles, families of autistic children have reported low family quality of life (FQoL) and high burden. The purpose of this study was to determine the effectiveness of family-management intervention by comparing FQoL and burden between the intervention and the control groups. A randomized control trial design was conducted to recruit participants of 40 primary caregivers of autistic children who received health services at National hospital in Hanoi, Vietnam, and later they were randomly assigned into each group equally. IRB approval was obtained prior to data collection (Code 02-04-2562). The Beach Center FQoL Scale and the Modified Caregiver Strain Index (C-M-CSI) were used to measure the outcome variables three times, at baseline, week 4 at immediately after completed the intervention, and week 8 at follow-up. The family-management intervention was adapted from the Building on Family Strengths program guided by the FMSF and intensive reviewed of relevant literature. The intervention group was implemented 4 sessions and a routine care while the control group received only the routine care. One-within and one-between mixed repeated measure ANOVAs were used to analyze the data. The results revealed that the total mean scores of FQoL and burden between intervention and control group was different over time ($F_{2,76} = 853.62$, $p < 0.001$ and $F_{2,76} = 144.45$, $p < 0.001$, respectively). The caregivers receiving the family-management intervention had better FQoL and lower burden than those who did not receive ($F_{1,38} = 1442.19$, $p < 0.001$ and $F_{1,38} = 514.43$, $p < 0.001$). Moreover, within the intervention group after receiving the family-management intervention, better FQoL and lower burden ($M_{diff} = -54.60$, $p < 0.001$; $M_{diff} = 1.85$, $p < 0.001$, respectively) than at baseline were found. These findings indicate effectiveness of the family management intervention on improving FQoL and reducing burden among families of children with autism. Policy makers, nursing administrators, and pediatric nurses should utilize this intervention as a part of regular activities to provide education and nursing care for families with autistic children.

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CHAPTER 1

INTRODUCTION

Statement and significance of the problems

Autism is a lifelong disability in social interaction, verbal and nonverbal communication, and restrictive and repetitive behaviors. Worldwide, according to Center for Disease Control and Prevention ([CDC], 2014), the prevalence of the disorder has increased more than 100% over the last 10 years and now the prevalence rates of autism in the United States are estimated at approximately one in 88 children. The CDC data showed a rate of about 1 in 42 boys and 1 in 189 girls identified with autism. Almost half (46%) of children identified with autism had average intellectual ability (IQ about 85). According to the National Autistic Society, it has been estimated that 700,000 people in the United Kingdom, or approximately 1 percent of the population, have autism (Crane et al., 2018). The first epidemiological study on autism in South Korea comprised a total population study of 7–12 year olds and estimated the prevalence to be 2.64 %, the highest rate ever reported for autism in any country (Pantelis & Kennedy, 2016). In Thailand, it was estimated that there were 180,000 children with autism nationwide with 2.8 per 1,000 population or 15 per 1,000 children age under 15 (Kopetz & Endowed, 2012). In Vietnam, although there are no accurate statistics on autistic children, according to an estimate by the Social Protection Agency - Ministry of Labor, Invalids and Social Affairs of Vietnam (2017) there are more than 500,000 people with autism, in which two third of the number are children younger than 15, at a prevalence of 1.25%. Researches shown that the number of autistic children to hospital diagnosis and treatment is increasing. At the National Hospital of Pediatrics, this rate risen up 50 times over the period 2000-2007. In Ho Chi Minh City, this rate increased to 160 times.

Most children diagnosed with autism do not have an etiology for their behavior, but researchers found autism could be linked to the environment, genetics and inheritance from parents. The researchers considered genetics, viral infections, and air pollutants transpired during pregnancy as possible initiators of the disorder (Evans, 2013).On average, children identified with autism were diagnosed after the age of 4 years old even though they could be diagnosed as early as age 2. Even so, clinicians prefer not to diagnose them at age 2, rather than wait until age 4 to prevent labeling or stigma (CDC, 2014). The American Psychiatric Association [APA] (2013) lists five criteria for the diagnosis of autism: 1) deficits in social communication and interaction, 2) circumscribed and repetitive behaviors, interests or activities, 3) symptoms are present early in life, but may not become evident until social demands exceed the child's abilities, 4) deficits cause clinically significant impairments in social, occupational, and adaptive functioning, and 5) symptoms cannot be explained by another intellectual disability or developmental delay.

Autistic children do not always exhibit the same characteristics with variations from mild to severe. Problems with eye contact, no response to their name, deficiencies in attention , poor skills in daily life, and problems with nonverbal communication are common symptoms (Baker & Jeste, 2015); Moulton, Barton, Robins, Abrams, & Fein, 2016). The severity of the disorder is based on impairments in social communication and restricted, repetitive patterns of behavior and ranges from level 1 - Requiring support to level 3 - Requiring very substantial support. Categorization can be 1) with or without accompanying intellectual impairment; 2) with or without accompanying language impairment; 3) associated with known medical or genetic cognition or environmental factor; 4) associated with another neuro-developmental, mental, or behavioral disorder; and 5) with catatonia (APA, 2013). Autism diagnosis and treatment methods remain controversial and are mostly based on behavioral history and assessments. Moreover, there are many parents who known their child with behavior problems. However they tried to hide the problems or provide incomplete information, making it difficult to diagnose and treat children with autism. Fortunately, the research results showed that early intervention **can be effective in improving the problems of autistic children** (Webb, Jones, Kelly, & Dawson, 2014; Vivanti, Prior, Williams, & Dissanayake, 2014)**.**

Findings from literature reviewed, the researchers revealed some effective interventions. The applied behavioral analysis is an effective process, where *the health care providers apply the psychological principles of learning theory in a systematic way to alter behavior* in autistic children. The pharmacological treatments are used for autistic children such as antipsychotics, selective serotonin for mood, repetitive and challenging behaviors. Children with severe symptoms of autism may be provided electroencephalography for seizures, stimulants for attention deficits and hyperactivity or a complementary and alternative medicine by their physician (Lindgren & Doobay, 2011). Nursing interventions are available and optional in some countries to improve social and communication skills in autistic children. Although many interventions exist for autism, not all families and autistic children use them. Many parents do not have much time to follow their autistic children during sessions of intervention processes. Some interventions are complicated with many sessions which challenge families and children to continue the interventions.

Families of children with autism play a critical role in their child's ability to adapt and live in daily life as well as receiving treatments. By taking of various roles, families of autistic children report a high burden (Anh, 2015). Externalizing behaviors in children with autism seem to be persistent and stable over time and create significant problems for the children, their families, and those around them (Strang et al., 2012). Autistic children have difficulties or deficits in communication and socialization skills (Matson, Hess, & Mahan, 2013). Therefore, family members have to spend numerous times to help the children adapting with their daily life. The costs for raising a child with autism is more than three times compared to the costs of raising a non-affected child because of assistance related to education, health and social services (Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2013). Additionally, information and service systems are difficult to understand and approach by families with new diagnosis (Cridland, Jones, Magee, & Caputi, 2014). Some countries with traditional believes often hide their child's disabilities and delay to receive treatment. There appears to be a bidirectional effect between the child's problem behaviors and family stress, burden and quality of life (Bayoumi, Ezzat, & Samarkandi, 2017; McStay, Trembath, & Dissanayake, 2014). This shared influence between the child and the family illustrates the importance of managing the child's problem behaviors and supporting the family to obtain their higher family quality of life [FQoL].

According to Zuna, Summers, Turnbull, Hu, and Xu (2010), FQoL is how family members identify and inform the dynamic sense of well-being of the family as a unit, collectively and subjectively. It is conceptualized as a multidimensional construct that can be measured by indicators that are family interaction, parenting, emotional well-being, Physical/ material well-being, and disability-related support. Family interaction refers to the relationships among and between family members; parenting means the kinds of activities families engage in to facilitate their child's development; emotional well-being involves perceptions of stress and support availability; physical/ material well-being refers to basic physical needs such as medical support and transportation; and disability-related support, including supports across the community contexts of school, work, and home (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006).

Recently, there is an increased focus on FQoL research on families of children with autism. Jones, Bremer, and Lloyd (2017) in the US conducted a research related to FQoL of family with autism claimed that families saw their child is benefitting from disability-related services such as medical, nursing, educational and occupational services. Therefore, families reported high FQoL. They have new social, vocational, and recreational freedom, and could devote more time and attention to fostering relationships with other family members.Schertz, Karni-Visel, Tamir, Genizi, and Roth (2016) stated that autistic children positively contributed to the family and families communicated positive perceptions regarding their FQoL, in which, families were highly satisfied with leisure and life enjoyment and family relationships. Conversely, A. M. Smith and Grzywacz (2014) showed that mothers of children with special needs have a low quality of life. Mothers reported increasing of exhaustion, sadness, anger, and resentment, and increased happiness, peace, and hopefulness. Juhásová (2015) carried out a study about the impact of the care for children with disability on the FQoL (Juhásová, 2015). The results showed that most of the challenges that mothers are faced with include the risk of losing physical, mental, and social well-being; the time limit for dealing with family issues and financial burden; and the lack of appropriate recreational programs. Yamaguchi, Wakimizu, and Kubota (2016) concluded that parents generally had low scores for family empowerment and quality of life, high caregiver burden, and low emotional support network, self-esteem, and self-efficacy. Moreover, a study showed that low FQoL have resulted in multidimensional problems such as psychological and physical health (Lovell, Moss, & Wetherell, 2012). Samuel, Rillotta, and Brown (2012) claimed in their research related to FQoL of families with autistic children that lower

FQoL can potentially result in negative family's capabilities and skills to deal with adversities and challenges across their entire lifespan. Therefore, low FQoL in turn, affect to autistic children outcomes as well.

Despite the negative consequences of raising a child with autism, some interventions have been effective. For example, Alwi, Harun, and Leonard (2015) conducted a research about multidisciplinary parent education for caregivers of children with autism and claimed that the intervention program have positive effects on caregivers' mental health-related quality of life. Tamar and Shirli (2016) examined the support resources contribute to family quality of life among religious and secular Jewish families of children with developmental disability (Tamar & Shirli, 2016). They found that family support and religious and spiritual support contributed to better FQoL. They claimed that successful management within the family may improve FQoL.

In addition to how the family is affected QoL, studies have confirmed the burden experienced by such families. Nowadays, the research results focus on stating that families with autistic children experience higher burden than other families (Estes et al. 2009; Griffith, Hastings, Nash, & Hill, 2010). Focusing on family burden are important as they provide a framework within which to identify key variables that may contribute to the experience of burden, therefore, leading to specific interventions to support families and facilitate family functioning. Most of the researches used Family Management Style Framework (FMSF) as intervention framework to guide for the intervention program (Knafl, Deatrick, & Gallo, 2008; Knafl et al., 2013).

The family management style framework [FMSF] was developed to understand family experience and functioning related to childhood chronic illness by identifying key aspects of the family experience related to health problems (Knafl & Deatrick, 2003; Knafl, Deatrick, & Havill, 2012). The framework has been studied from previous researches. Consequently, Knafl and colleagues developed the Family Management Measure [FaMM], which was used in a variety of settings to study various populations worldwide (Knafl et al., 2013). The FMSF has guided studies conducted to define family management styles in families of children with chronic illnesses, including spina bifida, congenital conditions, brain tumors, and other cancers, especially, children with autism (Rempel, Blythe, Rogers, & Ravindran, 2012). The FaMM is considered to measure the six different aspects of family management: child's daily life, condition management ability, condition management effort, family life difficulty, parental mutuality and view of condition impact (Knafl et al., 2009). Family management refers to families’ responses to a child’s chronic condition care and how families incorporate condition management into their everyday life (Knafl et al., 2008; Knafl et al., 2013). For autistic children, the primary goal includes managing child's behavior problems and family's daily living events. Moreover, family management also incorporates management of the child’s emotional, behavioral, physical and social needs.

The existing literature indicates that families with an autistic child potentially experience changes in family management, demonstrated by changes in social patterns and resources (Soltanifar et al., 2015). Researches related to family with autistic children claimed that family management could link to the family QoL and burden (Hsiao, Higgins, Pierce, Whitby, & Tandy, 2017; Knafl et al., 2013; McStay et al., 2014). Moreover, for autistic children, the family management style framework has been to determine components contributing to quality of life and burden (Knafl et al., 2012; Knafl et al., 2008; Knafl & Deatrick, 2003). The research results suggested that family efforts to intervene child's problems means focusing on the family management style and ultimately improve the family QoL and burden (Hsiao et al., 2017). The intervention can help family members cope with and manage their children’s conditions more effectively (Kieckhefer et al., 2014).

Despite the management perspective has aware, only a small number of studies have evaluated the broad impact of this approach on family QoL and burden. Moreover, most interventions evaluated child outcomes, rather than parent and family outcomes. Although, these interventions have developed, implemented and researched, both the health care providers and researchers should raise broadly awareness of families and community the need for these services. These researches themselves should be able to figure how to use and provide families the available options for these interventions for autistic children and their own families (Goepfert, Mule, von Hahn, Visco, & Siegel, 2015; Tanner, Hand, O'Toole, & Lane, 2015; Kuhaneck, Madonna, Novak, & Pearson, 2015 Kuravackel et al., 2018). Moreover, study findings have remained controversial of effectiveness on family and children outcomes. Some of the interventions using the FMSF should be simplified and structured, which makes evaluation of the effectiveness of these programs become clear, unbiased and having enough of follow-up support. In Vietnam, there are relatively lack of studies related to family-management intervention and what families actually understand by quality of life, burden and the impact of family-management on FQoL, burden and continually caring for and living with an autism throughout their life.

Considering these results, there was a clear need to determine the effectiveness of family-management intervention for family with autistic children, especially in Vietnam. The intervention would help Vietnamese family to increase understanding about diagnoses, behavior management principles, assessing necessary services, and developing skills to promote their child development. Additionally, the intervention included a session to confirm its effect sustainably. The researcher developed and administered the family-management intervention with an expectation of improving FQoL and lessening burden of family with autism in Vietnam.

Research purpose

The purpose of this study was to determine the effectiveness of family-management intervention among Vietnamese family of children with autism by comparing family QoL and burden between the intervention group and these in the control groups.

Research hypotheses

1. Participants in the intervention group have higher FQoL than that in the control group at immediately post-intervention, and follow-up period.
2. Within the intervention group, there is a significant difference in mean score of family quality of life across three-point times.
3. Participants in the intervention group have lower burden than that in the control group at immediately post-intervention, and follow-up period

4. Within the intervention group, there is a significant difference in mean score of family burden across three-point times.

Conceptual framework of the study

The conceptual framework of this study based on the family management style framework [FMSF] (Knafl et al., 2012). The FMSF focuses on internal family processes, beliefs, and behaviors as families incorporate condition management into everyday life, but it also acknowledges effects of socio-cultural factors on families. The FMSF includes conceptual themes based on symbolic interactionism that form three major components of dimension of family management in the framework including defining the situation, management behaviors and perceived consequences (Knafl & Deatrick, 2003; Knafl et al., 2012). Firstly, defining the situation examines the subjective meaning family members attribute to important elements of their situation. The conceptual sub-themes of defining the situation are child identity, illness view, management mindset and parental mutuality used to define that situation. Secondly, management behaviors are defined as the efforts directed toward caring for the illness and adapting family life to illness-related demands. The component includes the parenting philosophy and management approach. Thirdly, the perceived consequences examine the family focus on the condition and future expectations for the family and the child.

For purposes of this study, the selected variables address three components of defining the situation, family-management behaviors and perceived consequences. Defining the situation are parent views of child with autism and vulnerabilities; the cause, seriousness and predictability of autism; the difficulty of carrying out the treatment regimen and their ability to manage effectively. Management behaviors are efforts or behaviors family members make to manage autistic child and their own family problems; how families incorporate condition management into their everyday life. The perceived consequences component is the family perceptions of the consequence of having child with autism for family life in directing the family focus on the condition and future expectations for the family and the child. The outcomes are defined as quality of life and burden of family who are challenging by autistic children (Knafl et al., 2012). The family-management intervention provided knowledge of autism and family management approach; family goals and values of management; and how to plan their own routine approach to behavior management for autistic children. The intervention strengthened family capacity in managing their-own life and children with autism in order to improve FQoL and reduce burden. The study framework is illustrated as Figure 1-1.

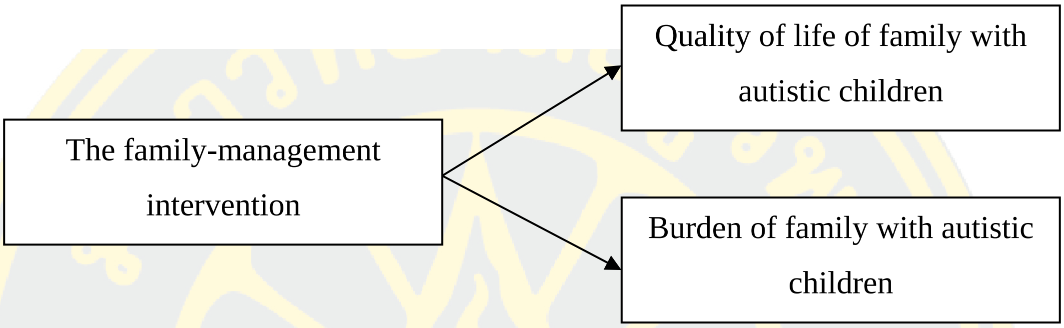

Figure 1-1 The conceptual framework of the study

Scope of the research

This research aimed to examine the effectiveness of the family-management intervention among Vietnamese family with autism by comparing FQoL and burden between the intervention and the control groups, as well as across three time points within the intervention group. The participants were primary caregivers of children with autism who receive health services at National hospital in Hanoi, Vietnam in 2019.

Definition of terms

Family-management intervention refers to a program of nursing intervention for family who face with the health care challenges of children with autism. The program aims to enhance or facilitate family behaviors providing care for their young family member diagnosed as autism. The researcher developed this program which adapted from the Building on Family Strengths program (Kieckhefer et al., 2014) guided by the FMSF and intensive reviews of relevant literature about intervention studies for families with autistic or chronically ill children. This intervention focuses on supporting family in managing autistic children and their own family problems. The duration of the family-management intervention takes around 60 to 90 minutes per session, one time per week for four weeks to develop families' knowledge of autism, routine approach to behavior management and balance family life.

Family quality of life [FQoL] refers to the perception of a family member, who is the representative of others, to identify and inform the dynamic sense of well-being of the unit, collectively and subjectively. It was measured by the Beach Center FQoL Scale with 5 domains of family interaction, parenting, emotional well-being, physical/ material well-being, and disability-related support (Hoffman et al., 2006).

Burden of family refers to perception of a family member about difficulties, strains, and other negative effects as a result of caring for a child with autism in Vietnam when the demands of care-giving outweigh the available resources, which included emotional, psychological, physical and financial resources. It was measured by the caregiver strain questionnaire (Brannan, Heflinger, & Bickman, 1997).

CHAPTER 2

LITERATURE REVIEWS

This chapter reviewed the literature related to the prevalence of autism, quality of life of family with autistic children and related factors, the family management style framework and interventions focused on family quality of life and burden of family with autistic children.

Autism

1. Definition

Autism is a developmental disorder that presents with lifelong disability in social interaction, verbal and nonverbal communication, restrictive and repetitive behaviors and unusual interests (The American Psychiatric Association [APA], 2013). The definition of autism has developed over time since it was introduced in the third edition of the *diagnostic and statistical manual of mental disorders* (Spitzer, 1980). The new DSM-5 diagnostic disorder autism has two main criteria including persistent social communication and social interaction deficits; and restricted, repetitive patterns of behavior, interests, or activities. A child may demonstrate all of the first criteria as early as age 2 years if the child does not respond to his or her name, has no or limited attention, and shows a lack of reciprocal interaction. An example of the second criteria in a toddler is an unusually strong interest in a play telephone during which time he does not engage with his mother, respond to his name, or share enjoyment with his mother about the phone. Adherence to restricted routines can lead to difficulties with transitions and challenging behaviors, such as tantrums (Weitlauf et al., 2014). The DSM-5 also requires clinicians to specify other diagnoses that may be present, such as cognitive or language impairment, known medical or genetic conditions, and other neuro-developmental or behavior disorders (APA, 2013). The clinician rates the severity of the autism on three levels. Level 1 requires support; level 2 requires substantial support; and level 3 requires extensive support (APA, 2013).

2. Prevalence of autism

In the United States, the Centers for Disease Control and Prevention [CDC] data showed that Autism is estimated at one in 88 children. CDC data showed about 1 in 42 boys and 1 in 189 girls identified with autism spectrum disorders. “About 1 in 63 white children, 1 in 81 black children, and 1 in 93 Hispanic children were identified with autism. Almost half (46%) of the children identified with autism had average intellectual ability (IQ about 85). Less than half (44%) of the children identified with autism were evaluated for developmental concerns by the time they were 3 years old” (Centers for Disease Control and Prevention [CDC], 2014. para 2.) On average, children identified with autism were diagnosed after age 4 even though they could be diagnosed as early as age 2. Even so, clinicians prefer not to diagnose them at age 2, instead chose to wait until the age of 4 years to minimize labeling the child. About 80% of children identified with autism were either referred from their schools or were diagnosed by a clinician. This means that about 20% of children are not diagnosed professionally (CDC, 2014. para 2.). According to the National Autistic Society, it is estimated that 700,000 people in the United Kingdom, or approximately 1 percent of the population, have autism (National Autistic Society, 2018). The first epidemiological study of autism in South Korea comprised a total population study of 7–12 year olds and estimated the prevalence to be 2.64 %, the highest rate ever reported for autism in any country (Pantelis & Kennedy, 2016). In Thailand, it was estimated that there were 180,000 children with ASD nationwide with 2.8 per 1,000 population or 15 per 1,000 children age under 15 (Kopetz & Endowed, 2012).

In Vietnam, information related to the prevalence of autism is limited (Browne, 2009). According to the Social Protection Agency - Ministry of Labor, Invalids and Social Affairs there are around 200,000 identified people with autism inVietnam, in which two thirds of the number are children, but there is no official data and no autism related books printed in Vietnamese. It has been estimated that of the children with special needs in Vietnam, about 95% of them do not receive any dedicated services (Villa, Van-Tac, Muc, Ryan, & Thuy, 2003). Researchers have shown that the number of autistic children diagnozed yearly is increasing worldwide. At the National Hospital of Paediatrics, this rate has risen 50 times over the period

2000-2007. In Ho Chi Minh City, this rate increased to 160 times (Ministry of Labor, Invalids and Social Affairs, 2017).

3. Etiology, symptoms and treatment.

The exact cause of autism is unknown, but researchers found autism could be linked to the environment, genetics and inheritance from parents. Despite medical and technological advancements, a test to diagnose autism before childbirth is not available. Genetics, viral infections, and air pollutants during pregnancy are possible causes of the disorder (Evans, 2013). Research has identified multiple factors that may affect the development of a child's brain during pregnancy and hinder normal functioning such as genetics, biological, and environmental factors (Evans, 2013).

