

**THE RELATIONSHIPS AMONG SELECTED FACTORS,
CAREGIVING BURDEN AND FAMILY WELL-BEING IN
MOTHERS OF CHILDREN WITH AUTISTIC DISORDERS**

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THE RELATIONSHIPS AMONG SELECTED FACTORS, CAREGIVING BURDEN, AND FAMILY WELL-BEING IN MOTHERS OF CHILDREN WITH AUTISTIC DISORDERS

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ABSTRACT

This descriptive research investigated the caregiving burden and family well-being of mothers with autistic children and identified factors and the ability of selected factors to predict caregiving burden on the family well-being of these mothers. Orem's conceptual framework was used to guide the study. The purposive samples consisted of 107 mothers of autistic children, who had received medical treatment and follow up treatment at the autistic clinic outpatient department of Sri Nakarin Hospital, Khon Kaen University, Khon Kaen Province, Thailand, from May to September 2003. All data were collected using three questionnaires: Demographic Data Form, Autistic Caregiving Burden Scale Form developed by McCubbin, Oberst & Smith (1990), and translated into the Thai language and modified by the researcher, and the Family Well-Being Assessment Form developed by Caldwell (1983) and translated into Thai by Bu-Hgar Phuchacram (B.E.2533). Data were analyzed by using the SPSS/FW version 10.0 program.

The results revealed that the mothers of the autistic children had a moderate caregiving burden and moderate family well-being. In addition, only caregiving burden and mothers' level of education could explain the 12.7 percent of variance of family well-being in the mothers of autistic children which was statistical significance at the level of $p < .01$.

The results of this study suggest that nurses and other healthcare professionals should help to provide knowledge and information about autism to mothers of autistic children, especially those who have a low level of education. Also the relationships between mothers and family members should be promoted to encourage them to participate in caring for autistic children as a way to help reduce the mothers' stress levels.

KEY WORDS: CAREGIVING BURDEN / FAMILY WELL-BEING /
MOTHERS OF AUTISTIC CHILDREN

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ความสัมพันธ์ระหว่างปัจจัยคัดสรรภาระการดูแลและความผาสุกในครอบครัวของมารดาที่มีบุตรออทิสติก (THE RELATIONSHIPS AMONG SELECTED FACTORS, CAREGIVING BURDEN AND FAMILY WELL-BEING IN MOTHERS OF CHILDREN WITH AUTISTIC DISORDERS)

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บทคัดย่อ

การศึกษานี้เป็นการวิจัยเชิงบรรยาย มีวัตถุประสงค์เพื่อศึกษาภาระการดูแลและความผาสุกในครอบครัวของมารดาที่มีบุตรออทิสติก และศึกษาอำนาจการทำนายของ ปัจจัยคัดสรร ด้านระยะเวลาในการศึกษา รายได้ จำนวนบุตรที่มีผลต่อความผาสุกในครอบครัวของมารดาที่มีบุตรออทิสติก ภายใต้กรอบทฤษฎีของโอเรียม กลุ่มตัวอย่างเป็นมารดา ที่พานบุตรออทิสติกมารับการรักษา และติดตามผลที่แผนกผู้ป่วยนอก โรงพยาบาลศรีนครินทร์ ระหว่างเดือน พฤษภาคม ถึง กันยายน พ.ศ. 2546 โดยเลือกกลุ่มตัวอย่างแบบเจาะจงคุณสมบัติจำนวน 107 คน โดยใช้ แบบสอบถาม 3 ชุด ประกอบด้วยแบบวัดภาระในการดูแลบุตรออทิสติก ซึ่งผู้วิจัยได้แปลเป็นภาษาไทยและดัดแปลงข้อคำถามจากแบบวัดภาระการดูแลเด็กป่วย ที่สร้างโดยแมคคัมบีน โอเบิร์สท์ และสมิท (McCubbin, Oberst, & Smith, 1990) และแบบสอบถามความผาสุกในครอบครัวของคาลด์เวลล์ (Caldwell, 1988) แปลเป็นภาษาไทยโดย นุหงา ภูชะคราม (2533)

ผลการวิจัยพบว่ากลุ่มตัวอย่างรับรู้ภาระการดูแลในระดับปานกลางและมีความผาสุกในครอบครัวปานกลางและพบว่าภาระการดูแลและระยะเวลาในการศึกษา สามารถร่วมกันอธิบายความแปรปรวนของความผาสุกในครอบครัวได้ร้อยละ 12.7 อย่างมีนัยสำคัญทางสถิติ ($p < .01$)

ผลการวิจัยครั้งนี้เสนอแนะว่า บุคลากรที่เกี่ยวข้องควรให้ความช่วยเหลือโดยเน้นการให้ความรู้และข้อมูลเกี่ยวกับโรคออทิสติกแก่มารดาโดยเฉพาะมารดาที่มีการศึกษาน้อย และ ส่งเสริมการสร้างสัมพันธ์ภายในครอบครัวและการมีส่วนร่วมในการดูแลบุตรออทิสติก เพื่อลดความเครียดของมารดา