The American Psychiatric Association lists five criteria for the diagnosis of autism including: (1) deficits in social communication and interaction; (2) circumscribed, repetitive behaviors, interests or activities; (3) symptoms are present early in life, but may not become evident until social demands exceed the child's abilities; (4) deficits cause clinically significant impairments in social, occupational, and adaptive functioning; and (5) symptoms cannot be explained by another intellectual disability or developmental delay (APA, 2013). The severity of the disorder is based on impairments in social communication and restricted, repetitive patterns of behavior and ranges from level 1 - Requiring support to level 3 - Requiring very substantial support. Further classifications include: 1) with or without accompanying intellectual impairment; 2) with or without accompanying language impairment; 3) associated with known medical or genetic cognition or environmental factor; 4) associated with another neuro-developmental, mental, or behavioral disorder; and 5) associated with catatonia (APA, 2013). In the past, children with autism requiring level 1 support and exhibiting no intellectual or language impairment might be diagnosed with Asperger syndrome, high-functioning autism, or Pervasive Developmental Disorder - Not Otherwise Specified. When the APA updated the diagnostic criteria in 2013, these diagnoses were subsumed into the category of autism.

Children with autism who are high functioning exhibit a range of behaviors, some of which are considered symptoms only because they are inappropriate for age or level of cognitive functioning; however, the overarching indicator is that of problems of social integration (Huerta & Lord, 2012). These children experience problems in social-emotional reciprocity and may not understand or recognize nonverbal communication, thus they are unable to understand how the mental state of others is reflected in their behavior or discern another's emotions from facial expression or nonverbal cues (Georgescu et al., 2013); Tracy, Robins, Schriber, & Solomon, 2011). Their ability to identify and express their own emotions is limited which may result in emotional reactions disproportionate to the situation. These children may keep their emotions to themselves while mentally replaying a situation in an attempt to process what happens, only to have these emotions spill out in a full-blown tantrum hours or days after the event, making it difficult at times to know what triggered the tantrum.

As many as one-half of children with autism exhibit externalizing behaviors which are negative behaviors directed outwardly towards others and may include oppositional behaviors; defiance; verbal, physical, and relational aggression; antisocial behaviors; impulsivity; and hyperactivity (Sukhodolsky, Smith, McCauley, Ibrahim, & Piasecka, 2016). Children with autism most commonly exhibit aggression in the home and generally directed toward the mother or caregiver (Fitzpatrick, Srivorakiat, Wink, Pedapati, & Erickson, 2016). Externalizing behaviors in children with autism seem to be persistent and stable over time and create significant problems for children with autism, their families, and those around them (Matson, Mahan, Hess, Fodstad, & Neal, 2010; Strang et al., 2012). There appears to be a bidirectional effect between the child's problem behaviors and quality of life and the family's adaptability, discord, and stress (L. E. Smith, Greenberg, & Mailick, 2013). This shared influence between the child and the family illustrates the importance of managing the child problem behaviors and supporting the family to their overall well-being.

Several treatments have been attempted to treat Autism such as 1) applied behavioral analysis as an effective process, 2) electroencephalography to treat seizures, 3) pharmacological treatments of antipsychotics, selective serotonin and reuptake inhibitors used for mood, repetitive and challenging behaviors, 4) stimulants to treat attention deficits and hyperactivity, and 5) sensory integration, a complementary and alternative medicine (John, 2014). Although these interventions have provided limited efficacy the most promising intervention is family support.

4. Affecting on family

The family is the primary force contributing to the development of children and youth (Breiner, Ford, & Gadsden 2016). This contribution may be positive, neutral, or negative in nature. Early interaction and secure attachment between a mother and baby result in the wellbeing and development of the child (Winston & Chicot, 2016). These early parent-child interactions are associated with social and cognitive development, academic performance, school attendance, behavior, and social skills (Penner, 2018). This relationship is particularly important for children/youth with disabilities. Individual characteristics of every member of the family can either strengthen or limit the entire family unit. When a child has a disability, members of the family may respond differently, depending on the characteristics of the child (e.g., the type and the severity of the disability, the onset age of the disability) as well as the characteristics of the family (e.g., family size, number of parents present in the home, birth order). Other characteristics that impact a family are the ability of the individual to problem solve, physical and mental health, communication, and motivation level (Farrell & Krahn, 2014).

When a member of a family has autism, the disability impacts the entire family, parents and siblings. For parents, this may include emotional effects (e.g., grief cycle), marital stress, and social pressure (Olawale, Deih, & Yaadar, 2013). For siblings, the influence may include negative feelings (e.g., resentment toward their sibling, responsibility, or a sense of being ignored by their parents). However, a disability is not always a burden; the presence of a child with a disability may have a positive or neutral impact on the family unit (Olawale et al., 2013). Parents reported that family relationships can be strengthened and enriched by the child with a disability. Unfortunately, many parents and families do not have adequate support to deal with a child with autism (Hartley & Schultz, 2015).

5. The case in Vietnam

Vietnam families have to face discrimination against their autistic children from the society and often times have to solve problems for raising their children with autism by themselves. Externalizing behaviors in children with autism seem to be persistent and stable over time and create significant problems for children with autism, their families, and those around them (Strang et al., 2012). Autistic children have difficulties or deficits in communication and socialization skills (Matson et al., 2013). Therefore, family members have to spend numerous effort to help the children adapting with their daily life. The costs for raising a child with autism was more than three times compared to those spent to normal child because of required assistances related to education, health and social services (Sun et al., 2013). Additionally, information and service systems are difficult to understand and approach by families with new diagnosis (Cridland, Jones, Magee, & Caputi, 2014). Some countries with traditional believes often hide their child's disabilities and delay to receive treatment. There appears to be a bidirectional effect between the child’s problem behaviors and family stress, burden, quality of life (Bayoumi et al., 2017; McStay et al., 2014). This shared influence between the child and the family illustrates the importance of managing the child problem behaviors and supporting the family to their higher family quality of life [FQoL] and lessen burden.

Family quality of life of children with autism

The family quality of life perspective provides a conceptual framework to seek positive approaches that can improve the quality of life of families raising a child with a disability. The outcome of this approach is families that are functioning optimally within their home and community, supporting the development of their children, and contributing to the ongoing stability of societies. Supporting the FQoL of families in the early childhood years can potentially enhance a family’s capabilities and skills to deal with adversities and challenges across their entire lifespan (Samuel, Rillotta, & Brown, 2012).

Zuna et al. (2010) reviewed 24 articles to identify the definitions, concepts, variables, and relationships among the domains of family quality of life. Zuna et al. (2010) concluded that family quality of life is how family members define and inform the dynamic sense of well-being of the unit, collectively and subjectively. While most authors do not provide a definition of family quality of life, Gupta and Sharma (1998) defined it as an enrichment of life, including social production, distribution, and perception of values. Bayat (2005) maintained that family quality of life was the overall well-being and ability of a family to meet its needs and enjoy life. For the purpose of this dissertation, family quality of life was defined as the dynamic sense of well-being of the family (Zuna et al., 2010). Family quality of life extends beyond a focus on the member with a disability. For the family unit, QOL cannot be attained until the needs of every member are met (Davis & Gavidia-Payne, 2009). Because of the multidimensionality of QOL, researchers have identified the domains encompassing the concept in order to better measure it and identify the manner in which the subsystems interact (Turnbull, Summers, Lee, & Kyzar, 2007).

The domains of family quality of life vary in the literature (Poston, Turnbull, Park, & Mannan, 2003; Turnbull et al., 2007). Poston et al. (2003) provided the conceptualization of family quality of life using focus groups and individual interviews. Ten domains of family quality of life were identified with six domains focusing on the individual (e.g., advocacy, emotional well-being, health, physical environment, productivity, and social well-being) and four domains concerned with the family unit (e.g., daily family life, family interaction, financial well-being, and parenting). International researchers (Isaacs et al., 2012) identified nine domains of family quality of life. These domains include health, financial well-being, family relationships, support from others, support from disability-related services; spiritual and cultural beliefs; careers and preparing for careers; leisure and enjoyment of life; and community/ civic involvement. In order to modify the family quality of life domains, Summers et al. (2005) created the Beach Center Family Quality of Life Scale. They reviewed the existing research and identified five domains to use in the measurement of the construct of family quality of life. These include: family interaction, parenting, emotional well-being, Physical/ material well-being, and disability-related support. The Beach Center Family Quality of Life Scale was developed to use with families of children with disabilities (Summers et al., 2005). Hoffman et al. (2006) maintained that the convergent validity measure indicated that the hypothesized subscales of the scale were highly correlated with the overall scale structure and test-retest reliability correlations were significant across subscales as well.

Quality of family functioning and satisfaction with family life are correlated with how families perceive their beliefs on different aspects of efficacy (e.g., self-efficacy, parental efficacy, and spousal efficacy), especially the consensus of the overall ability to manage family affairs (Bandura, Caprara, Barbaranelli, Regalia, & Scabini, 2011). Moreover, when families have a higher level of familial cohesion and satisfaction with their bonds, they rate their emotional well-being higher (Vandeleur, Jeanpretre, Perrez, & Schoebi, 2009). Typically, families in which the children do not have disabilities experience a higher QOL (Bowman, 2001; Brown, MacAdam-Crisp, Wang, & Iarocci, 2006).

The majority of the research conducted concerning QOL issues in special education has been conducted with families in which there is a child with an intellectual disability (Bertelli, Bianco, Rossi, Scuticchio, & Brown, 2011; Steel, Poppe, Vandevelde, Van Hove, & Claes, 2011; Werner, Edwards, & Baum, 2009). However, research concerning the conceptualization and measurement of the family quality of life domains is beginning to emerge for other disability groups (Poston et al., 2003). The focus of this research is on the ways in which family life is impacted differentially (e.g., by disability) and the impact of disability on the perceptions of family members concerning the family functioning (internally and externally). This research has examined the influence of services and the community on the family (Brown et al., 2006).

Previous research on quality of life has been focused on specific family members (e.g., mothers) (Hoffman et al., 2006). However, little research exists concerning the quality of life domains for families with children with autism (Bayat, 2005; Plimley, 2007). Studies on quality of life in the field of autism have focused on the parents, not the whole family system (Lee, Lahey, Owens, & Hinshaw, 2008; Lee et al., 2009). Thus, research specific to families in which there is a child with autism is needed.

Recently, there is an increased focus on FQoL research on families of children with autism. Jones et al. (2017) You said in the previous paragraph that little reseach exists conducted a research related to FQoL of family with autism claimed that families saw their child as benefitting from service, therefore, families reported high FQoL, they have new social, vocational, and recreational freedom, and could devote more time and attention to fostering relationships with other family members. Schertz et al. (2016) stated that autistic child had positively contributed to the family and families communicated positive perceptions regarding their FQoL, in which, families were highly satisfied with leisure and life enjoyment and family relationships. Conversely, Yaghmaei and Mohajeri (2013) showed that mothers of children with special needs have a low quality of life. Mothers reported increasing of exhaustion, sadness, anger, and resentment, and increased happiness, peace, and hopefulness. Juhásová (2015) carried out a study about the impact of the care for children with disability on the FQoL (Juhásová, 2015). The results showed that most of the challenges that mothers are faced with include the risk of losing physical, mental, and social well-being; the time limit for dealing with family issues and financial burden; and the lack of appropriate recreational programs. Wakimizu, Yamaguchi, and Fujioka (2016) concluded that parents generally had low scores for family empowerment and quality of life, high caregiver burden, and low emotional support network, self-esteem, and self-efficacy (Wakimizu et. al., 2016). Moreover, the researches showed that low FQoL have resulted in multidimensional problems such as psychological and physical health (Lovell et al., 2012). Samuel et al. (2012) claimed in their research related to FQoL of families with autistic children that lower FQoL can potentially result in negative family's capabilities and skills to deal with adversities and challenges across their entire lifespan. Therefore, low FQoL in turn, affect to autistic children outcomes as well.

The research results showed that support available to families of children with disability has a positive impact on FQoL. Binbin, Sun, Yi, and Tang (2014) conducted a research about multidisciplinary parent education for caregivers of childrenwith autism and claimed that the intervention program have positive effects on caregivers' mental health-related quality of life. Tamar and Shirli (2016) in a study examined the support resources contribute to family quality of life among religious and secular Jewish families of children with developmental disability (Tamar & Shirli, 2016). They showed that familial support and religious and spiritual support were found to contribute to the FQoL. The research results claimed that successful in management within family may improve FQoL. Most of the researches used family management style framework [FMSF] as intervention framework to guide for the intervention program (Knafl et al., 2008; Knafl et al., 2013).

Burden of family of children with autism

Caregiver burden is perception of mental and physical health of a person who giving care to a patient when the demands of care-giving outweigh the available resources, which include emotional, psychological, physical and financial resources. Caregiver burden can be described as either objective or subjective (Brannan, Heflinger, & Bickman, 1997). Objective burden refers to the tangible costs to the caregiver, such as physical demands and disruption to daily routine (Kang, Brannan, & Heflinger, 2005). Measurements of objective burden include the quantity of time performing a caregiving task, the type of tasks performed, and the resources (physical and financial) needed to maintain the caregiving role. Caregivers reported less objective and subjective strain eight months after initiating mental health services, with the greatest change occurring in the first four months. However, subjective internalized caregiver strain remained in a moderate range eight months after initiating treatment, even though much larger reductions in caregiver strain have been found in other usual care settings with time-limited therapy. It is possible that decreases in strain may largely be the result of initiating mental health services rather than actual receipt of services (Dada, Okewole, Ogun, & Bello-Mojeed, 2011). Subjective burden refers to the caregiver's perception of burden and is influenced by the caregiver's appraisal of the situation and the emotional impact that it has on the caregiver. Similarly, greater initial subjective externalized caregiver strain predicted less improvement in child behavior at four months. These results reinforce a possible causal relation between disruptive behavior problems and caregiver strain. Furthermore, they suggest there is a true bidirectional relationship between caregiver strain and disruptive behavior problems, such that reducing behavior problems may enhance positive changes in subjective strain, at the same time as reducing objective strain may lead to reductions in behavior problems (Hu, Dolansky, Hu, Zhang, & Qu, 2016).

In recent years, more studies have been conducted to assess the caregiver burden all over the world (Brown et al., 2010). These studies showed that a number of factors such as caregivers' financial status, occupation, supportive resources, and culture might affect the way they experience caring for a patient with chronic disease. The parents' financial status might also be considered as an outcome of their occupation. These two variables might also be influenced by the parents’ education level. Then, the combined effect of the caregivers’ financial, educational, and occupational status might affects not only their quality of life and mental health, but also their perceived burden. Availability of supportive resources was an important factor affecting caregiver burden. A number of studies also confirmed the beneficial effects of familial and social supports on decreasing the caregiver burden. The use of avoidance, collusion and coercion as coping strategies were also discovered to significantly influence caregiver burden (Kate et al., 2012). Furthermore, a Swiss study identified the severity of the child cerebral palsy conditions, aggressive behaviours and threats, as major factors impacting both the caregivers’ subjective and objective burden (Lauber, Eichenberger, Luginbuhl, Keller, & Rossler, 2003). Carona, Crespo, and Canavarro (2013) also concluded that the negative symptoms of cerebral palsy resulted in greater caregiver burden, as it was significantly related to both subjective and objective burden; while positive symptoms were only linked to subjective burden.

The literature has found that compare with normal children, the order of raising burden per year of three kinds of disabled children were: children with autism, children with physical disability, and children with mental disability. Families who care for a child with a disability are more likely to have non-reimbursed expenses for disability-related supports. The literature reports troubling findings that uncover an association between low income and children with special needs, with associations between these factors that might go both ways. In other words, children with a disability are often born into low income families; however, it has also been reported that families who care for a children with a disability often find themselves sliding towards poverty. The research results showed that parental stress and the child's depressive feelings strongly affected psychological well-being (Hernandez et al., 2017). They also found an indirect relation of restricted caregiver social activities through parental stress. To protect psychological well-being of caregivers, support services should address depressive feelings among children with intellectual disabilities, facilitate caregivers' social activity, and reduce stress (Cramm & Nieboer, 2011).

Stuart and McGrew (2009) investigated that parents of children with autism tend to experience more mental health issues, depression, anger and stress than other parents who have children with other developmental disabilities. It is plausible that the stressors of having a child with autism affect the couple relationship; however, few researchers have focused on this dynamic within these families. A previous model of stress has depicted predictors, moderators, and outcomes of parents of children with developmental disabilities. These parents may be less likely to receive informal social support given the nature of the child's disability. Perhaps the negative perception of the social and behavioral characteristics associated with autism may prevent informal social networks from providing ongoing or consistent support. Stuart and McGrew (2009) found that a reduction of informal social support is associated with increased caregiver burden, which could lead to increased stress.

Furthermore, caregivers may also have to deal with negative and judgmental views from others while in public (National Collaborating Centre for Mental Health [NCCMH], 2013). Several factors have been shown to work in concert to increase stress in parents of children with autism. First and foremost, the realization that there is no cure for the disorder may serve to increase parenting stress. Aspects of the child's behavior, specifically socially inappropriate and aggressive behaviors typically associated with autism, have been found to be associated with increases in parenting stress, as well as being confronted by antipathy for their child's behaviors due to a lack of understanding of autism. Additionally, raising a child with autism typically involves allocating extra time to meet the needs of the child. These findings suggest that multiple changes occur in the parental role to accommodate the challenges of raising a child with autism. While examining such changes is helpful in increasing our understanding of parenting stressors, examining the interplay of both parental and child factors as they contribute to the parent-child relationship will provide a greater understanding of the types of support and potential interventions needed by families of children with autism (Rezendes & Scarpa, 2011).

Although the studies mentioned above have ethnically biased samples, which consists of mainly Caucasians, some of the findings can still be generalized cross-culturally. Psychological burden often manifests as anxious and catastrophic thinking, as well as various somatic complaints such as breathing difficulties, pounding of the heart, and sweatiness of the palms. These complaints have been encapsulated as symptoms of anxiety disorders. Although no differential treatment effects were found in primary stress indices, mothers enrolled in Mindfulness-Based Stress Reduction showed significantly greater improvements, with larger effect sizes, in depression, anxiety, sleep, and life satisfaction. Such advantages in Mindfulness-Based Stress Reduction may be associated with the immediacy of physiologic relaxation responses incurred in mindfulness practice, including strengthened attention to bodily sensations, and less reliance on rumination or other automatic emotions (Goldin & Gross, 2010).

Caregivers of children with autism in Vietnam experienced discrimination and stigma and faced a range of obstacles in accessing appropriate diagnosis and assessment and intervention services (Quach, 2008). The experience of living with autism for these caregivers is one of frustrating and time consuming consultations with doctors, extensive and expensive searches for therapies, attempts to change schools, interventions at private centres and intensive management, protection and supervision of their children (Pham, 2008).Poorer families and those from rural Vietnam have neither the income, time nor opportunities to pursue interventions.

Caregiver strain may mediate the relationship between child problems and parental distress. Previous research modeled the relationship among caregiver burden child clinical symptoms, caregiver psychological distress, functioning, social support, stressful life events, and material resources. Findings indicated that global caregiver strain and caregiver psychological distress are only weakly related when other family variables were controlled (Sales, Greeno, Shear, & Anderson, 2004). As a result, caregiver of autistic children experience various forms of stress, burden, stigma and discrimination and more support, education is needed to counter misunderstandings about this disorder.

Family management style framework

The family management style framework [FMSF] was developed to understand family experience and functioning related to childhood chronic illness by identifying key aspects of the family experience related to health problems (Knafl & Deatrick, 2003; Knafl et al., 2012). The framework and family management measure

[FaMM] was used in a variety of settings to study various populations worldwide (Knafl et al., 2013). The FMSF has guided studies conducted to define family management styles in families of children with chronic illnesses, including spina bifida, congenital conditions, brain tumors, and other cancers (Rempel et al., 2012; Wollenhaupt, Rodgers, & Sawin, 2012), especially, children with autism (Kim, Ekas, & Hock, 2016).

Family management differs from other family concepts, such as family functioning or family environment, in that it is specifically concerned with identifying the domains of condition management rather than more general family phenomena or individual tasks that are associated with specific condition interventions. Studies examining unique conditions like asthma and diabetes have been informative for those diagnoses and tasks, but they do not necessarily incorporate family perspectives and may not be relevant to other conditions (Alderfer et al., 2008; McQuaid, Walders, Kopel, Fritz, & Klinnert, 2005). By identifying global management domains, the family management perspective examines issues related to management across medical diagnoses. As such, it provides a model for family management that can be applied both to specific conditions and across different conditions by recognizing the similarities and differences that exist for children with chronic diseases and their family members.

Family management of various chronic diseases has been studied from the parent perspective. Knafl and Deatrick have spent more than 20 years investigating family management, beginning with the original conceptual article and followed with the first empirical study that consisted of open ended qualitative interviews conducted with families of children with CHCs (Deatrick & Knafl, 1990; Knafl, Breitmayer, Gallo, & Zoeller, 1996; Knafl & Deatrick, 1990). The analysis of those interviews led to the development of the family management style framework [FMSF] (Knafl & Deatrick, 2003) and subsequently, the creation of the family management measure [FaMM] (Knafl et al., 2011). Researchers have used the FMSF and FaMM in a variety of settings to study various populations in the U.S. and worldwide (Wollenhaupt, Rodgers, & Sawin, 2012; Zhang, Wei, Han, Zhang, & Shen, 2013) while work continues on refining both the FMSF and FaMM (Knafl et al., 2011; Knafl et al., 2012; Knafl et al., 2013).

The FMSF conceptualizes the interplay of how individual family members define key aspects of having a child with a chronic condition (Definition of the situation), the behaviors they use to manage the condition (Management behaviors), and their perceptions of the consequences of the condition for family life (Perceived consequences). The resulting FMS is the pattern of family members' responses across these three components. The FMSF also includes family members' perception of factors that influence family life and their response to the child's condition (Sociocultural context). Different patterns reveal the extent to which family members have shared or discrepant perspectives on these three key elements of family life in the context of a child's condition. Knowing the FMS provides insights into family strengths with regard to condition management as well as areas of difficulty. FMS is conceptualized as mediating individual and family system outcomes (Figure 2-1).

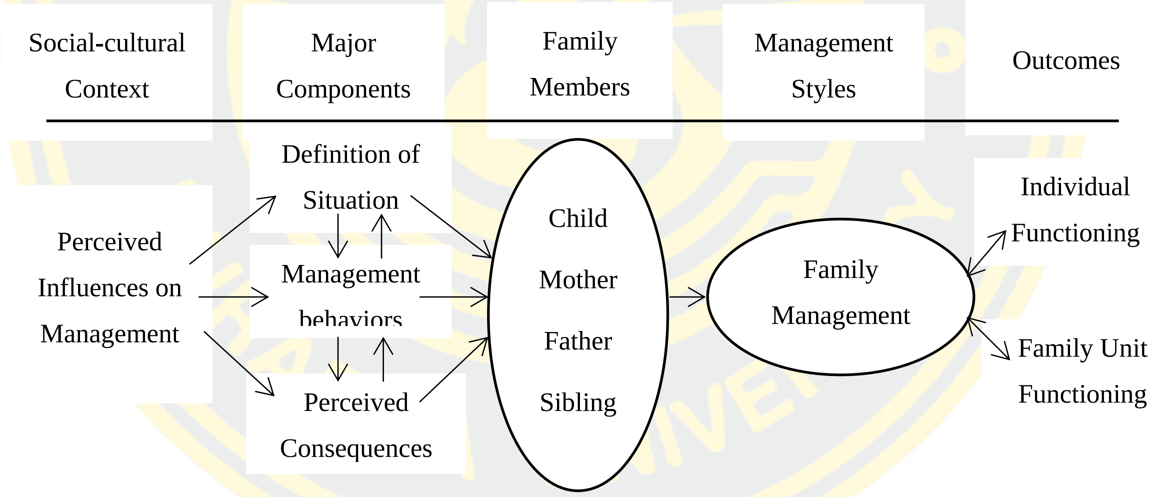

Figure 2-1 Family management style framework

The intent of the FMSF is to provide a useful guide for uncovering a more complete understanding of family life in the context of a child's chronic condition. It is meant to direct researchers' and clinicians' efforts to assess family response to a child's chronic condition, especially with regard to how condition management is incorporated into everyday family life. Typical of a conceptual framework, the FMSF focuses the researcher's or clinician's observations without predicting what they will see. In other words, the FMSF does not specify how the family defines or manages the condition. Rather, as we describe later, it identifies important aspects of the family's definition of the situation, management behaviors, and perceived consequences that shape their management efforts.

The FMSF focuses on internal family processes, beliefs, and behaviors as families incorporate condition management into everyday life, but it also acknowledges effects of socio-cultural factors on families (Knafl et al., 2012). Family management is comprised of three main conceptual components and eight specific dimensions that compose each component. The FMSF emphasizes the interplay of the dimensions including the definition of the situation, management behaviors, and perceived consequences. The definition of the situation is the subjective meaning of having a child with a chronic condition. Management behaviors are efforts or behaviors family members make to manage the condition. The perceived consequences dimension is defined as the family members' perceptions of the consequence of the condition for family life (Knafl et al., 2012). The eight dimensions of family management became a conceptual underpinning of the development of the FaMM (Knafl et al., 2011). The FaMM measures six different aspects: Child's daily life, condition management ability, condition management effort, family life difficulty, view of condition impact, and parental mutuality (Knafl et al., 2011). Although the FaMM items were developed based on the eight dimensions of the FMSF, not all subscales of the FaMM are identical with each dimension of family management. All of the items of the child's daily life scale came from the child identity dimension of family management. The condition management effort scale includes three items out of four from the view of illness dimension. On the other hand, items for family life difficulty and the view of condition impact scale are from four dimensions of family management. The items of the condition management ability scale were generated from six family management dimensions (Knafl et al., 2011). It indicates that three scales capture the intention of the FMSF, thus stressing the interplay of the three dimensions. The FMSF was developed from large empirical studies in the field of nursing and has been refined from a comprehensive review of the literature (Knafl et al., 2012). Also, it has been applied to families with diverse child chronic illnesses such as cancer (Kim & Im, 2015), brain tumors (Deatrick et al., 2006), diabetes (Rearick, Sullivan Bolyai, Bova, & Knafl, 2011), ADHD (Conlon, Strassle, Vinh, & Trout, 2008), and asthma (Gibson-Young, Turner-Henson, Gerald, Vance, & Lozano, 2014), and the studies have supported the applicability of the framework to various child chronic conditions.

Intervention focused on family quality of life and burden of family with autistic children

Despite the management perspective, only a small number of studies have evaluated the broad impact of this approach on FQoL and burden. Moreover, most interventions were evaluated in terms of child outcomes, and not parent or family outcomes. Although, these interventions have been developed, implemented and researched, most families are not able to implement the interventions (Goepfert et al., 2015; Tanner et al., 2015; Kuhaneck et al., 2015 Kuravackel et al., 2018). Moreover, most studies have not assessed the effectiveness of the interventions on both family and children outcomes. In Vietnam, there is a lack of studies looking at family-management interventions and outcomes on families' quality of life, burden and the impact of family-management on FQoL, burden and continually caring for and living with an autism throughout their life.

From the extensive literature review, the researches highlighted effectiveness of interventions for families of children with autism. The intervention programs and their effectiveness are various depending on development level, health care system characteristics, education level of family members. The importance of education intervention for family of autistic children cannot be overemphasized. The authors mentioned that education intervention is associated with an increased likelihood for the mental health related quality of life, family functioning and child outcomes as well (Ji, Sun, Yi, & Tang, 2014). The other researchers mentioned based on their study results that family education intervention should be offered especially to family of children with chronic health conditions who lack adequate support. The intervention can help family members cope with and manage their children's conditions more effectively (Kieckhefer et al., 2014). The existing literature revealed that psychological interventions for parents of individuals with autism may lead to both decreased stress in parents, and improvements in child behavior, therefore, the intervention should focus on psychological needs of families, especially, after receiving the diagnosis of their children as autism (Bekhet, 2017). The technology based intervention has been proved that families of autistic children would receive sufficient support although their geographical distance or a variety of other logistical difficulties with health care service systems (Ferdig et al., 2011). Additionally, other researches revealed that social support intervention reduced mental health problems and other negative outcomes of families of children with autism.

Education intervention: Parent education is defined as an educational effort that attempts to enhance or facilitate parent behaviors that will, in turn, influence positive developmental outcomes in the participants and their children (Schultz, Schmidt, & Stichter, 2011). Multidisciplinary parent education intervention was used to improve the mental health related quality of life, family functioning, self-efficacy and positive coping style in parents with autistic children (Ji et al., 2014). The multidiscipline parent education intervention was 8-week program with once-weekly group classes, each session were approximately 90 minutes taught by a multidisciplinary team including special education teachers, a community nurse, a psychologist and a physiatrist. In 8-week classes, the team provided lectures, case report, role play and discussion related to autism and family knowledge such as, autism issues, characteristics, family management of autism's problems, family management issues while taking care children in their daily life. The results revealed that a multidisciplinary parent education program have positive effects on caregivers' quality of life. The participants reported being highly satisfied with the multidisciplinary parent education program and wished for more and longer intervention (Ji et al., 2014).

The research on an education program for parents of children with chronic health conditions revealed that parent education program have effects on family self efficacy to manage the child’s condition, coping with childhood chronic illness, parent–child shared management of the condition, family quality of life, and, decreased depressive symptoms at the 6-month end-point (Kieckhefer et al., 2014). The intervention was total seven weekly two-hour sessions co-facilitated by a professional and a parent of a child with a chronic health condition who each received

10 hours of formal training in curriculum implementation. Each session last approximately one and half hour to provide chance for discussion about difficulties following the application of strategies since the last session, lectures of new concepts and discussion of future home activities. The contents of 7 sessions facilitate peer exchange of information and insights, modeling by co-facilitators to provide examples focusing on newly learned skills, and parent development of weekly, individualized action plans to promote participant's immediate practice of new skills. Class processes encouraged practice of positive, practical coping strategies and also supported parents in personally determining how they could involve their child in developmentally appropriate shared management tasks regardless of the child's age or unique capabilities. The researchers suggested that the education intervention can help parents cope with and manage their children's chronic conditions more effectively. The education interventions show a certain effect for families and children with autism. However, education programs developed was complicated and unstructured. Therefore, the evaluation of the effectiveness of these programs remained unclear and biased. Moreover, the interventions lacked of follow-up support, which may provide additional information about the long-term effects of education programs.

Psychological support intervention: In fact, while the research on services directed at specifically supporting the psychological needs of parents of individuals with autism, studies reporting on receipt or enactment of the psychological support intervention from families of autistic children, are rare from the literature. A research related to positive thinking training intervention for caregivers of persons with autism indicated that the positive thinking helped to improve positive thinking skills in caregivers, meaning caregivers of persons with autism in the intervention group were able to learn the positive skills and change their thinking (Bekhet, 2017). The positive thinking training intervention was six PowerPoint presentation sessions, in which, videos related knowledge and practice of positive thinking. Five weekly home works for group, in which caregivers were asked to indicate a life situation that they used the positive thinking training strategy after reviewing the weekly video. The intervention focused on developing eight positive thinking capabilities that can help autistic caregivers in many aspects of their daily lives. The findings suggested that adequate receipt and enactment fidelity was reflected in improvements in positive thinking skills for caregivers who received the online positive thinking training intervention. However, PowerPoint presentation may not help caregiver get insightful from caregiver, the research should include a transcript, printouts, or a written material as well as provide more concrete examples as suggested by the caregivers. A webinar with more interactions can also be included in future research. Petcharat and Liehr (2017) on her research of mindfulness training for parents of children with special needs indicated that mindful intervention for parents with special needs is associated with reduced stress, anxiety, and depression because mindful intervention help them more accepting of their children problems. In turn, their children would have fewer behavior problems and enhance positive interaction with their parents. She suggested that mental health nurses can effectively conduct the mindfulness program to increase psychological well-being among parents of children with special needs within 5 to 8 weeks program (Petcharat & Liehr, 2017).

Technology based intervention. Some researchers have attempted to address the limitations of traditional parent training programs. In order to make parent training more accessible, researchers have utilized technology to provide services to parents in remote locations. Elder et al. (2011) conducted a research related to in-home training for fathers of children with autism indicating that by using technology, fathers can effectively implement skills that promote father child social interactions and that children respond positively to this approach. The video tape and computer feedback were two technology methods used in the study process of three conditions. In first condition, the researcher used father child videotaped baseline sessions to teach fathers knowledge related to father child interaction. Accordingly, fathers applied the knowledge in father-child play sessions two times a week for some next weeks with videotape during sessions and teach the knowledge, skills for mothers. Mothers were videotaped during each home visit as well after getting instructions from father. Each parent was given access to a web-based discussion forum for private consultation with a researcher. Each family was videotaped twice a week for 8 - 12 weeks, the range in week reflection by computer is unique each family regarding need for training, family illness. The researchers suggested that collecting videotaped data over numerous sessions is very important in catching of father child interaction and parent involvement in intervention for autistic children (Elder et al., 2011).

Additionally, Elder et al. (2011) in their research related to autism and family interventions through technology, they confirmed again the importance of on-site, in-home training as a viable option due to geographical distance or a variety of other logistical constraints in parents with autistic children. The study described the development and initial use of an Internet-based tool to offer in-home training more broadly (Ferdig et al., 2011). Other research used video feedback to confirm effectiveness of technology based intervention with parents of autistic children. The research indicated that parents displayed positive levels of affect, increased confidence, decreased parenting stress and reported satisfaction with the video feedback; children displayed higher levels of affect and improved outcomes (Ence, 2012). The technology intervention presented their effectiveness in many researches; however, as in every new area of inquiry, more research is needed to further validate technology interventions in family with children of autism. Additionally, collecting videotaped data over numerous sessions rather than single pre and post-intervention is very important for behavioral variability in children with autism, which may be a limitation of the intervention, especially, for the families with logistic difficulties.

In summary, all these family management interventions have in common the involvement of the family in the intervention. The effectiveness of the intervention includes increased family quality of life, family functioning, self-efficacy and positive coping style in parents with autistic children, and reduced stress, anxiety, and depression, which not mentioned directly to the FQoL and burden. Some of the intervention programs were guided by FMSF as the framework to develop intervention. However, these interventions have their own strengths and limitations. Therefore, the education intervention programs should be simplified and structured with certain sessions, therefore family member would be able to follow their autistic children through all sessions. The psychological support intervention indicated their effectiveness on supporting the psychological needs of parents of individuals with autism; however, sessions with only PowerPoint presentation may not be enough for caregivers understanding all the contents, they should be provided more written material as well as concrete examples to improve caregiver's knowledge and skills.

The technology based on intervention with videotaped data is reasonable strategy of characteristics' autistic children and their families. The technologies enable health care workers and researchers to observe or follow in detail the daily behaviors of autistic children and their families during the intervention. The thing is that the intervention program with collections of videotaped data over numerous sessions also becoming the limitation of the intervention. Therefore, programs developed need to be more structured and feasibility which will be suitable for Vietnam family with autism. These intervention need to provide enough follow-up support by simply technology method for the long-term effects of intervention programs. Researchers suggested that future studies should develop a family-management intervention with phone call support. The program would build the strengths of families in supporting for children with autism. The intervention could help improve the quality of life and burden for families with autistic children and in turn, improve outcomes in autistic children.

The case in Vietnam: Vietnam families have to face discrimination against their autistic children from the society and often times have to solve problems for raising their children with autism by themselves. Additionally, there are relatively lack of studies looking at family-management intervention and what families actually understand by quality of life, burden and the impact of family-management on FQoL, burden and continually caring for and living with an autism throughout their life. From the review literatures, there is a clear need to validate the effectiveness of family-management support intervention for family with autistic children, especially in Vietnam. The intervention would help the Vietnamese family to increase understanding diagnoses, behavior management principles, assessing necessary services, and developing skills to promote their child development. Additionally, the intervention will include a session to confirm its effect sustainably.

CHAPTER 3

RESEARCH METHODOLOGY

This chapter described the research design, the population and the sample, the setting, and the methods. Data collection procedure and data analyses also were discussed along with ethical consideration.

Research design

A randomized control trial [RCT] and follow-up were used to determine effectiveness of a family-management intervention to improve FQoL and burden of family with autistic children. The primary caregivers of autistic children were recruited and randomly assigned to an intervention or a control group. The intervention was the family-management intervention. The control group received the usual rehabilitation at the hospital. The outcome variables were FQoL and burden of family with autistic children.

The RCT design is the gold standard causal inferences which are the strongest empirical evidence of a treatment's efficacy. The research design minimizes bias by randomization, blinding and allocation concealment, simultaneously, minimizing the confounding factors. The readily interpretable statistical test of significance and adequate sample size make the RCT design statistical reliability.

Setting of the study

This study was conducted at the out patient department [OPD] of the National Hospital of Pediatrics located in Hanoi, Vietnam.This hospital was founded in 1969, and was the first pediatric hospital in the north of Vietnam. It is the largest pediatric institution in Vietnam with 30 clinical units and 1800 beds. There are about 2000 children with autism who were admitted per year for receiving services (National Hospital of Pediatrics statistics, 2016). On weekdays at the OPD, there are three examination rooms where psychiatrists diagnose children with autism or provide follow-up care. Additionally, there are classes of rehabilitation where the psychologists provided intervention for children with autism. There are approximately 140 children with autism receiving services monthly and about four to five new diagnosis cases every day. There are about 500 children documented with autism in the year 2018.

Population and sample

Target population

The target population were the primary caregivers of children with autism who were either during their first or follow-up visits at the National Hospital of Pediatrics, Hanoi, Vietnam.

Sample and sampling

The participants were recruited through the target population using the following inclusion criteria:

1. The primary caregiver of four to nine years old children diagnosed as autism,
2. Age 18 years or older,
3. A biological relationship with the child (can be mother, father or grandparent),
4. Provide care to the children without receiving wage or any payment,
5. Live at the same house with the child at least 6 months prior to the data collection,
6. Able to read and write in the Vietnamese language, and
7. No serious mental health problems such as severe depression or serious physical conditions such as end stage renal disease.

Exclusion criteria included:

Unable to complete all sessions of the intervention.

Sample size

The G*Power 3.1.9.2 (Faul, Erdfelder, Lang, & Buchner, 2007) was used to calculated the sample size. Using F-test, repeated measure ANOVA to compare difference within and between intervention. The FQoL and burden of caregivers of autistic children were measured three times including baseline, immediately after intervention and one month after intervention. The effect size of family management support from previous study was 0.30 (Thijssen, Vink, Muris, & de Ruiter, 2016). According to Cohen's medium effect size (Polit & Beck, 2012), at a level of significance of 0.05 and a power of .80, the minimum sample size was 30 participants. Considering an attrition of 20-25 % an additioned 10 participants were recruited (Polit & Gillespie, 2009). Therefore, the researcher recruited 20 participants for the intervention group and 20 participants for the control group.

Sampling

At the OPD of National Hospital of Pediatrics, the researcher approached the target population of 283 the primary caregivers of autistic children who were receiving services in the unit based on inclusion and exclusion criteria. A total of 40 caregivers were randomly assigned to either the control or the intervention groups as followings:

1. A sample of 40 caregivers who met the inclusion criteria were recruited through target population.
2. The caregivers were randomly assigned to either the control or the intervention groups using a random number assigned by a research assistant who are blinded to group numbering.
3. The caregivers were asked to sign informed consents.

Instrumentations

There were 3 self-report questionnaires used for data collection:

1. A demographic questionnaire was developed by the researcher. There were two sections of information related to the child and the caregivers. Child characteristics included gender, age, number of siblings, birth order, age at diagnosis and duration of the illness. The caregiver' characteristics included relationship with the child, gender, age, educational level, occupation, marital status and family income.

2. The family quality of life questionnaire was measured by using the Beach Center FQoL Scale developed by Hoffman et al. (2006). The scale included 25 items with five domains of family life: (a) family interaction (6 items), parenting (6 items), emotional well-being (4 items), Physical/ material well-being (5 items), and disability-related support (4 items). The instrument asked how the families' levels of satisfaction with their quality of life of each item on a 5-point rating scale, where 1= very dissatisfied, 2 = dissatisfied 3 = neither, 4 = satisfied and 5 = very satisfied. It usually took about 10 - 15 minutes to complete this questionnaire. The total score ranged from 25 to 125 which were summed from all items' score. The scores of each subscale were 6 to 30 for family interaction, 6 to 30 for parenting, 4 to 20 for emotional well-being, 5 to 25 for Physical/ material well-being, and 4 to 20 for disability-related support. The higher total and subscale scores indicated the better FQoL and each subsclae, and the lower total and subscale scores indicated lower FQoL and each subsclae. Hoffman, et al., (2006) reported that the instrument demonstrated good reliability of 0.88. The subscale reliabilities of family interaction, parenting, emotional well-being, physical/ material well-being and disability-related support are 0.75, 0.71, 0.76, 0.77 and 0.60, respectively. The convergent validity was tested between the FQoL subscales and another validated instruments such as the Family APGAR with a correlation of r = 0.68 (Hoffman, et al., 2006).

3. The Modified Caregiver Strain Index (C-M-CSI) was used to measure burden of the family caregiver about the degree to which family experience difficulties, strains, and other negative effects as a result of caring for a child with autism (Chan, Chan, & Suen, 2013). The scale included 13 items with five domains of employment, financial, physical, social, and time. The participants were asked to consider and rate the families' levels of burden with each item on a 3-point scale from 0 to 2 (0 = no, 1= sometimes, 2 = yes). It usually took about 5-10 minutes to complete this questionnaire. Scores were summed and divided into two groups, the group with mean scores above 6 indicated high burden of care and below 6 indicated low burden. The total C-M-CSI demonstrated good internal consistency with Cronbach's alpha coefficient of 0.91. Predictive validity was assessed by correlations of the C-M-CSI score with stress which resulted in a significant correlation of r =0.88 (Chan et al., 2013).

The Beach Center FQoL Scale and C-M-CSI were both original in the English language. Therefore, they were translated into Vietnamese language using the WHO guidelines (World Health Organization [WHO], 2015). The translated questionnaires in Vietnamese were tested for language understandability prior to conducting the actual data collection with 30 caregivers who met the same criteria as prospective participants.

The family-management intervention was validated by three content experts, and pilot tested for feasibility with five participants.

The back-translation technique

In order to have an appropriate instrument in the Vietnamese, the Beach Center FQoL Scale and C-M-CSI were translated from English into Vietnamese by process of back-translation and adaptation of instruments as recommended by WHO criteria (WHO, 2015). The following process was used in this study:

1. The original questionnaires in English was independently translated into Vietnamese by two translators who were bilingually experts in both English and Vietnamese (Vietnamese English teachers in a University Professor).
2. The two Vietnamese versions from each translator was then compared and refined into one by the researcher based on content of individual item agreement for their equivalence.
3. A native Vietnamese speaking translator who was expert in English language translated the final Vietnamese version back into English. The researcher and the researcher's major advisor checked the back-translated English version and the original English version for language accuracy and comparability of the contents as well as cultural appropriateness. This step was to ensure the scale’s content validity.
4. Testing reliability of the final Vietnamese version was implemented for 30 participants who met the selection criteria.

Instrument for the implementation: The family-management intervention

The family-management intervention was adapted from the Building on Family Strengths program (Kieckhefer et al., 2014) guided by the FMSF and intensive reviewed of relevant literature about intervention studies for family with autistic or chronically ill children. In this study, the intervention protocol included four-weekly face to face sessions and four-weekly follow up. The intervention's materials included the program, the family booklet and the telephone log.

1. The program

The program included brief presentations by the researcher with common foundations of knowledge related to autism and family management, structured parent discussions related to the topics, discussion of parent development and individualized action plans. The program plan included groups of 8 to 12 family members in four-weekly sessions. Each session lasted about 60 minutes. Content for the brief presentations were based on previously documented needs of parents of children with autism. The four-session program was implemented to create caregiver's action plans. The researcher provided information and explained the action plan for parents to complete at home. At their homes, the caregivers were facilitated by the researcher to perform action plans by arranged phone. In the next session, the researcher and caregivers discussed how the action plans implemented and problem solving strategies. Details of each session were presented as bellow.

Session one: Introduction to the family-management intervention.

The family- management intervention focuses on internal family processes, beliefs, and behaviors as families incorporate condition management into everyday life, but it also acknowledges effects of socio-cultural factors on families (Knafl et al., 2012). Defining the situation are caregiver views of child with autism and vulnerabilities; the cause, seriousness and predictability of autism; the difficulty of carrying out the treatment regimen and their ability to manage effectively which were impact to FQoL and burden of family with autistic children (Hsiao et al., 2017; Knafl et al., 2013).

The objective of this session was to overview the impact of living with an autistic child on family life and the effective family-management strategies. This lecture was offered using a Powerpoint Presentation (PP) about 20 minutes. Based on the PP provided knowledge, the researcher and caregivers discussed together the impact of living with an autistic child: an overview key issues and challenges families face, managing family life and parent–child shared management, making an effective action plan. The discussion parts lasted about 40 minutes after an action plan was developed. Evaluation and suggestions from caregivers for the next sessions were encouraged.