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CHAPTER I

INTRODUCTION

Background and Rationale

Autistic disorder (also called autism and sometimes called classical autism) is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASDs) (<http://www.ninds.nih.gov/disorders/autism/autism./htm>). It is a severely incapacitating lifelong developmental disability that typically appears during the first three years of life and may be the result of a neurological disorder that affects the brain. Autism is classified by the American Psychiatric Association as a Pervasive Development Disorder (APA, 1994). It is defined by symptoms that appear before the age of three which reflect delayed or abnormal development in Language, Social Skills and Behavioral Repertoire (http://www.psychnet-uk.com/dsm_iv/autistic_disorder.htm). It occurs to be more commonly occurs in boys than girls in the ratio of approximately 4:1 ([http://www.occ.ac.uk/documents/What is_autism_OFE_notes.pdf](http://www.occ.ac.uk/documents/What_is_autism_OFE_notes.pdf)). It has been found throughout the world in families of all racial, ethnic and social backgrounds. No known factors in the psychological environment of a child have been shown to cause autism (http://www.togetherforautism.org/articles/autism_symptoms_disorder.php). In addition, due to the impact autism has on children's physical, emotional and psychological development, it increases the problems in raising them.

In England, Wing (1980: 6) investigated autistic spectrum in the south-eastern municipality of London and found 21 autistic children out of 1,000. The numbers of epidemiological studies of autism have increased in recent years, including in the United States, where investigators are now catching up in what has been traditionally a weak area of child psychiatric research in North America. In the issue reported by Fombonne, Yeargin-Allsopp et al. (2003), report the findings of a survey, which was funded by the Centers for Disease Control and Prevention. The survey a rate of 34 per 10,000 children for autism spectrum disorders (ASDs) among 3 to 10-year-old children in metropolitan Atlanta (<http://www.autisticsociety.org/modules.php?>

name=News&file=article&sid=130). Furthermore, the estimate of children having autism varies considerably depending on the country. Estimates range from 2 out of 10,000 children in Germany to as high as 16 out of 10,000 children in Japan (<http://www.autisticsociety.org/modules.php?name=News&file=article&sid=91>).

In Thailand, the Department of Mental Health, Ministry of Public Health, has launched a survey of incidence and prevalence of autistic children (1-6 years) since the fiscal year B.E. 2545. The statistical records found that the risk of autism was 1,832 children out of 299,338 children and 6,106 children out of 1,132,446 children in B.E. 2546 and 2547, respectively. Hence, it is reasonable to conclude that the numbers of autistic children in Thailand are also increasing. Currently the private and state sectors cannot provide adequate services. Consequently, more than ever before the concerned state agencies have a policy to expand help to communities and encourage the families to participate in helping autistic children.

Autistic disorders can vary from being relatively mild to quite severe. The prognosis for individuals depends on the degree of their disabilities and on the level of therapy they receive (<http://health.allrefer.com/health/autism-prognosis.html>). Delay in language development is the most common reason children's caregivers seek medical assistance and bring them to see a physician; subsequently they are diagnosed with autism (http://www.medformation.com/ac/crspa.nsf/file/crs-pa-hg_autism.and.perv.dev.dis). For many children, autism symptoms improve with treatment and with age. Some children with autism grow up to lead normal or near-normal lives. Children whose language skills regress early in life, usually before the age of 3, appear to be at a higher risk of developing epilepsy or seizure-like brain activity (<http://www.ninds.nih.gov/disorders/autism/autism.htm>). Success in individual cases seems to be best with early recognition and intervention (<http://www.healthcentral.com/mhc/top/001526.cfm>). At present, there is no cure for autism. Therapies and behavioral interventions are designed to remedy specific symptoms and can bring about substantial improvement. The ideal treatment plan coordinates therapies and interventions that target the core symptoms of autism: impaired social interaction, problems with verbal and nonverbal communication, and obsessive or repetitive routines and interests (<http://www.ninds.nih.gov/disorders/autism/autism.htm>). Thus,

caregivers and parents of these children should be ready to adjust treatments for their child as needed.

According to the reviewed literature, parents and family members, which are the children's first guardian, have the responsibility to provide help to the children. It is the basic source of beneficial resources that are essential in managing and responding to the needs for self-help of these children (Taylor, 1989: 131 –137). In a family, the mother plays the most significant role in taking care of and dealing with various problems in order to maintain family balance. Therefore, the mother is a crucial figure in the treatment process, both at home and at the hospital.

The unique personalities and behaviors of autistic children have far reaching impacts, on not only themselves and their mothers, but also the family as a whole and society in general. Autistic children, especially those with violent and aggressive behavior, have limitations in the performance of activities in daily living. For example; they tend to exhibit aggressive behavior and damage objects, thus requiring close and constant care (Siriporn Suwanatos, B.E.2535: 8). Therefore, the mother has to care continuously for her autistic child in order to carry out and meet the basic demands of her autistic child. In addition, the mother has to bear other burdens in caring for and satisfying the demands of other family members. As a result, the mother may experience stress, and said stress may have an enormous effect upon other family members. Hence, autism can lead to particular problems within the family system as well as society as a whole.