Session two: Management of family caregivers' emational dimension and the child life.

Management behaviors are efforts or behaviors family members make to manage autistic child and their own family problems; how families incorporate condition management into their everyday life (Knafl et al., 2012; McStay et al., 2014). The family member try to manage their autistic child and their own family problems in their daily life, therefore, reducing impact on family's emotional dimensions of parenting and the impact on the child's life which help to improve their FQoL and burden.

The objective of this session was to explore how having a child with autism can impact on their emotion and coping skills; the impact on the child of having autism and how to support the child skills in their daily life. The researcher provided the brief lecture using a PP about 20 minutes. Based on the provided knowledge, the researcher and caregivers discussed how having a child with autism can impact them emotionally and methods of managing difficult emotions; the impact of having autism on the child and methods for helping the child manage skills and behaviors using child directed interactions and play, social and communicaton skills. It lasted 40 munites after which an action plan was developed.

Session three: Supporting family relationships, family communications and parenting.

Management behaviors are how families incorporate condition management into their everyday life to enhance management mindset and parental mutuality (Knafl et al., 2012; McStay et al., 2014). The family member try to manage their autistic child and their own family problems in their daily life by enhancing management mindset and parental mutuality, therefore, reducing impact of having a child with autism on family relationships, family communications and parenting which help to improve their FQoL and burden.

The objective of this session was to support the impact of having child with autism on parents' relationships, family communication, the parenting and manage these impacts using fundamental communication skills and leadership skills. The researcher provided the brief lecture using a PP about 20 minutes. Based on the provided knowledge, the researcher and caregivers discussed how to support their relationships, family communication and parenting while having a child with autism by using useful communication techniques, effective communication and listening skills; promoting child capabilities through developmentally appropriate shared-management, three styles of communication including assertive communication, using distraction with yourself and your child. It lasted 40 munites after which an action plan was developed.

Session four: Finding available resources and transitions into having a meaningful life.

The finding available resources and transitions into having a meaningful life were important for caregivers of autistic children; they direct to family focus and future expectations (Knafl et al., 2012). The objective of this session was to support caregivers in obtaining support from available resources and explored the process of going through major life transitions into having a meaningful life. The researcher provided a brief lecture using a PP in 20 minutes. Based on the provided knowledge, the researcher and caregivers informed families about available resources in Vietnam: healthcare and education systems; strategies in approaching the future with confidence: transition timeline, the family plan, finding meaning in their experience, transitioning out of the class and enhancing their future success. It lasted 40 minutes after which an action plan was developed. At the end of the session, an evaluation form was offered to participants along with date for follow-up plan.

The intervention group received weekly phone calls to assess how they are implementing each action plan. The researcher and caregivers made an appointment for the telephone calls at the end of each session. The phone calls included discussion on how the family members implemented the action plan. The researcher documented the contents of dicussion. Each phone call lasted about 30 minutes.

2. The parent booklet

The contents of the intervention program included in a parent booklet with a schedule of sessions, contents of presentation, key class concepts, additional references, examples of successful strategies in managing children with autism, action plan and evaluation form. The booklet was given to the participants in the seesion one. They were encouraged to used at home, at classes and after completion of each session. Caregivers developed their own action plan at the end of every session. They followed the action plan at home and discussed based on it for prolem-solving strategies before beginning of the following session.

3. The telephone logs

The telephone logs were the report that researcher used to work with the participants in the intervention group by phone.The contact schedule, duration and contents of phone calls in the intervention group were discussed with participants in every session of the intervention program.

Summary of the family-management intervention program included in the participant booklet. The summary provided biefly contents of each session which helped the participants having an overview of the entire intervention program.

Table 3-1 Summary of the family-management intervention program

Week/ Session	Objectives	Intervention contents
1	To overview the impact of living with an autistic child on family life and the effective family-management strategies	Introduction to the family-management intervention (60 minutes). • Welcome and class introduction • Course overview • Managing family life • Leadership model • Making an action plan • Closing and appointing for phone call follow-up
2	To explore how having a child with autism can impact on their emotion and coping skills; the impact on the child of having autism and how to support the child skills in their daily life.	Management of family caregivers' emotional dimension and the child life (60 minutes). • Feedback/problem solving on action plan • Impact of living with an autistic child on you and your emotions • Impact on your child/what's been helpful • Child Directed Interactions and Play • Toilet training • Action Plan • Closing and appointing for phone call follow-up

Table 3-1 (Continued)

Week/ Session	Objectives	Intervention contents
3	To support the impact of having child with autism on parents' relationships, family communication, the parenting and manage these impacts using fundamental communication skills and leadership skills.	Supporting family relationships, family communications and parenting (60 minutes). • Feedback/problem solving on action plan • Exploring the Impact on Your Relationships / Family Communication • Introduction to Communication / Listening Skills • Impact on Your Parenting / What's Been Helpful • Coping Skill: Distraction • Action Plan • Closing and appointing for phone call follow-up
4	To support caregivers in obtaining support from available resources and explored the process of going through major life transitions into having a meaningful life.	Finding available resources and transitions into having a meaningful life (60 minutes) • Feedback/ problem solving on action plan • Systems Large Group Discussion and Communication Skills for Working with Large Systems • Community Resources • Your transition out of this class • Action plan • Closing, appointing for phone call follow-up and program evaluation

Validity and reliability of instruments

Validity

The family-management intervention was validated by 3 content experts including, a psychiatric pediatrician, a maternal-newborn nursing and midwifery instructor and a pediatric nursing instructor. The experts were asked to evaluate individual contents on the intervention as well as the entire intervention program. An evaluation was whether individual contents were relevant and appropriate in terms of the construct. The researcher and the major advisor then revised content and others in the intervention following the experts' comments and suggestions.

The Beach Center FQoL Scale and the C-M-CSI were already given permission to translate and use from the tool's developer. The back-translation method recommended by WHO criteria (WHO, 2015) was used to translate both measures.

Reliability

The Beach Center FQoL Scale and the C-M-CSI were tested for their internal consistency reliability with a total sample of 30 caregivers who had the same characteristic as the study sample. The Cronbach's alpha of the Beach Center FQoL Scale was 0.78, and its subscales ranged from 0.76 to 0.79. The Cronbach's alpha of the C-M-CSI was 0.82.

Protection of human subjects

The proposal of this research was submitted for approval from the Institutional Review Board (IRB) for Graduate Study, Faculty of Nursing, Burapha University, Thailand. Permission for conducting the study was also obtained from the National Hospital of Pediatrics, Vietnam. For data collection, all participants were informed clearly about the purpose of the study, the data collecting procedure, risks that might occur and their rights. The participants were informed that their participation was purely voluntary and no compensation was given. During data collection and the intervention process if a participant wanted to refuse or withdraw from the study, the researcher respected their decisions and assured anonymity and confidentiality and no penalty for withdrawal or termination from the study. This study did not include any physical examination or interference with the child's care. No name was included in the analysis or publication and code numbers of participants were given instead of patient names. All information was destroyed completely after publication of the findings.

The pilot study

The pilot study aimed to test for feasibility of the family-management intervention program. Additionally, after conducting the pilot study, the researcher gained more experience to perform the intervention with the participants in the actual study. In the pilot study, the researcher provided four sessions for the 5 caregivers who met the inclusion criteria in the National Hospital of Pediatrics, Vietnam. All implementation and procedures were conducted the same as in the intervention group.

In the pilot study process, one participant left from forth session quite early therefore, she may not get enough information related to the follow-up period, as a result, she missed phone calls from the researcher for time 3 measurement. Time to complete the questionnaires was about 25 minutes, which was perceived as quite long time. Planned time for each session was expected about two hours, the session one and session four were more than two hours, therefore, the researcher and research assistants discussed and re-arranged more reasonable before the main study. The participants reported that they were feeling very grateful for the information they received and found the contents of sessions are useful and very effective. However, one participant commented that there are some abstract information in the session two and session three, such as Child Directed Interactions and Play Communication/ Listening Skills, Coping Skill-Distraction. Therefore, these contents were modified by creating the case studies for problem-solving in main study.

Data collection procedures

The program of collecting data was as followings:

1. After the IRB approval obtained, the researcher received a letter asking permission for data collection from Burapha University, and, submitted it to the Director of National Hospital of Pediatrics, Hanoi, Vietnam.

2. The purpose and method of the study were informed to the authorities at the OPD of National Hospital of Pediatrics for the hospital's IRB and permission for data collection.

3. After receiving the hospital's IRB and permission for data collection, the researcher approached the primary caregivers of autistic children to invite them to participate in this study. If they agreed to participate, they were asked to sign a consent form.

4. The participants were randomly assigned to either the control or the intervention groups using a random number assigned by a research assistant who are blinded to group numbering.

Research assistant training

Two research assistants who were Vietnamese nurse instructors worked in the OPD, National Pediatric Hospital, Vietnam. They were trained how to use the research instruments to measure the outcome variables. They were also trained to support the researcher in sampling procedure.

The intervention group: Implementation

Week 1 - day 1: The researcher approached the potential participants who were interested in the study and explain the intervention objectives, procedure, duration, evaluation and follow-up process. Additionally, the researcher informed them about risks and benefits for participating in the study; as well as confidentiality for all personal data. If they were willing to participate, they were asked to sign a consent form and made an appointment for the telephone call of baseline surveys. The researcher interviewed the participants to complete the demographic information, the Beach Center FQoL Scale and the C-M-CSI by phone (pre-test, T_1). This was pre-test data (pre-test, T_1).

Week 1 – day 2 to week 4: The participants received the intervention at the hospital, in which the four-session program was implemented to create caregiver's action plans. The program plan included groups of 8 to 12 family members in four-weekly sessions. Each session lasted about 60 minutes. At the end of each session, the researcher and caregiver made an appointment for the weekly telephone calls. After completing the intervention, the researcher interviewed the participants to complete the Beach Center FQoL Scale and the C-M-CSI (post-test, T_2) and schedule an appointment of the T_3 measurement.

Week 8: At the end of week 8, the researcher interviewed the participants to complete the Beach Center FQoL Scale and the C-M-CSI (post-test, T_3).

The control group

Week 1: The researcher approached the potential participants who were interested in the study. The participants were explained about the study objectives, procedure, duration, evaluation and follow-up process. Additionally, the researcher informed them about the benefits, disadvantages and confidentiality of participants. If they were willing to participate in the study, they were asked to sign the consent form. The researcher interviewed the participants to complete the demographic information, the Beach Center FQoL Scale and the C-M-CSI by phone (pre-test, T_1) and asked for schedule an appointment of time 2 measurements.

Week 1 to week 4: The participants received the usual rehabilitation at the hospital, in which, the nurses sent them the weekly report of their child's progress and provide brief guidelines in supporting their child at home. At week 4, the participants were asked to complete post-test of the Beach Center FQoL Scale and the C-M-CSI (post-test, T_2) and schedule an appointment of the T_3 measurement.

Week 8: the researcher interviewed participants to complete the Beach Center FQoL Scale and the C-M-CSI (post-test, T_3).

The participants in the control group were provided the materials that used for the intervention group to study by themselves at the end of week 8.

Summarized of data collection procedures was shown in the figure 3 below.

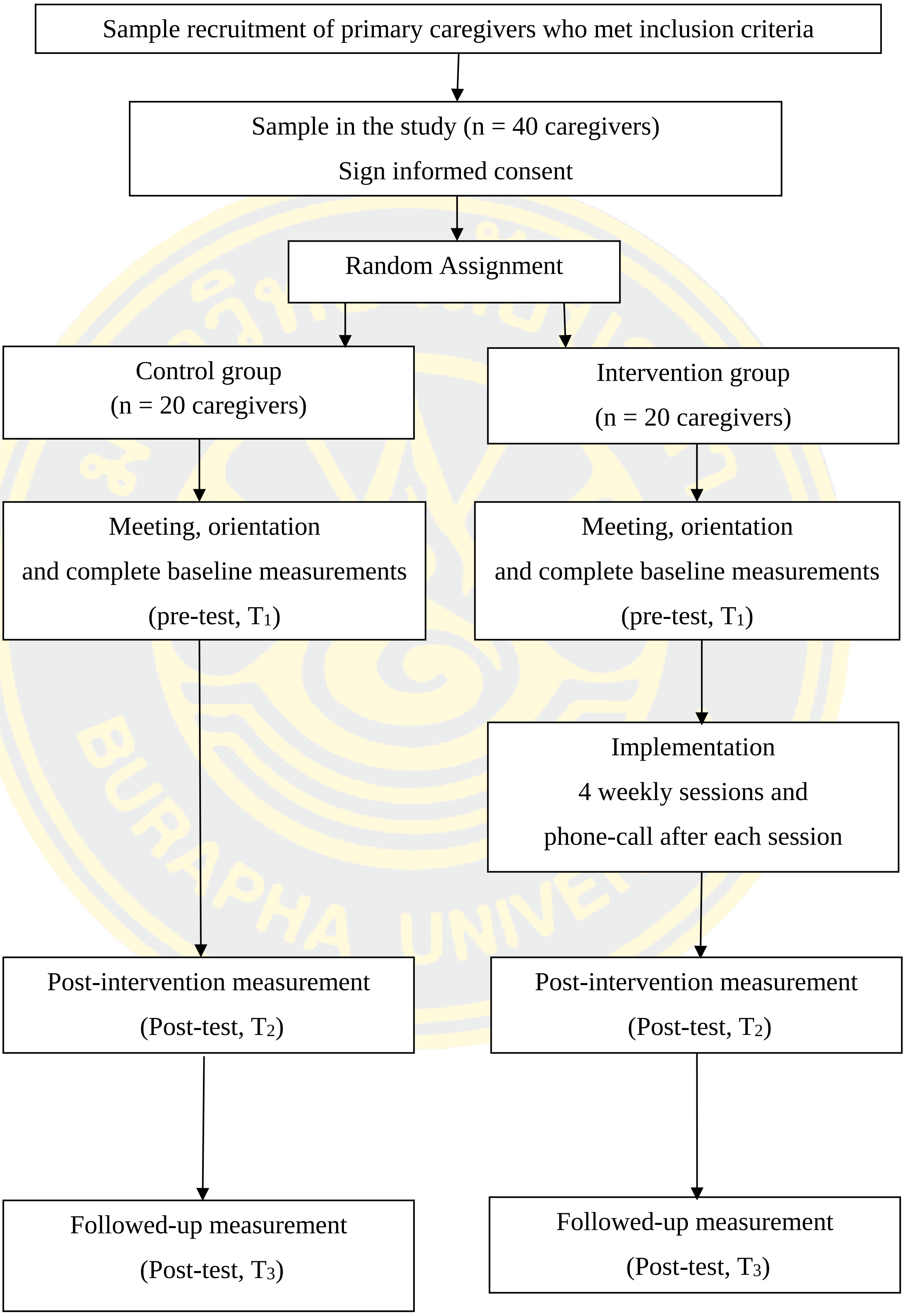

Figure 3-1 Summary of data collection procedures

Data analyses

All data were analyzed by using a statistical software computer program. Descriptive statistics were used to describe characteristics of the participants and the children. Statistical significance level was set at $p < 0.05$.

1. Descriptive statistics included the frequency and percent for categorical variables, and mean, standard deviation and range for the continuous variables. The results of the instruments for the FQoL and the burden of family with autistic children were described in mean, standard deviation and range.
2. Repeated measured ANOVA was used to examine differences in mean scores of FQoL and burden between the intervention and the control group and among measures of three time points within the intervention group.

CHAPTER 4
RESULTS

This chapter summarized findings of the study, including sample allocation, characteristics of the autistic children and caregivers; FQoL and burden variables at three time points; statistical assumptions and repeated-measures ANOVA.

Summary of the sample allocation

A total of 283 caregivers were eligible to be invited in the study. There were 40 caregivers who were invited to participate in the study. They consented to the form and were randomly assigned 20 into the control and 20 in to the intervention groups using a random number assigned by research assistants who were blinded to group numbering (Figure 4).

In the intervention group, the researcher interviewed the participants to complete the demographic information, the Beach Center FQoL Scale and C-M-CSI (pre-test, T_1) in day one of week one. A weekly intervention session was implemented for four weeks from day two of week one to week four. The post-intervention measurements (T_2) were conducted during week four. The participants were interviewed to complete measurements (T_3) while they came back hospital for follow-up as plan. In the control group, there were the same procedures as in the intervention group at baseline measurement (pre-test, T_1). The participants received the usual intervention at the hospital. In the week four and week eight, the caregivers were asked to complete the post-intervention measurements (T_2) and measurements (T_3). There was no participant drop out of the study.

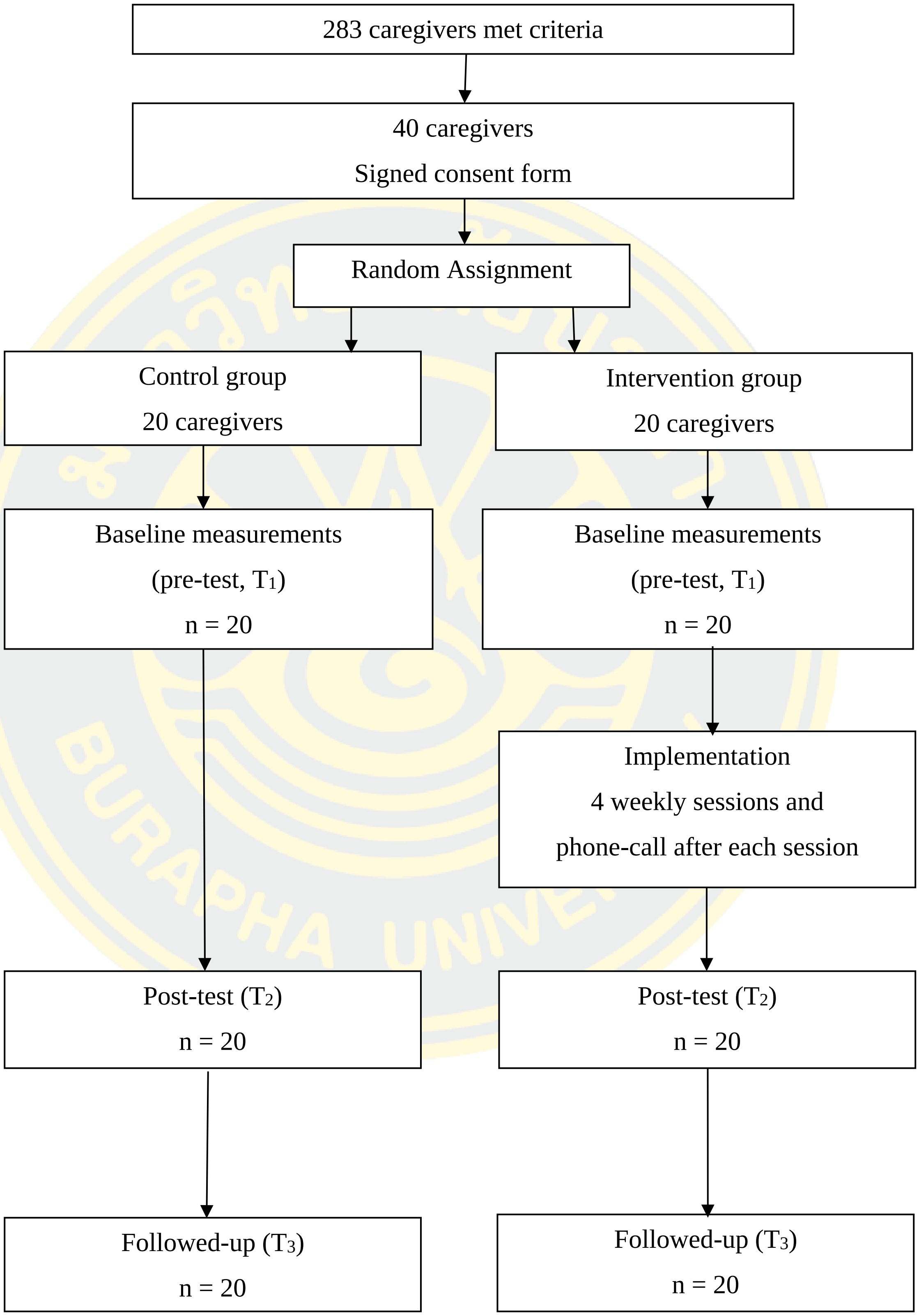

Figure 4-1 Summary of the sample allocation following the Consort diagram

Characteristics of the participants

Children characteristics

Descriptive statistics of autistic children were presented in the table 4-1. Of the 20 intervention participants, 15 (75%) were boys while 5 (25%) were girls. Sixteen (80%) children were the first child in the family while 4 (20%) were the second child. The mean age of the children was 6.05 years (*SD* = 1.90 years) and ages ranged from 4.00 to 9.00 years. The average years of being diagnosed from a physician as having autism was 2.50 (*SD* = 1.57) ranged from 1 to 5 years.

For the control group, 19 (95%) were boys while 1 (5%) were girls. Fifteen (75%) children were the first child in the family while 5 (25%) were the second child in the family. The mean age of the children was 5.60 years (*SD* = 1.35 years) and ages ranged from 4.00 to 8.00 years. The average years of being diagnosed from physician as having autism was 2.45 (*SD* = 1.23) ranged from 1 to 4 years.

Comparing the children's characteristics between the intervention and the control groups using independent *t*-test with interval data, and χ^2 Fisher Exact test with categorical data, there was found no significant difference (*p* > .05).

Table 4-1 Descriptive statistics for children with autism

Characteristic	**Group**				***t***	χ^2	***p*-value**
	Intervention (*n* = 20)		**Control (*n* = 20)**				
	n	**%**	***n***	**%**			
Age (Year)	*M* = 6.05, *SD*±1.90 range = 4-9		*M* = 5.60, *SD*±1.35 range = 4-8		0.86		.40
Number of siblings	*M* = 1.55, *SD*±.51 range = 1-2		*M* = 1.05, *SD*±.22 range = 1-2		4.01		<.001
Duration since diagnosed (years)	*M* = 2.50, *SD*±1.57 range = 1-5		*M* = 2.45, *SD*±1.23 range = 1-4		0.11		.91

Table 4-1 (Continued)

Characteristic	**Group**				t	χ^2	***p*-value**
	Intervention (*n* = 20)		**Control (*n* = 20)**				
	n	**%**	***n***	**%**			
Gender							
Boy	15	75	19	95		3.13	.08
Girl	5	25	1	5			
Birth order							
1st	16	80	15	75		0.14	.71
2nd	4	20	5	25			

Caregivers' characteristics

In the intervention group, 20 (100%) caregivers are parents of autistic children. Most of them were female (80%) and married (65%). About 40% had high education level of university and above. Most of them (70%) were officer while only 5% were house-wife. The mean age of the caregivers was 32.25 years (*SD* = 6.14 years) and ages ranged from 24 to 46 years. The average years of duration of care was 6.05 (*SD* = 1.91) ranged from 4 to 9 years.

In the control group, 18 (90%) caregivers are parents of autistic children. Most of them were female (80%) and married (75%). The same portion of participants compared to intervention group had high education level of university and above. Half of the caregivers were officer. The mean age of the caregivers was 37.50 years (*SD* = 11.38 years) and ages ranged from 29 to 72 years. The average years of duration of care was 5.35 (*SD* = 1.78) ranged from 1 to 8 years.

The independent-samples t-tests and the Fisher Exact tests were conducted to determine whether continuous variables of children and caregivers' characteristics significantly differed between intervention and control group. There were no significant differences between intervention and control group ($p > .05$). Details were presented in Table 4-2.

Table 4-2 Descriptive statistics for caregiver

Characteristic	**Group**				***t***	χ^2	***p*- value**
	Intervention (*n* = 20)		**Control (*n* = 20)**				
	n	**%**	***n***	**%**			
Age (years)	*M* = 35.25, *SD*±6.14 range = 24-46		*M* = 37.50, *SD*±11.38 range = 29-72		-0.78		.44
Duration of care (years)	*M* = 6.05, *SD*±1.91 range = 4-9		*M* = 5.35, *SD*±1.78 range = 1-8		1.21		.23
Relationship with the child						2.5	.15
Parents	20	100	18	90			
Grandparents	0	0	2	10			
Gender						0.00	1.00
Female	16	80	16	80			
Male	4	20	4	20			
Marital status						.54	.76
Married	13	65	15	75			
Single	1	5	1	5			
Divorced	6	30	4	20			
Education						5.09	.28
Primary school or lower	0	0	4	20			
Secondary school	4	20	2	10			
High school	2	10	1	5			
Diploma/ college	6	30	5	25			
University or above	8	40	8	40			

Table 4-2 (Continued)

Characteristic	**Group**				***t***	**χ^2**	***p*- value**
	Intervention (*n* = 20)		**Control (*n* = 20)**				
	n	**%**	***n***	**%**			
Occupation							
Officers	14	70	10	50		3.81	.28
Farmers	2	10	6	30			
Industrial workers	3	15	4	20			
House wife	1	5	0	0			

Testing of assumptions for a repeated-measures ANOVA

The assumptions for subsequently statistical analyses were tested. The assumptions were examined to ensure the validity of statistical calculations. In the assumption testing, there are assumptions that need to be met for within-group, between-group, and between-within group (mixed) ANOVAs (Warner, 2014).
A zskewness value that is greater than ± 3.29 indicates non-normality. The degree of association among dependent variables was conducted by using t-test analysis. Another assumption of repeated measures ANOVAs is sphericity. A significant Mauchly's W test of sphericity indicates a violation of this assumption (Abdi, 2010). Levene's tests of equality of variances were conducted to determine if the equality of variances assumption was met. Significant Levene's tests (at $p < .05$) indicate that the dependent variable variances significantly differ across the intervention and control group and that the assumption of equality of variances is violated. Once the assumptions of ANOVA were tested, the ANOVA analyses were conducted to address the study purposes. The ANOVA results included F-values, with $p < .05$, based on a Bonferroni correction. Then, six ANOVA analyses were conducted to examine the exactly subscale-different pairs.

1. Normal distribution

The assumption does need to be met for repeated-measures ANOVA (Abdi, 2010). The first assumption for repeated-measure ANOVA is dependent variable univariate normality. Calculation of Z-skewness values for each post-test variable, the results were conducted to test for the assumption of variable normality. The Z-skewness values were all less than ± 3.29, indicating that the assumption of normality was met for the dependent variables.

2. Homogeneity of variance (between-subject)

The next assumption for a between-within or mixed ANOVA is equality of variances, which means that the variances of the dependent variables are similar across the intervention and control groups. The assumption of homogeneity of variance was tested by the Levene’s test for the between-subjects design. Almost of the Levene’s test results showed not significant ($p > .05$), only Burden at time 3 was not met. This is due to one outlier from score of Burden at time 3. However, repeated-measure ANOVA is robust test, therefore, this minor violation of assumption can be accepted.

3. Assumption of sphericity (within-subject)

The Mauchly’s test of sphericity was tested to evaluate the sphericity assumed F value for test of within-subjects effects. The results showed that Sphericity of burden was not significant ($p > .05$), then the sphericity assumption of burden was met. The study selected Sphericity Assumed to report the results of repeated measure ANOVA for burden variable. However, the sphericity of FQoL was significant ($p < .05$), indicating the sphericity assumption of FQoL was not met, then the study selected Huynh-Feldt to report the results of repeated measure ANOVA for FQoL variable.

4. Test of outlier

The box plots results indicated that there was one small outlier for FQoL variable time 1. However, the standardized residual values ranged from – 1.88 to 2.42, falling well within the recommended ± 3. These values indicated that the identified outlier was not largely influential. The burden variable did not have any outlier. The standardized residual values ranged from -2.45 to 2.26, falling well within the recommended ± 3, thereby indicating a lack of influential points in the dataset.

Descriptive statistics and comparisons at baseline of outcome variables

The outcome variables included FQoL and burden. They were measured at three point times of week 0 (T_1), week 4 (T_2) and week 8 (T_3). Mean and standard deviations of total and subscale scores of FQoL and burden of the intervention and the control groups among three point times were presented in Table 4-3.

Table 4-3 Means and standard deviations of FQoL and burden

Variable	**Week**	**Intervention (*n* = 20)**		**Control (*n* = 20)**	
		M	***SD***	***M***	***SD***
Family quality of life [FQoL] Total score	0	35.50	3.24	37.10	2.77
	4	90.10	2.81	45.05	4.50
	8	104.70	2.25	46.30	4.50
Subscale score					
Family interaction	0	8.85	2.06	9.30	2.05
	4	25.20	1.85	10.95	2.11
	8	25.90	1.41	10.60	2.16
Parenting	0	8.55	1.96	8.95	1.96
	4	27.30	1.17	10.90	2.40
	8	27.40	1.35	11.25	2.92
Emotional well-being	0	5.35	1.42	5.60	1.19
	4	12.70	1.13	7.35	2.01
	8	19.35	0.93	7.90	2.27
Physical/ material well-being	0	7.50	1.70	7.90	1.21
	4	14.65	1.98	8.60	2.11
	8	21.55	1.28	9.20	1.99
Disability-related support	0	5.25	1.21	5.35	1.18
	4	10.25	0.97	7.25	1.83
	8	10.50	1.10	7.35	1.39

Table 4-3 (Continued)

Variable	**Week**	**Intervention (*n* = 20)**		**Control (*n* = 20)**	
		M	***SD***	***M***	***SD***
Burden	0	22.45	1.88	23.35	1.18
Total score	4	8.45	1.99	22.40	1.90
	8	10.30	2.56	21.60	1.64

Comparisons of FQoL and burden between the control and the intervention groups measured at baseline (pre-test) by using independent *t*-test. Results showed no significant difference of these variables at baseline (T_1) between the intervention and the control group ($p > .05$) (Table 4-4).

Table 4-4 Comparison of mean scores of outcome variables between the control and the intervention groups measured at baseline (T_1) by independent *t*-test

Variable	**Group**				***t***	***p*- value**
	Intervention (*n* = 20)		**Control (*n* = 20)**			
	M	***SD***	***M***	***SD***		
Family quality of life	35.50	3.24	37.10	2.77	-1.68	.10
Family interaction	8.85	2.06	9.30	2.05	-0.69	.49
Parenting	8.55	1.96	8.95	1.96	-0.65	.52
Emotional well-being	5.35	1.42	5.60	1.19	-0.60	.55
Physical/ Material well-being	7.50	1.70	7.90	1.21	-0.86	.40
Disability-related support	5.25	1.21	5.35	1.18	-0.26	.79
Burden	22.45	1.88	23.35	1.18	-1.81	.08

Testing of research hypothesis

1. Participants in the intervention group have higher FQoL than that in the control group at immediately post-intervention, and follow-up period**.** Within the intervention group, there is a significant difference in mean score of family quality of life across three-point times.

Two-way mixed repeated measures ANOVA (one between and one within) was used to determine mean differences of total score of FQoL between the control and the intervention groups among three time points at baseline (T_1), post-intervention (T_2) and follow-up (T_3). Results from the first repeated-measures ANOVA are reported in Table 4-5. The main effect of FQoL mean total scores was statistical significance between subjects ($F_{1,38} = 2758.21$, $p < .001$). There was significant differences in FQoL mean total scores within the intervention group in at least one pair of the three time points, ($F_{2,76} = 1478.07$, $p < .001$). The results showed that mean total scores of FQoL were statistical significance of interaction effect (time and group effect) ($F_{2,76} = 853.62$, $p < .001$) indicating the FQoL mean total scores between intervention and control group was different over time.

Table 4-5 Repeated measures ANOVA of total score of FQoL

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Family quality of life					
Within subjects					
Time	34367.62	2.00	17183.81	1478.07	< .001
Time*Group	19848.15	2.00	9924.08	853.62	< .001
Error time	883.57	76.00	11.63		
Between subjects					
Group	34578.08	1.00	34578.08	2758.21	< .001
Error	476.38	38.00	12.54		

The simple effect of group results showed that before intervention (T_1), there was not difference of FQoL mean scores between the intervention and the control group ($p = .10$). However, immediately after intervention (T_2) and follow-up time

(T_3), there were statically difference of FQoL mean scores between intervention and control group, ($F_{1,38} = 1442.19$, $p < .001$) and ($F_{1,38} = 2697.78$, $p < .001$), respectively. The finding indicated that the caregivers receiving the family-management intervention had better FQoL than those who were in control group (Table 4-6).

Table 4-6 Simple effect of groups on FQoL between 2 groups at 3-point times

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Pre-intervention (T_1)					
Between subjects	25.60	1.00	25.60	2.82	.10
Error	344.80	38.00	9.07		
Post-intervention (T_2)					
Between subjects	20295.03	1.00	20295.03	1442.19	< .001
Error time	534.75	38.00	14.07		
Follow-up (T_3)					
Between subjects	34105.60	1.00	34105.60	2697.78	< .001
Error	480.40	38.00	12.64		

$p < .05$, $F_{0.5}$ (1, 40) = 7.31

The simple effect of time results showed that in the intervention group, there were statically difference of FQoL mean scores between before intervention (T1), immediately after intervention (T_2) and follow-up time (T_3), ($F_{2,38} = 13.71$, $p = .02$). Interestingly, in the control group, there was statically difference of FQoL mean scores between before intervention (T1), immediately after intervention (T_2) and follow-up time (T_3), ($F_{2,38} = 10.48$, $p = .03$). (Table 4-7).

Table 4-7 Simple effect of time on FQoL scores in the intervention and control groups

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Intervention group					
Between subjects	116174.81	19			
Interval	384545.86	2	192272.93	13.71*	.02
Error	533050.14	38	14027.64		
Total	1033770.81	59			
Control group					
Between subjects	33200.49	19			
Interval	110586.54	2	55293.27	10.48*	.03
Error	200529.46	38	5277.09		
Total	344316.49	59			

*$p < .05$, $F_{0.5}(2,38) = 3.23$

Pairwise comparisons were used to identify the differences in FQoL mean scores in three time points. In the intervention group, the mean score of FQoL at follow-up (T_3) were higher than those at baseline (T_1) and post-intervention (T_2), ($M_{diff} = -69.20$ and $M_{diff} = -14.60$, $p < .001$, respectively). The mean score of FQoL after intervention was significantly higher than those at baseline ($M_{diff} = -54.60$, $p < .001$). The findings indicated that participants in the intervention group had better FQoL after receiving the family-management intervention and remain the results over time. The results were presented in the table 4-8.

Table 4-8 Pairwise comparisons of mean FQoL at each time points within the intervention group

Time	**M$_{diff}$**	**SE**	***p*-value**
Intervention group			
T_1 vs. T_2	-54.60^*	1.11	< .001
T_1 vs. T_3	-69.20^*	0.93	< .001
T_2 vs. T_3	-14.60^*	1.18	< .001
Control group			
T_1 vs. T_2	-7.95	1.11	.08
T_1 vs. T_3	-9.20^*	0.93	.04
T_2 vs. T_3	-1.25	1.18	.30

The graph results showed that there was a sharply increase of FQoL mean scores after intervention and minor change in follow-up time in the intervention group, while there was almost no difference in the control group. Mean scores of FQoL in the intervention group were higher than that in the control group after intervention and follow-up time. The results were presented in the Figure 4-2.

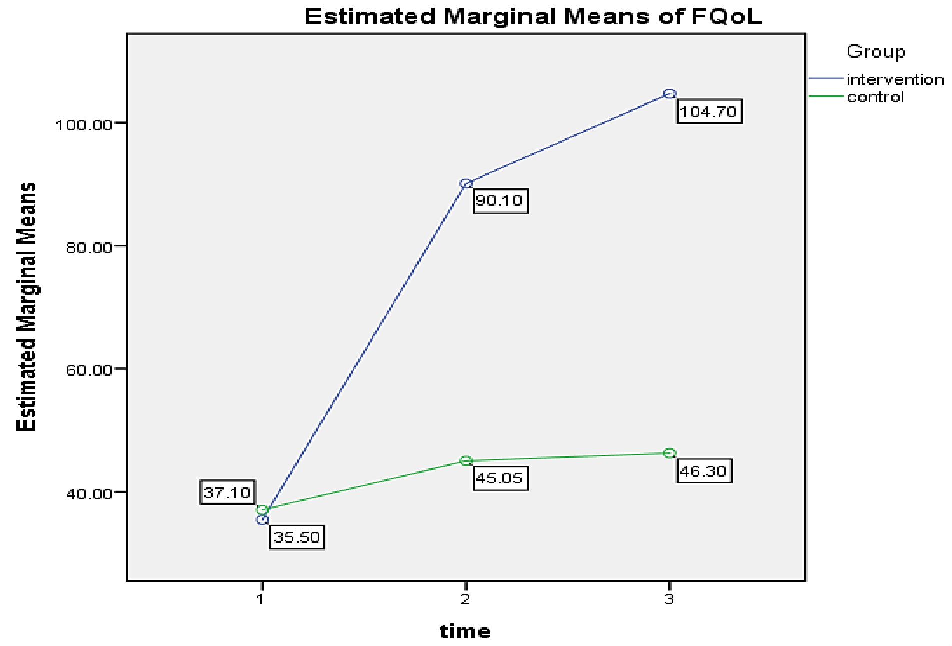

Figure 4-2 Comparisons of mean total scores of FQoL

The family quality of life scale has five subscales including family interaction, parenting, emotional well-being, Physical/ material well-being, and disability-related support.

Family interaction

The main effect of family interaction mean scores was statistical significance between subjects ($F_{1,38} = 479.21$, $p < .001$). There was significant differences in family interaction mean scores within the intervention group in at least one pair of the three time points ($F_{2,76} = 391.76$, $p < .001$). The mean scores of family interaction were statistical significance of interaction effect (time and group effect) ($F_{2,76} = 275.81$, $p < .001$), indicating the family interaction mean scores between the intervention and the control group was different over time. In addition, the simple effect of group results showed that there were statically difference of family interaction mean scores between groups after the intervention (T_2) and follow-up time (T_3), ($F_{1,38} = 513.91$, $p < .001$) and ($F_{1,38} = 702.64$, $p < .001$), respectively. The simple effect of time results showed that in the intervention group, there were statically difference of family interaction mean scores between before intervention (T1), immediately after intervention (T_2) and follow-up time (T_3), ($F_{2,38} = 13.71$, *p* = .02). In the intervention group, the mean score of family interaction at post-intervention were higher than those at baseline (M_{diff} = 16.350, *p* < .001), but it was not different with the mean score at follow-up (*p* > .05). In the graph, the line of intervention group showed sharply increased after intervention, while those in the control group approximately remained the same mean scores. It could be interpreted that the caregivers receiving the family-management intervention had better family interaction than those who were in control group, however, it did not remain the over time. The results were presented in the Table 4-9, Table 4-10, Table 4-11, Table 4-12 and Figure 4-3.

Table 4-9 Repeated measures ANOVA of family interaction

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Family Interaction					
Within subjects					
Time	2202.82	2.00	1101.41	391.76	< .001
Time*Group	1550.85	2.00	775.43	275.81	< .001
Error time	213.67	76.00	2.81		
Between subjects					
Group	2822.70	1.00	2822.70	479.21	< .001
Error	223.83	38.00	5.89		

Table 4-10 Simple effect of groups on family interaction between 2 groups at 3-point times

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Pre-intervention (T_1)					
Between subjects	2.03	1.00	2.03	0.48	.49
Error	160.75	38.00	4.23		
Post-intervention (T_2)					
Between subjects	2030.63	1.00	2030.63	513.91	< .001
Error time	150.15	38.00	3.95		
Follow-up (T_3)					
Between subjects	2340.90	1.00	2340.90	702.64	< .001
Error	126.60	38.00	3.33		

$p < .05$, $F_{0.5}(1, 40) = 7.31$

Table 4-11 Simple effect of time on family interaction scores in the intervention and control groups

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Intervention group					
Between subjects	6660.67	19			
Interval	21828.83	2	10914.42	13.37*	.02
Error	31019.83	38	816.31		
Total	59509.33	59			
Control group					
Between subjects	33200.49	19			
Interval	110586.54	2	55293.27	10.48*	.03
Error	200529.46	38	5277.09		
Total	344316.49	59			

*$p < .05$, $F_{0.5}(2,38) = 3.23$

Table 4-12 Pairwise comparisons of mean family interaction at each time points within the intervention group

Time	M_{diff}	SE	***p*-value**
Intervention group			
T_1 vs. T_2	-16.350^*	0.57	< .001
T_1 vs. T_3	-17.050^*	0.53	< .001
T_2 vs. T_3	-0.70	0.49	.16
Control group			
T_1 vs. T_2	-1.650	0.57	.11
T_1 vs. T_3	-1.300	0.53	.20
T_2 vs. T_3	0.35	0.49	.48

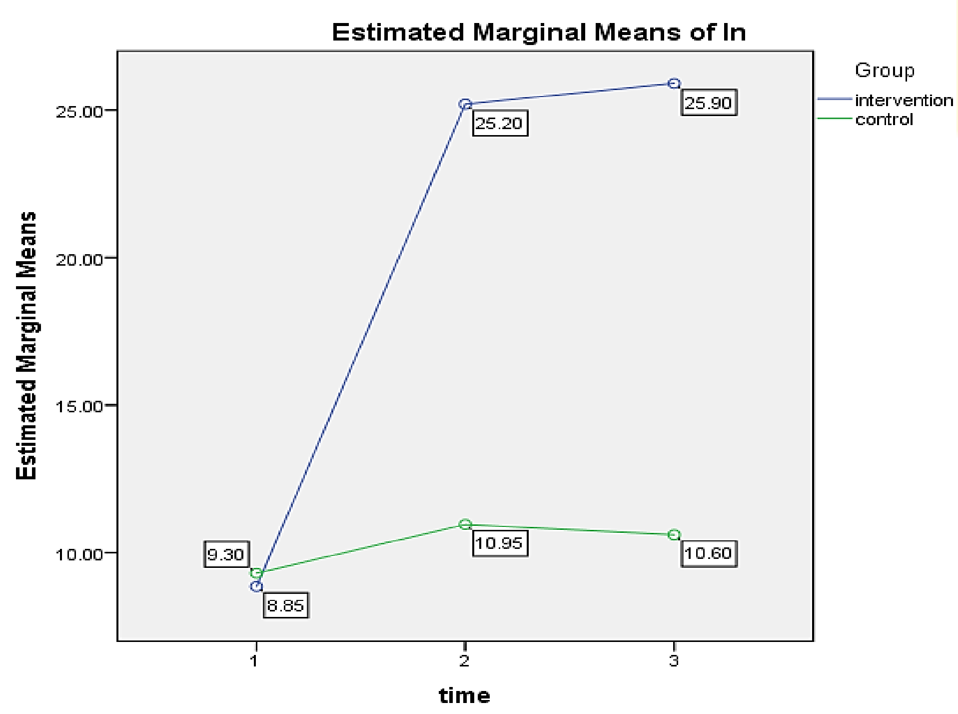

Figure 4-3 Comparisons of mean scores of family interaction

Parenting

The results showed that the main effect of parenting mean scores was statistical significance between subjects ($F_{1,38} = 479.21$, $p < .001$). There was significant differences in parenting mean scores within the intervention group in at least one pair of the three time points, ($F_{2,76}$ = 308.50, $p < .001$). The mean scores of parenting were statistical significance of interaction effect (time and group effect) ($F_{2,76}$ = 291.02, $p < .001$), indicating the parenting mean scores between the intervention and the control group was different over time. Moreover, immediately after intervention (T_2) and follow-up time (T_3), there were statically difference of parenting mean scores between groups, ($F_{1,38}$ = 751.51, $p < .001$) and ($F_{1,38}$ = 504.26, $p < .001$), respectively. The simple effect of time results showed that in the intervention group, there were statically difference of parenting mean scores between before intervention (T1), immediately after intervention (T_2) and follow-up time (T_3), ($F_{2,38}$ = 13.72, $p = .02$). In the intervention group, the mean score of parenting at post-intervention was higher than those at baseline (M_{diff} = 18.90, $p < .001$), but it was not different with the mean score of parenting at follow-up ($p > .05$). In the graph, the line of intervention group showed a strong raise after intervention. It could be interpreted that the caregivers who received the family-management intervention program had better parenting than those who were in control group, however, it did not remain the over time. The results were presented in the Table 4-13, Table 4-14, Table 4-15, Table 4-16 and Figure 4-4.

Table 4-13 Repeated measures ANOVA of parenting

Source	SS	df	MS	*F*	*p*-value
Parenting					
Within subjects					
Time	2465.02	2.00	1232.51	308.50	< .001
Time*Group	2325.35	2.00	1162.68	291.02	< .001
Error time	303.63	76.00	4.00		
Between subjects					
Group	2822.70	1.00	2822.70	479.21	< .001
Error	223.83	38.00	5.89		

Table 4-14 Simple effect of groups on parenting between 2 groups at 3-point times

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Pre-intervention (T_1)					
Between subjects	1.60	1.00	1.60	0.42	.52
Error	145.90	38.00	3.84		
Post-intervention (T_2)					
Between subjects	2689.60	1.00	2689.60	751.51	< .001
Error time	136.00	38.00	3.58		
Follow-up (T_3)					
Between subjects	2608.23	1.00	2608.23	504.26	< .001
Error	196.55	38.00	5.17		

$p < .05$, $F_{0.5}(1, 40) = 7.31$

Table 4-15 Simple effect of time on parenting in the intervention and control groups

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Intervention group					
Between subjects	6787.44	19			
Interval	22347.56	2	11173.78	13.72*	.02
Error	30947.11	38	814.40		
Total	60082.11	59			
Control group					
Between subjects	2140.28	19			
Interval	6852.86	2	3426.43	10.25*	.03
Error	12700.47	38	334.22		
Total	21693.61	59			

*$p < .05$, $F_{0.5}(2,38) = 3.23$

Table 4-16 Pairwise comparisons of mean score of parenting at each time points within the intervention group

Time	$\mathbf{M}_{diff}$	**SE**	***p*-value**
Intervention group			
T_1 vs. T_2	-18.90*	0.56	< .001
T_1 vs. T_3	-19.00*	0.60	< .001
T_2 vs. T_3	-0.10	0.73	.89
Control group			
T_1 vs. T_2	-0.10	0.56	.86
T_1 vs. T_3	-0.45	0.60	.46
T_2 vs. T_3	-0.35	0.73	.63

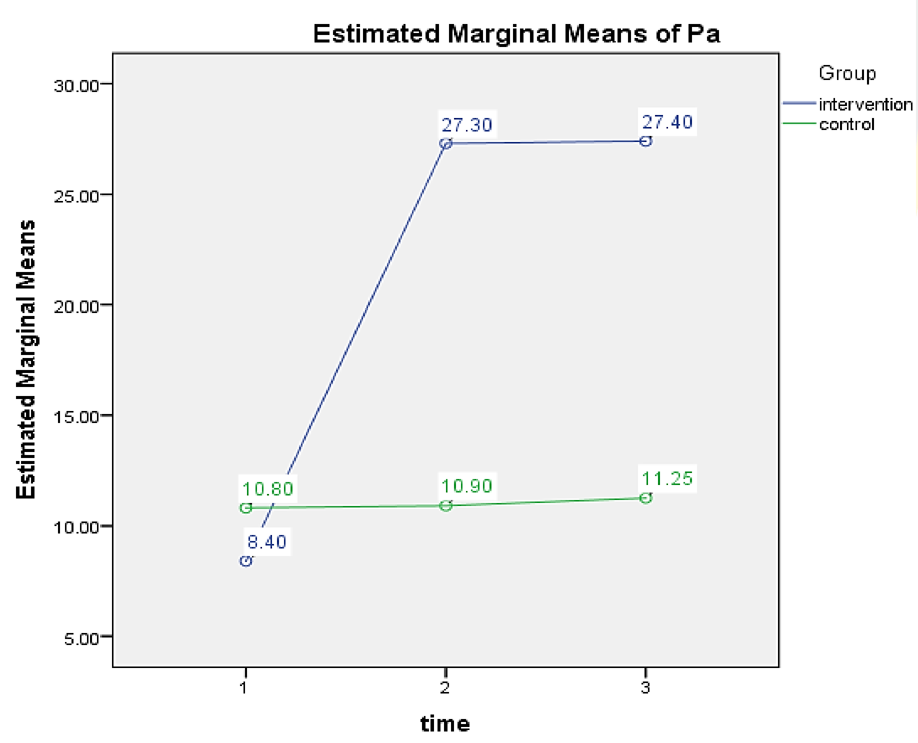

Figure 4-4 Comparisons of mean scores of parenting

Emotion well-being

The main effect of emotional well-being mean scores was statistical significance between subjects ($F_{1,38}$ = 245.93, $p < .001$). There was significant differences in emotional well-being mean scores within the intervention group in at least one pair of the three time points, ($F_{2,76}$ = 220.86, $p < .001$). The mean scores of emotional well-being were statistical significance of interaction effect (time and group effect) ($F_{2,76}$ = 166.01, $p < .001$), indicating the emotional well-being mean scores between the intervention and the control group was different over time. Moreover, immediately after intervention (T_2) and follow-up time (T_3), there were statically difference of emotional well-being mean scores between groups, ($F_{1,38}$ = 107.96, $p < .001$) and ($F_{1,38}$ = 435.67, $p < .001$), respectively. The simple effect of time results showed that in the intervention group, there were statically difference of emotional well-being mean scores between three time points, ($F_{2,38}$ = 13.80, $p = .02$).

In the intervention group, the mean score of emotional well-being at follow-up (T_3) were higher than those at baseline (T_1) and post-intervention (T_2), (M_{diff} = 14.00 and M_{diff} = 6.65, $p < .001$, respectively). The mean score of emotional well-being after intervention was significantly higher than those at baseline (M_{diff} = 7.35, $p < .001$). In the graph, the line of intervention group showed a strong raise after intervention and at follow-up. It could be interpreted that the caregivers who received the family-management intervention program had better emotional well-being than those who were in control group and remain by the time. The results were presented in the Table 4-17, Table 4-18, Table 4-19, Table 4-20 and Figure 4-5.

Table 4-17 Repeated ANOVA of emotion well-being

Source	SS	df	MS	*F*	***p*-value**
Emotion well-being					
Within subjects					
Time	1125.60	2.00	562.80	220.86	< .001
Time*Group	846.07	2.00	423.03	166.01	< .001
Error time	193.67	76.00	2.55		
Between subjects					
Group	775.21	1.00	775.21	245.93	< .001
Error	119.78	38.00	3.15		

Table 4-18 Simple effect of groups on emotion well-being between 2 groups at 3-point times

Source	SS	df	MS	*F*	***p*-value**
Pre-intervention (T_1)					
Between subjects	0.63	1.00	0.63	0.36	.55
Error	65.35	38.00	1.72		
Post-intervention (T_2)					
Between subjects	286.23	1.00	286.23	107.96	< .001
Error time	100.75	38.00	2.65		
Follow-up (T_3)					
Between subjects	1311.03	1.00	1311.03	435.67	< .001
Error	114.35	38.00	3.01		

$p < .05$, $F_{0.5}(1, 40) = 7.31$

Table 4-19 Simple effect of time on emotional well-being scores in the intervention and control groups

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Intervention group					
Between subjects	2934.32	19			
Interval	9563.55	2	4781.77	13.80*	.02
Error	13169.78	38	346.57		
Total	25667.65	59			
Control group					
Between subjects	991.58	19			
Interval	3104.10	2	1552.05	10.16*	.03
Error	5802.57	38	152.70		
Total	9898.25	59			

*$p < .05$, $F_{0.5}(2,38) = 3.23$

Table 4-20 Pairwise comparisons of mean score of emotion well-being at each time points within the intervention group

Time	M_{diff}	**SE**	***p*-value**
Intervention group			
T_1 vs. T_2	-7.35	0.51	< .001
T_1 vs. T_3	-14.00	0.52	< .001
T_2 vs. T_3	-6.65	0.49	< .001
Control group			
T_1 vs. T_2	-0.45	0.51	.38
T_1 vs. T_3	-1.00	0.52	.06
T_2 vs. T_3	-0.55	0.49	.26

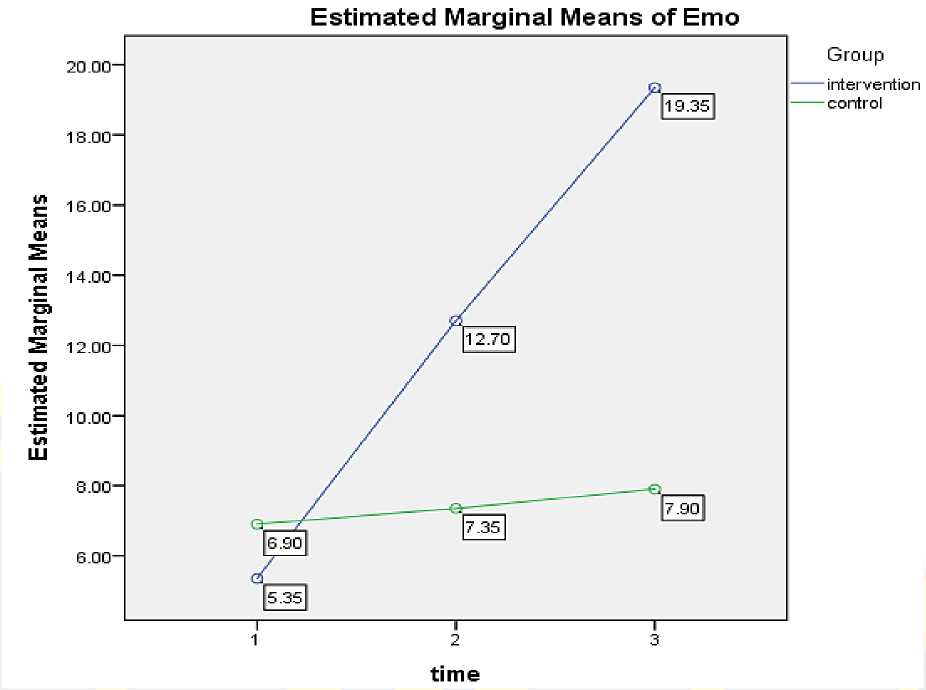

Figure 4-5 Comparisons of mean scores of emotion well-being

Physical/ material well-being

The results showed that the main effect of physical/ material well-being mean scores was statistical significance between subjects ($F_{1,38}$ = 407.14, $p < .001$). There was significant differences in physical/ material well-being mean scores within the intervention group in at least one pair of the three time points, ($F_{2,76}$ = 180.91, $p < .001$). The mean scores of physical/ material well-being were statistical significance of interaction effect (time and group effect) ($F_{2,76}$ = 124.80, $p < .001$), indicating the Physical/ material well-being mean scores between the intervention and the control group was different over time. Moreover, immediately after intervention (T_2) and follow-up time (T_3), there were statically difference of physical/ material well-being mean scores between groups, ($F_{1,38}$ = 87.29, $p < .001$) and ($F_{1,38}$ = 546.01, $p < .001$), respectively. The simple effect of time results showed that in the intervention group, there were statically difference of physical/ material well-being mean scores between three time points ($F_{2,38}$ = 13.42, $p = .02$). In the intervention group, the mean score of physical/ material well-being at follow-up (T_3) were higher than those at baseline (T_1) and post-intervention (T_2) (M_{diff} = 14.05 and M_{diff} = 6.90,

$p < .001$, respectively). The mean score of Physical/ material well-being after intervention was significantly higher than those at baseline ($M_{diff} = 7.15$, $p < .001$). In the graph, the line of intervention group showed a constant increase after intervention and at follow-up. It could be interpreted that the caregivers who received the family-management intervention program had better Physical/ material well-being than those who were in control groups (Table 4-21, Table 4-22, Table 4-23, Table 4-24 and Figure 4-6).

Table 4-21 Repeated measures ANOVA of Physical/ material well-being

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Physical/ material well-being					
Within subjects					
Time	1178.32	2.00	589.16	180.91	< .001
Time*Group	812.85	2.00	406.43	124.80	< .001
Error time	247.50	76.00	3.26		
Between subjects					
Group	1080.00	1.00	1080.00	407.14	< .001
Error	100.80	38.00	2.65		

Table 4-22 Simple effect of groups on physical/ material well-being between two groups at 3-point times

Source	SS	df	MS	*F*	*p*-value
Pre-intervention (T_1)					
Between subjects	1.60	1.00	1.60	0.73	.40
Error	82.80	38.00	2.18		
Post-intervention (T_2)					
Between subjects	366.03	1.00	366.03	87.29	< .001
Error time	159.35	38.00	4.19		
Follow-up (T_3)					
Between subjects	1525.23	1.00	1525.23	546.01	< .001
Error	106.15	38.00	2.79		

$p < .05$, $F_{0.5}(1, 40) = 7.31$

Table 4-23 Simple effect of time on physical well-being scores in the intervention and control groups

Source	SS	df	MS	*F*	*p*-value
Intervention group					
Between subjects	4821.33	19			
Interval	15796.78	2	7898.39	13.42*	.02
Error	22371.22	38	588.72		
Total	42989.33	59			
Control group					
Between subjects	1301.37	19			
Interval	4185.57	2	2092.78	10.39*	.03
Error	7652.43	38	201.38		
Total	13139.37	59			

*$p < .05$, $F_{0.5}(2,38) = 3.23$

Table 4-24 Pairwise comparisons of mean score of Physical/ material well-being at each time points within the intervention group

Time	**M_{diff}**	**SE**	***p*-value**
Intervention group			
T_1 vs. T_2	-7.15	0.59	< .001
T_1 vs. T_3	-14.05	0.49	< .001
T_2 vs. T_3	-6.90	0.62	< .001
Control group			
T_1 vs. T_2	-0.70	0.59	.24
T_1 vs. T_3	-1.30	0.49	.01
T_2 vs. T_3	-0.60	0.62	.34

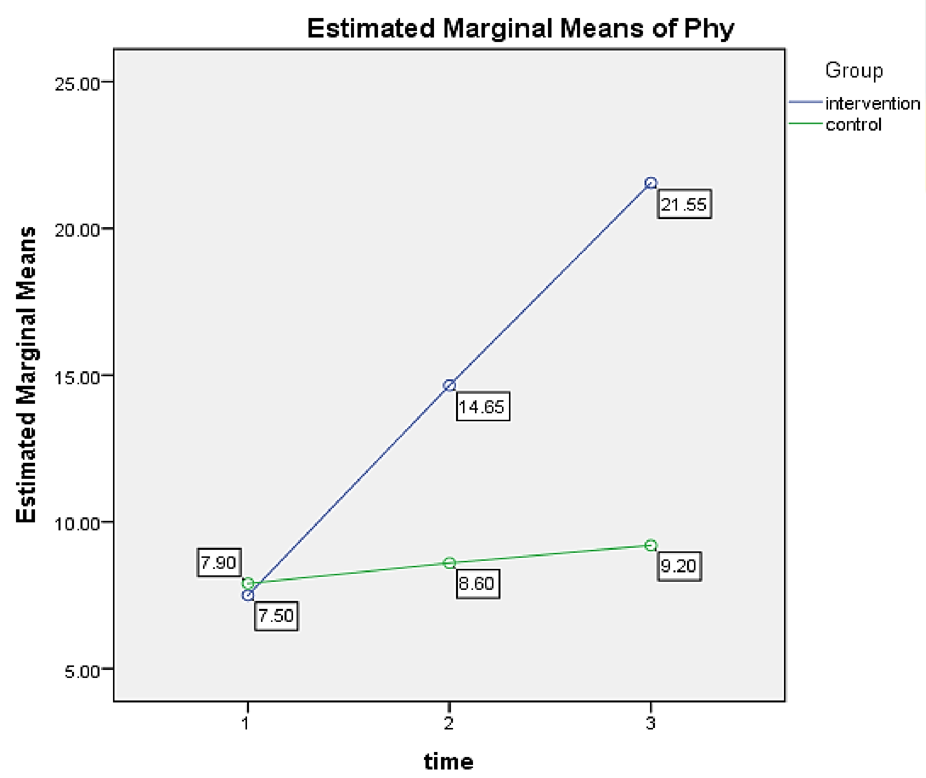

Figure 4-6 Comparisons of mean scores of physical/ material well-being

Disability-related support

The main effect of disability-related support mean scores was statistical significance between subjects ($F_{1,38} = 55.56$, $p < .001$). There was significant differences in disability-related support mean scores within the intervention group in at least one pair of the three time points, ($F_{2,76} = 86.54$, $p < .001$). The mean scores of disability-related support were statistical significance of interaction effect (time and group effect) ($F_{2,76} = 30.96$, $p < .001$), indicating the disability-related support mean scores between the intervention and the control group was different over time. Moreover, immediately after intervention (T_2) and follow-up time (T_3), there were statically difference of disability-related support mean scores between groups, ($F_{1,38} = 41.96$, $p < .001$) and ($F_{1,38} = 63.32$, $p < .001$), respectively. The simple effect of time results showed that in the intervention group, there were statically difference of disability-related support mean scores between before intervention (T_1), immediately after intervention (T_2) and follow-up time (T_3), ($F_{2,38} = 13.42$, $p = .02$). In the intervention group, the mean score of disability-related support after intervention (T_2) and at follow-up (T_3) were significantly higher than those at baseline (T_1) ($M_{diff} = 5.050$, $p < .001$) and ($M_{diff} = 5.30$, $p < .001$), respectively. However, the mean score of disability-related support after intervention was not different with the mean score of parenting at follow-up ($p > 0.05$). In the graph, the line of intervention group showed a sharply increase after intervention and remain mostly the results at follow-up. It could be interpreted that the caregivers who received the family-management intervention program had better disability-related support than those who were in control groups and remain mostly the results over time. The results were presented in the Table 4-25, Table 4-26, Table 4-27, Table 4-28 and Figure 4-7.

Table 4-25 Repeated-measures ANOVA of disability-related support

Source	SS	df	MS	*F*	***p*-value**
Disability-related support					
Within subjects					
Time	280.12	2.00	140.06	86.54	< .001
Time*Group	100.22	2.00	50.11	30.96	< .001
Error time	123.00	76.00	1.62		
Between subjects					
Group	95.41	1.00	95.41	55.56	< .001
Error	65.25	38.00	1.72		

Table 4-26 Simple effect of groups on disability-related support between two groups at 3-point times

Source	SS	df	MS	*F*	***p*-value**
Pre-intervention (T_1)					
Between subjects	0.10	1.00	0.10	0.07	.79
Error	54.30	38.00	1.43		
Post-intervention (T_2)					
Between subjects	90.00	1.00	90.00	41.96	< .001
Error time	81.50	38.00	2.14		
Follow-up (T_3)					
Between subjects	99.23	1.00	99.23	63.32	< .001
Error	59.55	38.00	1.57		

$p < .05$, $F_{0.5}(1, 40) = 7.31$

Table 4-27 Simple effect of time on disability-related support scores in the intervention and control groups

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Intervention group					
Between subjects	3033.33	19			
Interval	9888.72	2	4944.36	13.42*	.02
Error	13304.62	38	350.12		
Total	26226.67	59			
Control group					
Between subjects	844.21	19			
Interval	2700.58	2	1350.29	10.43*	.03
Error	4918.09	38	129.42		
Total	8462.88	59			

*$p < 0.05$, $F_{0.5}(2,38) = 3.23$

Table 4-28 Pairwise comparisons of mean score of disability-related support at each time points within the intervention group

Time	$\mathbf{M}_{diff}$	**SE**	***p*-value**
Intervention group			
T_1 vs. T_2	-5.05^{*}	0.42	< .001
T_1 vs. T_3	-5.30^{*}	0.33	< .001
T_2 vs. T_3	-0.25	0.45	.58
Control group			
T_1 vs. T_2	-1.25^{*}	0.42	.01
T_1 vs. T_3	-1.35^{*}	0.33	< .001
T_2 vs. T_3	-0.10	0.45	.82

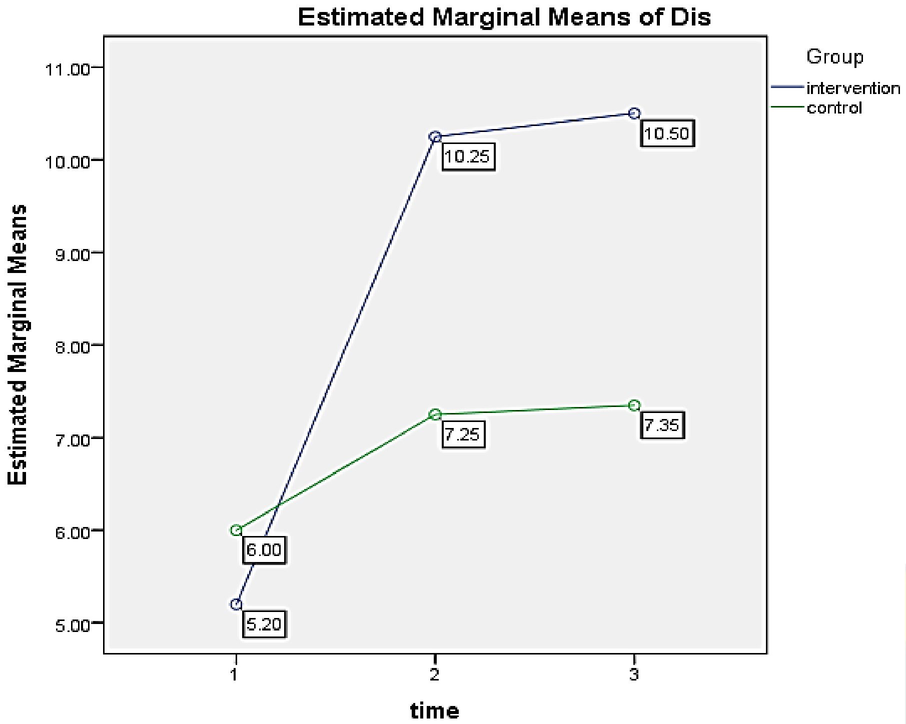

Figure 4-7 Comparisons of mean scores of disability-related support

2. Participants in the intervention group have lower burden than that in the control group at immediately post-intervention, and follow-up period**.** Within the intervention group, there is a significant difference in mean score of burden across three point times.

Results from the repeated-measures ANOVA are reported in Table 4-29. The main effect of burden mean scores was statistical significance between subjects ($F_{1,38}$ = 534.95, $p < .001$). There was significant differences in burden mean scores within the intervention group in at least one pair of the three time points, ($F_{2,76}$ = 211.41, $p < .001$). The results showed that mean scores of burden were statistical significance of interaction effect (time and group effect) ($F_{2,76}$ = 144.45, $p < .001$) indicating the burden mean scores between the intervention and the control group was different over time.

Table 4-29 Repeated measures ANOVA of burden

Source	SS	df	MS	*F*	*p*-value
Burden					
Within subjects					
Time	1392.72	2.00	696.36	211.41	< .001
Time*Group	951.62	2.00	475.81	144.45	< .001
Error time	250.33	76.00	3.29		
Between subjects					
Group	2279.41	1.00	2279.41	534.95	< .001
Error	161.92	38.00	4.26		

The graph results showed that there was a sharply reduce of burden mean scores after intervention and minor increase in follow-up time in the intervention group, while there was almost no difference in the control group. The mean scores of burden in the intervention group were lower than those in the control group after intervention and follow-up time.

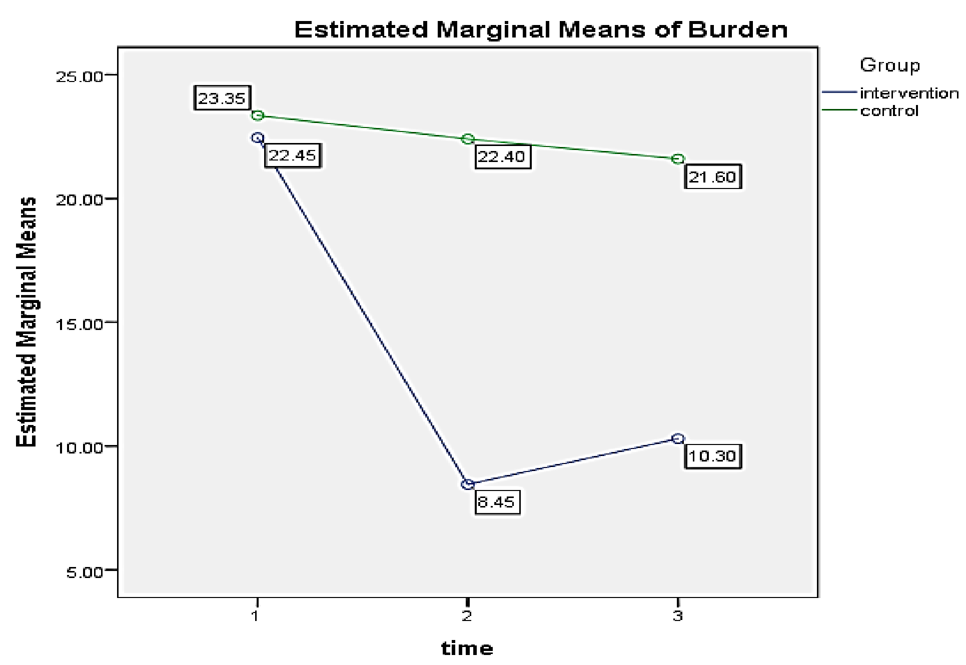

Figure 4-8 Comparisons of mean total scores of burden

The simple effect of group results showed that before intervention (T_1) there was not difference of burden mean scores between the intervention and the control group (*p* = 0.08). However, immediately after intervention (T_2) there were statically difference of burden mean scores between the intervention and the control group, ($F_{1,38} = 514.43$, $p < .001$) and follow-up time (T_3), ($F_{1,38} = 277.27$, $p < .001$), respectively. The finding indicated that the caregivers received the family-management intervention had less burden than those who were in control group.

Table 4-30 Simple effect of groups on burden between two groups at 3-point times

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Pre-intervention (T_1)					
Between subjects	8.10	1.00	8.10	3.29	.08
Error	93.50	38.00	2.46		
Post-intervention (T_2)					
Between subjects	1946.03	1.00	1946.03	514.43	< .001
Error time	143.75	38.00	3.78		
Follow-up (T_3)					
Between subjects	1276.90	1.00	1276.90	277.27	< .001
Error	175.00	38.00	4.61		

$p < .05$, $F_{0.5}(1, 40) = 7.31$

The simple effect of time results showed that in the intervention group, there were minor difference of burden mean scores between before intervention (T1), immediately after intervention (T_2) and follow-up time (T_3), ($F_{2,38} = 14.88$, $p = .02$). However, in the control group, there was not difference of burden mean scores between before intervention (T1), immediately after intervention (T_2) and follow-up time (T_3), ($F_{2,38} = 2.11$, $p = .13$). The finding indicated that the caregivers received the family-management intervention had less burden over time. (Table 4-31).

Table 4-31 Simple effect of time on burden scores in the intervention and control groups

Source	**SS**	**df**	**MS**	***F***	***p*-value**
Intervention group					
Between subjects	4030.39	19			
Interval	13028.00	2	6514.00	14.88*	.02
Error	16632.00	38	437.68		
Total	33690.39	59			
Control group					
Between subjects	8293.23	19			
Interval	7813.00	2	3906.50	2.11	.13
Error	70401.00	38	1852.66		
Total	86507.23	59			

$^*p < .05$, $F_{0.5}(2,38) = 3.23$

Pairwise comparisons were used to identify the differences in burden mean scores in three time points. In the intervention group, the mean score of burden after intervention (T_2) and at follow-up (T_3) were lower than those at baseline (T_1) ($M_{diff} = 14.00$ and $M_{diff} = 12.15$, $p < .001$, respectively). The mean score of burden at follow-up was significantly higher than those after intervention ($M_{diff} = 1.85$, $p < .001$). Interestingly, in the control group, the mean score of burden at follow-up was significantly higher than those at baseline ($M_{diff} = 1.75$, $p < .001$). The findings indicated that participants in the intervention group had lower burden after receiving the family-management education intervention, however, the improvement was not sustainable over time. The results were presented in the table 4-32.

Table 4-32 Pairwise comparisons of burden over three time points within the intervention group

Time	M_{diff}	SE	*p*-value
Intervention group			
T_1 vs. T_2	14.00	0.56	< .001
T_1 vs. T_3	12.15	0.57	< .001
T_2 vs. T_3	-1.85	0.59	< .001
Control group			
T_1 vs. T_2	0.95	0.56	.10
T_1 vs. T_3	1.75	0.57	< .001
T_2 vs. T_3	0.80	0.59	.18

CHAPTER 5
CONCLUSION AND DISCUSSION

This chapter is to summary the study and its findings. Discussion, recommendations and application for nursing practice and future research are also presented. Limitations of the study are denoted.

Summary of the study

This RCT study was to test the effectiveness of the family-management intervention on FQoL and burden of family with autistic children. Participants were 40 caregivers of autistic children in National Pediatric Hospital, Vietnam. Of 20 participants for each group was randomly assigned to either the control or the intervention group using a random number assigned by a research assistant who are blinded to group numbering.

In the intervention group, the caregivers were female (80%) and married (65%). The mean age of the caregivers was 32.25 years (*SD* = 6.14 years). The average years of duration of care was 6.05 (*SD* = 1.91). 75% of them were boys with mean age of 6.05 years (*SD* = 1.90 years) and the average years of being diagnosed from physician as having autism was 2.50 (*SD* = 1.57). 100% caregivers are parents of autistic children.

In the control group, 90% of caregivers are parents of autistic children. Most of them were female (80%) and married (75%). The mean age of the caregivers was 37.50 years (*SD* = 11.38 years) and the average years of duration of care was 5.35 (*SD* = 1.78). 95% of children were boys and 75% of them were the first child in the family. The mean age of the children was 5.60 years (*SD* = 1.35 years) with the average years of being diagnosed from physician as having autism was 2.45 (*SD* = 1.23).

The family-management intervention protocol included four-weekly face to face sessions with phone call follow-up after every session. Each session lasted 60 minutes. The FQoL and burden were measured at 3 time points including at baseline (T_1), post-intervention (T_2), and follow up (T_3). The research instruments included the

Beach Center FQoL Scale and the C-M-CSI with their reliability of Cronbach's alpha of 0.78 and 0.82, respectively. Data were carried out at National Hospital of Pediatrics, Hanoi, Vietnam from October to December, 2019.

The results showed that the FQoL and burden mean total scores between intervention and control group was different over time ($F_{2,76} = 853.62$, $p < .001$ and $F_{2,76} = 144.45$, $p < .001$, respectively). The caregivers receiving the family-management intervention had better FQoL and lower burden than those who did not receive ($F_{1,38} = 1442.19$, $p < .001$; $F_{1,38} = 514.43$, $p < .001$) . Moreover, the participants in the intervention group had better FQoL and lower burden after receiving the family-management intervention ($M_{diff} = -54.60$, $p < .001$; $M_{diff} = 1.85$, $p < .001$, respectively).

Discussion of the findings

The study findings are discussed following the research hypotheses as followings:

Hypotheses 1 and 2: Participants in the intervention group have higher FQoL than those in the control group at immediately post-intervention, and at follow-up period. Within the intervention group, there is a significant difference in mean score of family quality of life across three point times.

The findings indicated that after receiving the family-management intervention, the participants in the intervention group had better FQoL than those who did not received the intervention and the results remain over time. The findings supported the FMSF in that the family-management intervention program provided knowledge of autism and family management approach; family goals and values of management; and how to plan their own routine approach to behavior management for autistic children. Family management refers to families' responses to a child's chronic condition care and how families incorporate condition management into their everyday life (Knafl et al., 2008; Knafl et al., 2013). These findings were congruent with previous studies (Hsiao et al., 2017; Ji et al., 2014; Kieckhefer et al., 2014); Tamar & Shirli, 2016). For autistic children, the primary goal includes managing child's behavior problems and family's daily living events. Moreover, family management also incorporates management of the child’s emotional, behavioral, physical and social needs. The intervention strengthened family capacity in managing their own life and children with autism in order to improve FQoL. Moreover, the research results suggested that family efforts to intervene child's problems means focusing on the family management style and ultimately improve the FQoL. The intervention can help family members cope with and manage their children’s conditions more effectively.

Five subscales of the FQoL were also better among the intervention group the control group. Family interaction refers to the relationships among and between family members; such as enjoying spending time together, solving problems together, supporting each other to accomplish goals (Hoffman et al., 2006). Family interaction is an aspect of FQoL that related to health and life satisfaction. The results showed that the caregivers experiencing the family-management intervention had better family interaction than those who did not receive the intervention. However, it was not different mean score between after intervention and at follow-up because improving family interaction related to many factors. One of the important reason is that while experiencing the intervention (T_1 to T_2), the caregivers get closely support from the researcher in their own action plan and solving problems and they did not receive any support from researcher at follow-up time. Other factors came from caregivers’ characteristics that in the intervention group, 100% of caregivers are parents. When their child got the diagnosis of autism, parents are the most stressed in the family, which greatly affects the previous interaction between family members, especially the spousal relationship. So when they received the intervention to improve the interaction between family members, they were eager to change for better interaction, but this was not easy, especially when their child has been diagnosed with autism for a relatively long time (M = 2.50, $SD\underline{+}1.57$), once the intervention support is no longer available, the family interaction gradually decrease. It was congruent with the previous study that factors affecting family interaction includes personal characteristics, besides the important factor is the health problem that one of the family members is experiencing (Thomas, Liu, & Umberson, 2017).

Parenting means the kinds of activities families engage in to facilitate their child’s development such as helping the children learn to be independent, helping the children with schoolwork and activities, teaching the children to make good decisions (Hoffman et al., 2006). The results indicated that the caregivers experiencing the family-management intervention had better parenting than those who did not receive the intervention; however, it was not different mean score between after intervention and at follow-up. The family-management intervention also focused on caregivers' discussion to care their autistic children, it improved the parenting ability, however, after finishing intervention, parenting ability of caregivers gradually reduced. These findings were congruent with previous studies that mental status, self-efficacy and parenting stress affect to the parenting (Matson et al., 2013). Autistic children have difficulties or deficits in communication and socialization skills. Therefore, family members have to spend numerous times to help the children adapting with their daily life. The costs for raising a child with autism is more than three times compared to the costs of raising a non-affected child because of assistance related to education, health and social services. Additionally, information and service systems are difficult to understand and approach by families with new diagnosis. Therefore, family members illustrated mental problem, self-efficacy and parenting stress which affected to parenting style. Although, in the intervention time, the caregivers get closely support from researcher to strengthen parenting ability, however, after finishing intervention, the parenting style gradually reduce.

Emotional well-being involves perceptions of stress and support availability, such as has the support we need to relieve stress, have friends or others who provide support, have some time to pursue their own interests; and physical/ material refers to basic physical needs such as medical support and transportation (Hoffman et al., 2006). The results indicated that the caregivers who received the family-management intervention program had better emotional and physical/ material well-being than those who did not receive and remain by the time. These findings were congruent with previous studies that emotional and physical/ material well-being are parent perceptions of having child with autism, they effort to balance role demands (Hsiao et al., 2017). Although, these were oftentimes in competition but they sought to balance finite resources and supports. Therefore, although the intervention finish, the positive results of emotional and physical/ material well-being remain.

Disability-related support, including supports across the community contexts of school, work, and home such as having support to make progress at school or workplace, having support to make progress at home, support to make friends and having a good relationship with the service providers (Hoffman et al., 2006). The results showed that the caregivers who received the family-management intervention program had better disability-related support than those who did not received and remain mostly the results over time. These findings were congruent with previous study that the caregivers also made reference to support after getting the diagnosis of autism of their child; however, they were very general in nature (Jones et al., 2017). Caregivers noted only the importance of having access to disability-related support when needed, and somewhat vaguely indicated that this could help to ease the strain of family demands and promote an emotionally-healthy family environment. Therefore, experiencing of the family-management intervention strengthen their own support and continue to remain the positive results.

Hypotheses 3 and 4: Participants in the intervention group have lower burden than those in the control group at immediately post-intervention, and at follow-up period. Within the intervention group, there is a significant difference in mean score of burden across three point times. The results indicated that the burden mean scores between intervention and control group was different over time. In addition, before intervention (T_1), there was not difference of burden mean scores between intervention and control group, however, after intervention (T_2) there were statically difference of burden mean scores between intervention and control group. It could be interpreted that the caregivers experiencing the family-management intervention had less burden than those who did not receive the intervention.

The findings supported that the FMSF guided the intervention on improving family management of children with autism; therefore, the intervention had the positive influenced on lessening family burden. This finding was supported by previous studies (Hsiao et al., 2017; Kieckhefer et al., 2014; Knafl et al., 2013; McStay et al., 2014). The research results suggested that family efforts to intervene child's problems means focusing on the family management style and ultimately reduce burden. The intervention can help family members cope with and manage their children’s conditions more effectively Moreover, caregivers played an essential role in implementation of effective family-management intervention to reduce burden.

In summary, the findings supported the family management style framework [FMSF] (Knafl et al., 2012), the theoretical base of the study. The findings are also relevant to pertinent empirical research. The most robust result from the current study was found for FQoL. Parents consistently showed a large and significant increase in FQoL among participations in the family intervention. These finding were supported by previous studies (Goepfert et al., 2015; Tanner et al., 2015; Kuhaneck et al., 2015 Kuravackel et al., 2018). The caregivers of autistic children had higher levels of FQoL after receiving the intervention. Further, burden have been found to be lesser after intervention. Previous literature on FQoL of families of children with autism has some changes from baseline to post-intervention and follow-up. Though, in the research, the caregivers who enrolled in the current intervention showed an increase in FQoL from baseline to post-intervention and follow-up. The overall increase in FQoL and decrease burden suggests that material from the current intervention program was successfully communicated to the majority of caregivers with autistic children.

Strengths

1. There were no participants who dropped out from the research. One of the important reasons is that the primary strength of this study is that the family-management intervention has positive results on caregivers, helping them to improve their FQoL and lessen family burden. Moreover, the specific intervention program attracted attention of caregivers because the program helped the Vietnamese family to increase understanding diagnoses, behavior management principles, assessing necessary services, and developing skills to promote their child development.
2. This is the randomized control trial considered as the gold standard for determining causation and the sample of the study were randomly assigned to either an intervention group or a control group.
3. The intervention included a follow-up session to confirm its effect sustainably.

Limitations

The research had some limitations including research assistants, outcome variables and generalizability issues.

1. Research assistant issue: Researcher recruited two research assistants who are practical instructors at the Unit. This may affect the accuracy of the research results because these two nurses provide care services for autistic children in the Unit. Therefore, it may affect the participants while they answering questions in the research measurements. Recommendations for future research should recruit health care workers who do not provide direct intervention on autistic children at the Unit.
2. According to the conceptual framework, the component of outcome includes individual functioning family unit functioning, however, the researcher only measured outcome related to family. The reason the researchers made this decision was the researchers' ability to measure behavioral problems in autistic children, and the limitations of the dissertation only allowed researchers to measure family outcomes. It is recommended in the future to conduct a multidisciplinary study that allows to measure variables in autistic children as well as their families.
3. Generalizability issues: The data was collected only one setting, therefore, the results may have limited to generalize to other settings.

Implications and recommendations

1. The results from the study were evidences about effectiveness of the family-management in improving FQoL and burden for family of children with autism. Basing on the study results, health care institutions and policy makers could develop a policy related to intervention for autistic children not only focus on children but also their family. The results of this study provided a structure for family management to improve FQoL and burden outcomes of Vietnam families. The interagency efforts and collaboration should be established to provide more family supports to families of children with autism.
2. Nursing practice: Research results showed the practical effect of the nursing intervention on families with autistic children. At present, autism-related service providers usually focus most of their time on interventions for children as well

as instructing caregivers to intervene for children. They did not provide enough support the families managing their own challenges while giving care for children with autism, which increases the burden and reduces FQoL resulting in improved inefficiencies of the autistic child. Therefore, the National Hospital of Pediatrics as well as autistic intervention units should consider this intervention as one of interdisciplinary interventions should be provide for family with autistic children.

3. Future research: A longitudinal studies of further research should be conducted to prolong the duration of follow-up to help the family members managing their challenges effectively. The invention should incorporate with components of intervening for autistic problems which would be gotten more involving from family members.

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APPENDICES

APPENDIX A

Booklet of family-management intervention

Author, Year & Title	Participants	Measurements	Intervention	Results	Others
Atefeh (2016) Effectiveness of a Brief Psychosocial Intervention on Quality of Life of Primary Caregivers of Iranian Children With Cancer: A Randomized Controlled Trial	Sixty-five PCCCs participated in Mahak Hospital and Rehabilitation Complex in Tehran, Iran *A double-arm randomized controlled trial study*	The Caregiver Quality of Life Index-Cancer-Persian version (CQOLC-P) prior to intervention, post-intervention, and at follow-up (i.e. 30 days after the intervention)	- A 5-week long BPI (which comprised of 5 counseling sessions and followed by 5 telephone follow-up) was delivered to the intervention group in addition to usual service, - The control group was provided with usual service Table attached	- Significant improvement was found within the intervention group on QOL ($p < 0.001$) including improvements on subscale measures of mental/ emotional burden ($p < 0.001$), disruption ($p < 0.001$), and positive adaptation ($p < 0.001$), compared with the control group over time. - There was no difference between the intervention and control groups on the financial subscale measure after intervention ($p > 0.05$)	- BPI was an feasible and effective strategy to improve the quality of life of PCCCs. - Similar interventions can be planned by practitioners to reduce the burden of childhood cancer on PCCCs. - Implementation of a randomized clinical trial of a brief *dyadic* intervention for child cancer patients and their primary caregivers. - The effects sustainability research should conduct in the same clinical trial with a bigger sample size and more follow ups (3 and 6 months after intervention

Author, Year & Title	Participants	Measurements	Intervention	Results	Others
.					
.					
.					
Coucouvanis (1997) Behavioral Intervention for Children With Autism	Case study: Ryan Smith 3 years old Adam, age 16 Frank, age 11 John, age 15		Environmental Modifications Using Positive Consequences Altering Consequences	This offers direction in how to start a program; - Continued monitoring and evaluation are necessary to determine whether to persist or to change the intervention. - Parents must be consulted and their personal goals and slulls taken into account when designing a program. We often forget that the child spends such a short segment of hs/ her Me in our care, and we must be teaching parents to be effective change agents as well as advocates for their child.	

APPENDIX B

Booklet of family-management intervention

BURAPHA UNIVERSITY

FACULTY OF NURSING

Booklet of family-management education intervention program

Dissertation research project

October, 2019

Booklet of family-management education intervention program

Session 1: Introduction to the family-management intervention.

Session two: Management of family caregivers’ emotional dimension and the child life.

Session three: Supporting family relationships, family communications and parenting.

Session four: Finding available resources and transitions into having a meaningful life.

APPENDIX C

Plan for the family-management intervention program

Plan for the family-management intervention program (Sample)

Session	Purpose	Key concept	Activity	Time (m)	Suggestions
Session 1: Introduction to the family management education program for families of children with autism.	• Establish a climate of trust and safety • Introduce the group members to each other • Look at the impact of living with an autistic child • Identify the common challenges faced by families of children with an autistic child	• Subjective meaning family members about child identity and illness view [FMSF]	**Welcome and Class introduction:** • Welcome to the family management education program for families of children with autism • Introduction to the class: – What to include in your introduction – Leader introductions • *Look at "problems"* • Points out there are common issues.	10	
	• Introduction to the family management education program		**Course Overview:** • Introduce and pass out parent booklet. • Ask parents to find course overview in workbook • Introduce the overall focus of each session, paraphrasing the session titles.	5	

Session	Purpose	Key concept	Activity	Time (m)	Suggestions
. Session 2	……..				
. Session 3	……..				
Session 4: Finding available resouces and transitions into having a meaningful life.	• To review action plans and make a new one • To introduce and practice problem solving	• Management approach, management mindset (FMSF) • Increased parent coping (BFS)	**Feedback/Problem Solving:** • *Feedback on action plan* • Introduce problem-solving steps • *Discuss on problem-solving for each participants*	10	
	• To learn about resources available for parents concerned about childhood stress		**Stress and strict to help your child manage stress and pain:** • Many children with autism experience stress • Symptoms of autistic childhood stress • Finding resources if you feel your child may need help • Coping skills for children • The “tricks” to manage stress	5	
	• To make an action plan		**Making an Action Plan:** • Action plans answer 5 questions • *Spend 1 minutes per parent on their action plan.*	10	

APPENDIX D

Instruments for data collection

PART I

The Demographic Questionnaire

I Information of the child:

1.Is the child?

☐ boy

☐ girl

2.

3.

4.

5. How long have your child been diagnosed with autism?

............years

II Information of the caregiver:

1.Relationship with the child?

☐arent

☐ Grandparent

☐ Aunt/ uncle

☐ Other

2.

3.

4.

5.

6. Marital status

☐Married

☐ Single

☐Divorced

☐ Widowed

7. How long have you taken care of your child?

______ years

PART II

Family quality of life questionnaire

We are interested in how satisfied you are with these things in your family. Read each statement carefully. Indicate how you feel about each statement by collecting one number from 1 to 5. Meaning of the number is:

1 = very dissatisfied
2 = dissatisfied
3 = neither satisfied nor dissatisfied
4 = satisfied
5 = very satisfied

No	**How satisfied am I that:**	**Values for responses**				
1	My family enjoys spending time together.	1	2	3	4	5
2	My family members help the children learn to be independent.	1	2	3	4	5
.						
.						
.						
.						
24	My family member with autism has support to make friends.	1	2	3	4	5
25	My family has a good relationship with the service providers who provide services and support to my family member with autism	1	2	3	4	5

PART III

Modified Caregiver Strain Index

We are interested in how difficult you are with these things. Read each statement carefully. Indicate how you feel about each statement by collecting one number from 0 to 2. Meaning of the number is:

0 = No
1 = Yes, Sometimes
2 = Yes, On a Regular Basis

No	How difficult am I that:	Values for responses		
1	My sleep is disturbed.	0	1	2
2	Caregiving is inconvenient.	0	1	2
3	Caregiving is a physical strain.	0	1	2
.				
.				
.				
11	There have been work adjustments.	0	1	2
12	Caregiving is a financial strain.	0	1	2
13	I feel completely overwhelmed.	0	1	2

APPENDIX E

Institutional review board

THE INSTITUTINAL REVIEW BOARD (IRB) FOR GRADUATE STUDY
FACULTY OF NURSING, BURAPHA UNIVERSITY, THAILAND

Thesis Title Effectiveness of Family-management Education Intervention on Improving Quality of Life and Burden of Family with Autistic Children in Vietnam

Name Mrs. Mai Thi Lan Anh
ID: 60810014
Doctoral of Philosophy in Nursing Science (International Program)

Number of the IRB approval 02 - 04 - 2562

The Institutional Review Board (IRB) for graduate study of Faculty of Nursing, Burapha University reviewed your submitted proposal. The contingencies have been addressed and the IRB **approves** the protocol. Work on this project may begin. This approval is for a period of one year from the date of this letter and will require continuation approval if the research project extends beyond **May 14th, 2020.**

If you make any changes to the protocol during the period of this approval, you must submit a revised protocol to the IRB committee for approval before implementing the changes.

Date of approval May **14th**, 2019

Chintana Wacharasin, R.N., Ph.D

Chairperson of the IRB
Faculty of Nursing, Burapha University, THAILAND

Tel.: 66-038-102823
Fax: 66.038-393476
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Vietnam National Children's Hospital (VNCH)
Research Institute for Child Health (RICH)

18/879 La Thanh road
Dong Da District, Hanoi, Vietnam
Tel +84 4 6273 8648
Fax +84 4 6273 8648
Website: rich.org.vn

Ethics Committee

31st October, 2019

NOTICE OF APPROVAL TO BEGIN RESEARCH

Reference number: VNCH – RICH – 2019 - 61

PI: Mai Thi Lan Anh (Burapha University, ThaiLand)

Project title: Effectiveness of family-management education intervention on improving quality of life and burden of family with autistic children in Vietnam

Research site: Vietnam National Children's Hospital
Project Time: from October, 2019 to December, 2019

Review date:	October 31st, 2019
Approved date:	October 31st, 2019
Expiration:	October 30th, 2020
CHAIRPERSON:	A/prof. Tran Minh Dien, MD., Ph.D.

BỆNH VIỆN NHI TRUNG ƯƠNG

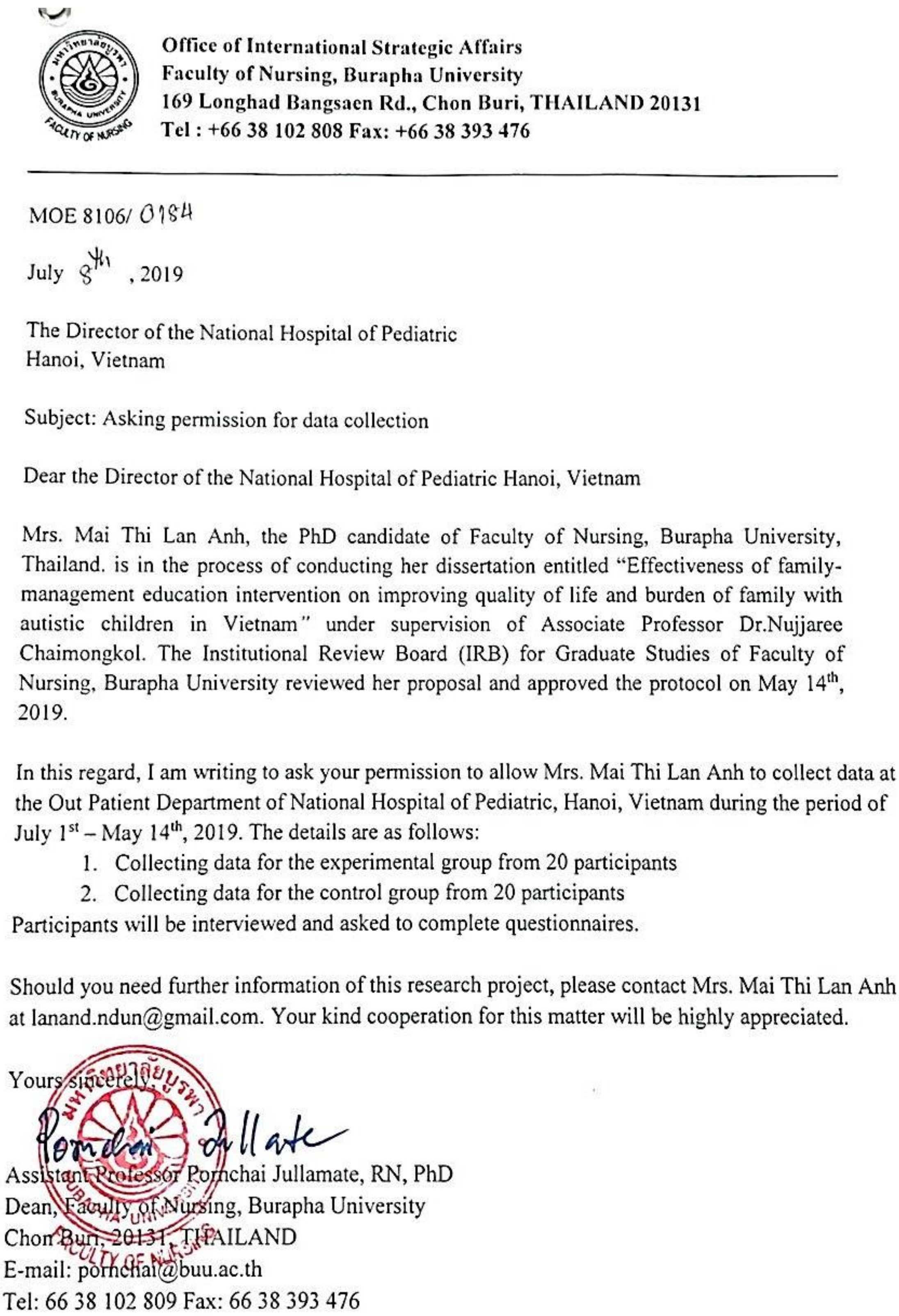
K/T GIÁM ĐỐC
PHÓ GIÁM ĐỐC

Trần Minh Điển

Please note the following conditions of approval:

1. The co-ordinating investigator will immediately report anything that might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project.
2. Proposed changes to the research protocol, conduct of the research, or length of the Ethics Committee (EC) approval, will be provided to the EC for review in the specified format.
3. The EC will be notified, giving justification, if the project is discontinued at a site before the expected date of completion.
4. The co-ordinating investigator will provide an annual report to the EC and at completion of the study.
5. Your approval is valid for **one year** from the date of the final approval letter. If your project extends beyond one year, you are required to resubmit your protocol at the one year anniversary, according to the latest guidelines, seeking the renewal of your previous approval. In the event of a project not having commenced within 12 months of its approval, the approval will lapse and reapplication to the EC will be required.

Should you have any queries about the EC's consideration of your project please contact Ms.Pham Thi Lan Lien, Secretary of the Ethics Committee, by email: lienptl@nch.org.vn



Office of International Strategic Affairs
Faculty of Nursing, Burapha University
169 Longhad Bangsaen Rd., Chon Buri, THAILAND 20131
Tel : +66 38 102 808 Fax: +66 38 393 476

MOE 8106/ 0184

July 8th , 2019

The Director of the National Hospital of Pediatric
Hanoi, Vietnam

Subject: Asking permission for data collection

Dear the Director of the National Hospital of Pediatric Hanoi, Vietnam

Mrs. Mai Thi Lan Anh, the PhD candidate of Faculty of Nursing, Burapha University, Thailand. is in the process of conducting her dissertation entitled "Effectiveness of family-management education intervention on improving quality of life and burden of family with autistic children in Vietnam" under supervision of Associate Professor Dr.Nujjaree Chaimongkol. The Institutional Review Board (IRB) for Graduate Studies of Faculty of Nursing, Burapha University reviewed her proposal and approved the protocol on May 14th, 2019.

In this regard, I am writing to ask your permission to allow Mrs. Mai Thi Lan Anh to collect data at the Out Patient Department of National Hospital of Pediatric, Hanoi, Vietnam during the period of July 1st – May 14th, 2019. The details are as follows:

1. Collecting data for the experimental group from 20 participants
2. Collecting data for the control group from 20 participants

Participants will be interviewed and asked to complete questionnaires.

Should you need further information of this research project, please contact Mrs. Mai Thi Lan Anh at lanand.ndun@gmail.com. Your kind cooperation for this matter will be highly appreciated.

Yours sincerely,

Assistant Professor Pornchai Jullamate, RN, PhD
Dean, Faculty of Nursing, Burapha University
Chon Buri, 20131, THAILAND
E-mail: pornchai@buu.ac.th
Tel: 66 38 102 809 Fax: 66 38 393 476

APPENDIX F

Permission for using instruments

From: Anh Mai Thi Lan [lananh.ndun@gmail.com]
To: Beach Center on Disability Managers [beachcenter@ku.edu]
Subject: Instrument request and permission to use

Dear Beach Center on Disability Managers,

My name is Thi Lan Anh Mai, a Vietnamese PhD candidate in Pediatric nursing pathway in Faculty of Nursing, Burapha University, ThaiLand. I am developing my dissertation proposal with the title "Effectiveness of family-management education intervention on improving quality of life and burden of family with autistic children in Vietnam". My major advisor is Associate Professor Dr. Nujjaree Chaimongkol. I read your journal included The Beach Center Family Quality of Life Scale and identified that the instrument is appropriate to use in my study. So I would like to use your instrument to measure DV (family quality of life). Therefore, I would like to receive your permission to use the instrument.

Thank you very much for your help and your kindness.

Sincerely yours,

Mai Thi Lan Anh

Monday, December 10, 2018

Dear Thi Lan Anh Mai,

I apologize for the delay in response as our team at the Beach Center has recently had a transition in folks who monitor this inbox.

Thanks for your interest in the FQOL scale. Please find this resource available online at https://beachcenter.lsi.ku.edu/beach-families.

The Beach Center Family Quality of Life Scale is available free of charge. Permission is granted for use in any educational or research purpose, provided appropriate reference is given in any reports or publications reporting results of studies using the Scale. Recommended citations are located on the cover sheet of the Scale.

Carley Blevins

KU Center on Developmental Disabilities (KUCDD)/Beach Center
From: Anh Mai Thi Lan [lananh.ndun@gmail.com]
To: Prof. Lisa L Onega [lonega@radford.edu]
Subject: Instrument request and permission to use

Dear Dr. Lisa L. Onega,

My name is Thi Lan Anh Mai, a Vietnamese PhD candidate in Pediatric nursing pathway in Faculty of Nursing, Burapha University, ThaiLand. I am developing my dissertation proposal with the title "Effectiveness of family-management education intervention on improving quality of life and burden of family with autistic children in Vietnam". My major advisor is Associate Professor Dr. Nujjaree Chaimongkol. I read your journal included The Modified Caregiver Strain Index (C-M-CSI) and identified that the instrument is appropriate to use in my study. So I would like to use your instrument to measure DV (family's burden). Therefore, I would like to receive your permission to use the instrument.

Thank you very much for your help and your kindness.

Sincerely yours,
Mai Thi Lan Anh

Wednesday, January 16, 2019
Dear Thi Lan Anh Mai,

You have my permission to use The Modified Caregiver Strain Index (C-M-CSI) in your study. You also have my permission to translate the scale into Vietnamese.

I have attached a copy of the original English version of the C-M-CSI, with scoring information included on the 2nd page. Also attached is a document listing several articles that have reported on the psychometric characteristics of the C-M-CSI.

Sincerely yours,

Lisa L Onega, Ph.D.
School of Nursing, Radford University

To: Asst. Prof. Dr, Sherwin Churchill [shervinc@uw.edu]
Subject: Instrument request and permission to use
Dear Asst. Prof. Dr, Sherwin Churchill,

My name is Thilananh Mai, a Vietnamese student. Currently, I am studying first year of the PhD program in Nursing Science at Burapha University, Thailand under supervision of Assoc.Prof.Dr. Nujjaree Chaimongkol. I have read your research project entitled "A Randomized Clinical Trial of the Building on Family Strengths Program: An Education Program for Parents of Children with Chronic Health Conditions ", and very interested in the program.

Therefore, I really would like to learn more in details about the program and may possibly obtain to apply with Vietnamese families of children with autism in my future dissertation. Moreover, I would also like to ask if I could be trained for the Curriculum with you as a mentor, which could be helpful for my dissertation and my contribution for Vietnam nursing professional in the future.

I am looking forward to hearing from you. Thank you very much for your kindness.
Best regards,

Dear Thilananh Mai and professor Chaimongkol,

Thank you for your interest in the Building on Family Strengths intervention. I am forwarding your message to Dr. Gail Kieckhefer who is the original principal investigator and creator of the program. She will be able to send information and the curriculum materials to you. Unfortunately at this time it is not feasible to provide any kind of training to students. I wish you all the best in your endeavors and hope that you will adapt the program for Vietnamese families—that would be wonderful!

Warm regards,
Shervin Churchill

Shervin S. Churchill, PhD, MPH
Affiliate Assistant Professor

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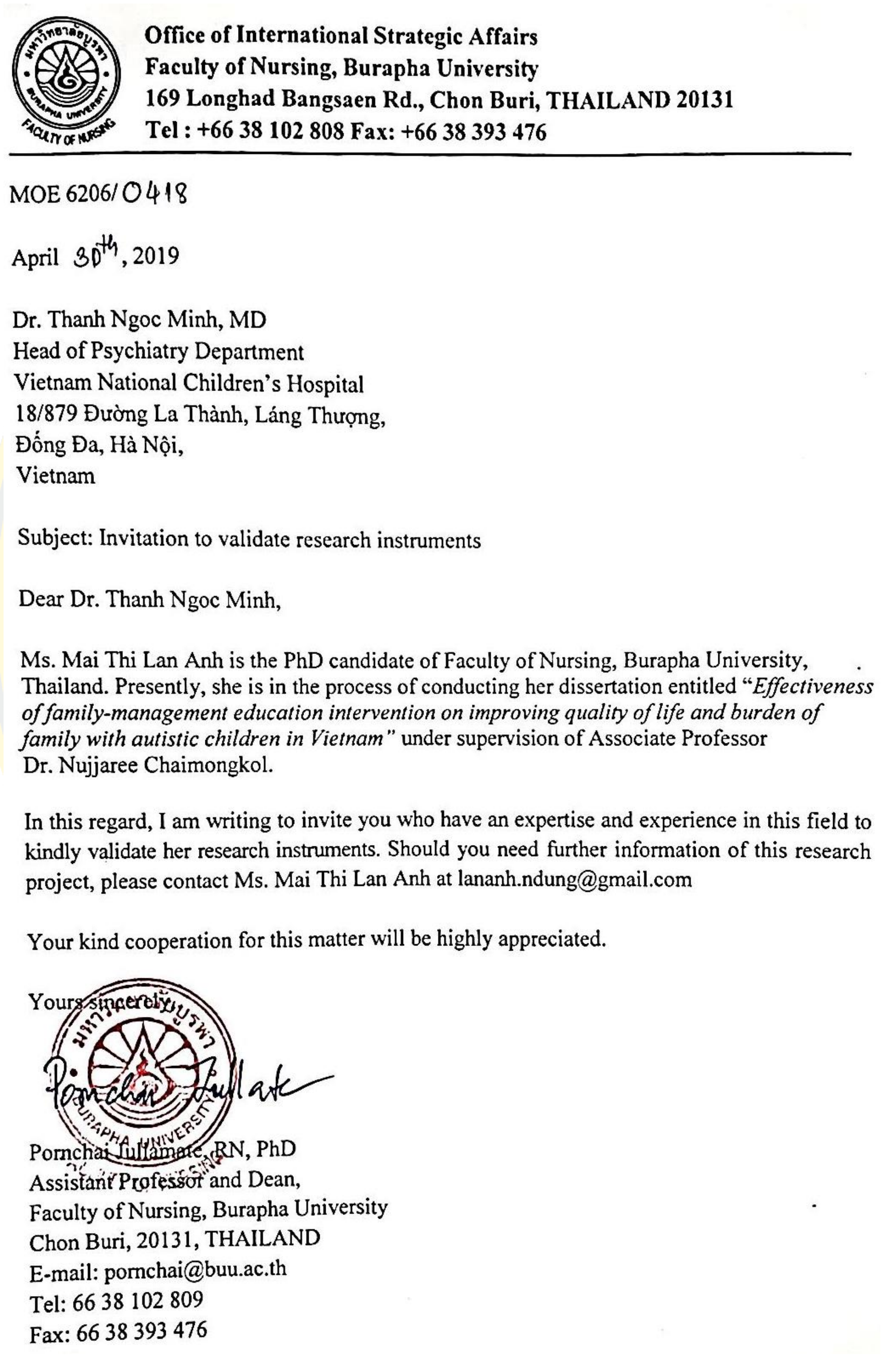
"Love is a light that never dwelleth in a heart possessed by fear." *–Baha'u'llah (1817-1892)*

APPENDIX G

Letter to experts



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MOE 6206/0418

April 30th, 2019

Dr. Thanh Ngoc Minh, MD
Head of Psychiatry Department
Vietnam National Children's Hospital
18/879 Đường La Thành, Láng Thượng,
Đống Đa, Hà Nội,
Vietnam

Subject: Invitation to validate research instruments

Dear Dr. Thanh Ngoc Minh,

Ms. Mai Thi Lan Anh is the PhD candidate of Faculty of Nursing, Burapha University, Thailand. Presently, she is in the process of conducting her dissertation entitled "*Effectiveness of family-management education intervention on improving quality of life and burden of family with autistic children in Vietnam*" under supervision of Associate Professor Dr. Nujjaree Chaimongkol.

In this regard, I am writing to invite you who have an expertise and experience in this field to kindly validate her research instruments. Should you need further information of this research project, please contact Ms. Mai Thi Lan Anh at lananh.ndung@gmail.com

Your kind cooperation for this matter will be highly appreciated.

Yours sincerely,

Pornchai Jullamate, RN, PhD
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APPENDIX H

Assumption testing

1. Test for univariate normality

Variable	Intervention group			Intervention group		
	Skew	**SE.skew**	**SK/ SE**	**Skew**	**SE.skew**	**SK/ SE**
FQoL_T1	.21	.51	0.41	-0.03	0.51	-0.06
FQoL_T2	-.23	.51	-0.44	-3.85	6.76	-0.57
FQoL_T3	-.37	.51	-0.72	-7.66	13.00	-0.59
Burden_T1	.43	.51	0.84	0.71	0.51	1.38
Burden_T2	-.03	.51	-0.06	-0.16	0.51	-0.30
Burden_T3	-.27	.51	-0.52	0.67	0.51	1.30
In_T1	-.19	.51	-0.36	0.92	0.51	1.79
Pa_T1	.49	.51	0.96	-0.26	0.51	-0.51
Emo_T1	-.11	.51	-0.21	0.26	0.51	0.51
Phy_T1	.94	.51	1.83	0.22	0.51	0.44
Dis_T1	.80	.51	1.56	0.52	0.51	1.01
In_T2	-.69	.51	-1.35	-0.48	0.51	-0.95
Pa_T2	-.35	.51	-0.68	-0.20	0.51	-0.39
Emo_T2	.06	.51	0.11	-0.32	0.51	-0.62
Phy_T2	.02	.51	0.04	-0.12	0.51	-0.23
Dis_T2	-.36	.51	-0.69	-0.07	0.51	-0.13
In_T3	-.34	.51	-0.66	0.52	0.51	1.02
Pa_T3	-.15	.51	-0.29	-0.30	0.51	-0.59
Emo_T3	-.46	.51	-0.89	0.03	0.51	0.05
Phy_T3	0.76	0.51	1.48	-0.01	0.51	-0.03
Dis_T3	0.37	0.51	0.73	0.12	0.51	0.23

2. Test for multivariate normality

Variable	Intervention group			Control group		
	Skew	SE.skew	SK/ SE	Skew	SE.skew	SK/ SE
Standardized Residual (FQoL)	0.18	0.51	0.35	0.11	0.51	0.22
Standardized Residual (Burden)	-0.65	0.51	-1.28	0.08	0.51	0.15
Standardized Residual (In)	-0.72	0.51	-1.40	0.62	0.51	1.22
Standardized Residual (Pa)	0.18	0.51	0.34	-1.05	0.51	-2.05
Standardized Residual (Emo)	-0.09	0.51	-0.17	-0.22	0.51	-0.43
Standardized Residual (Phy)	0.94	0.51	1.84	-0.63	0.51	-1.22
Standardized Residual (Dis)	0.95	0.51	1.85	-0.33	0.51	-0.64

3. Levene's test of equality of error variance Assumption of sphericity

Dependent variables and subscales	F	df1	df2	Sig.
FQoL_T1	0.11	1	38	0.74
FQoL_T2	0.00	1	38	0.98
FQoL_T3	2.55	1	38	0.12
In_T1	0.13	1	38	0.72
In_T2	0.75	1	38	0.39
In_T3	0.26	1	38	0.61
Pa_T1	0.35	1	38	0.56
Pa_T2	4.72	1	38	0.06
Pa_T3	3.72	1	38	0.06
Emo_T1	0.06	1	38	0.81
Emo_T2	0.00	1	38	0.98
Emo_T3	2.08	1	38	0.16
Phy_T1	0.14	1	38	0.71
Phy_T2	0.02	1	38	0.88
Phy_T3	2.70	1	38	0.11
Dis_T1	4.68	1	38	0.37
Dis_T2	14.94	1	38	0.50
Dis_T3	0.42	1	38	0.52
Burden_T1	0.18	1	38	0.67
Burden_T2	0.07	1	38	0.80
Burden_T3	4.65	1	38	0.04

4. Mauchly's test of sphericity (within-subject)

Dependent variables and subscales	Mauchly's W	Approx. Chi-square	df	Sig.
FQoL	0.94	2.42	2	0.03
In	0.98	0.91	2	0.64
Pa	0.91	3.63	2	0.16
Emo	0.95	2.11	2	0.35
Phy	0.94	2.39	2	0.30
Dis	0.95	1.79	2	0.41
Burden	1.00	0.17	2	0.92

BIOGRAPHY

NAME	Ms. Mai Thi Lan Anh
DATE OF BIRTH	April 21, 1983
PLACE OF BIRTH	Namdinh, Vietnam
PRESENT ADDRESS	151, Dang Xuan Bang Street, Namdinh city, Vietnam
POSITION HELD	2007- 2015 Lecturer at Department of Fundamental Nursing, Namdinh University of Nursing (NDUN), Namdinh city, Viet Nam 2015- Present Vice Director of Pre-clinical Practice Center, NDUN 2017-Present Deputy Head of International Cooperation Department, NDUN
EDUCATION	2002- 2006 Bachelor of Nursing (B.S.N), Hanoi Medical University, Hanoi capital, Vietnam 2013 – 2015 Master of Nursing Science (M.N.S), Faculty of Nursing, Burapha University (BUU), Chon Buri, Thailand 2017 – Present PhD of Nursing Science, BUU