Previous studies on the effects of children's illness on the family have shown that the family of children who have impairments and suffer from chronic illness or any handicap, affects family bonding and stability. This is because family members are confronted with conflicts, stress and fatigue from the delivery of care to the ill child (Sataporn Suwanoos, B.E.2531: 486). A similar study, with an emphasis on the relations among the children's parents and siblings, found that cooperation of and the roles played by individual family members were vital for family adjustment and well-being (Morgan, 1988: 263). In addition, studies show that the effects on parents who have autistic children were both physically and mental. The affected parents expressed a high level of anxiety concerning symptoms and sources of services for their child. They also exhibited a higher level of depression as compared to what is

considered a normal level in raising children who do not suffer from Autistic disorders (Kanya Tunyamanta, B.E.2534: 56). The impact is particularly strong for families of autistic children because these children suffer from a chronic condition that requires long-term treatment. It affects time management, work responsibilities, social tasks, free time, and one's personal life (Hoyert & Seltzer, 1992: 74-81).

On account of the aforementioned burdens and their impacts, mothers of autistic children have to use everything in their capacity in caring for her dependants, as well as specific skills and abilities for the needs and well-being of her autistic child. When considering that they have to carry out these additional activities as part of their daily lives, high levels of anxiety and depression can increase. They may consequently think of their autistic child as a caregiving burden, leading to additional stress in the mothers and other family members.

According to the concept of family well-being proposed by Caldwell (1988: 396-422), a family facing more stress has less well-being because family well-being is a dynamic family process that is associated with stress. A mother's burden in looking after an autistic child can affect a family's well-being and, consequently, the family well-being has an effect on the autistic children. This is because the mother is a key member of the family and the major party responsible in giving care to the children (Jariya Witayasuporn & Jongruk Uttrarachakit cited in Somchit Hanucharurnkul, Ed., B.E.2536: 227).

There are several basic conditioning factors that can promote a person's ability in caring for dependent persons and in facilitating the self-care of dependants (Somchit Hanucharurnkul, B.E.2536: 40). These factors can affect the awareness of caregiving burden and family well-being in mothers of autistic children. The basic conditioning factors are mothers' level of education, family income, and number of children in the family.

Mothers' level of education is crucial to the development of knowledge, skills, and attitudes concerning caregiving for dependants (Orem, 1985: 175). People who are better educated are able to recognize associations among factors more readily, which facilitates transference of knowledge and utilization of previously learned and successful behavior (Jalowiec & Powers, 1981: 14). A number of studies have been conducted to examine the relationship of the educational background to the awareness

of caregiving burden and to family well-being (Strauss & Monton, 1985: 372; Oberst et al., 1989: 211; Chuanruedee Kaewbud, B.E. 2535: 39; Wipawan Chaoum, B.E.2536: 56).

Family income determines socioeconomic status of the family. It is a beneficial resource for the initiation of continuous self-care, as well as dependent care (Orem, 1985: 122). A large number of studies have revealed that family income is related to caregiving burden and family well-being (Montgomery et al., 1985: 21; Oberst et al., 1989: 212; Bull, 1990: 773; Chuanruedee Kaewbud, B.E. 2535: 39; Wipawan Chaoum, B.E. 2536: 57).

The number of children in the family is also a factor that may induce limitations for mothers on account of an increase in caring demands. Some studies found that number of children is a vital variable that can predict a mother's ability in caregiving (Hass, 1990: cited in Chuanruedee Kaewbud, B.E. 2535: 40). However, a number of other studies found no relationship between the number of children in the family and caring capacity with family well-being (Autchareeya Patoomwan, B.E.2534: 57; Chuanruedee Kaewbud, B.E. 2535: 40). Mothers who have children may increase their families need for more caring demands. Subsequently it can produce more burdens for the mothers who look after autistic children. And because these mothers have to play many roles within the family system for the care of not only the autistic child but their siblings, other normal conflicts that may arise within any family system can be adversely magnified. Consequently, the implications the impact of burdens that said burdens impact on the status of other family members can within itself produce additional confictions that negatively influence the families well-being.

According to the current concept of holistic nursing approach, nurses play significant active roles in helping patients and their families. Nurses, therefore, have to be aware of the relevant factors that can satisfy mothers' needs and enhance their ability and potential in caring for autistic children in such a way that they do not feel troubled while carrying out their daily duties.

There were not many studies on caregiving burden and family well-being in the family of autistic children. The studies concerning autism in Thailand were mainly conducted with the population residing in Bangkok and its suburbs. There have been very few studies carried out in other provinces, where the characteristics of basic

conditioning factors are very different from those in the city. The researcher was interested in investigating the families of autistic children in the northeast of Thailand. The research order took to describe how mothers of autistic children perceive and cope with the caregiving burden; how and to what extent that the differences in basic conditioning factors, i.e. Mothers' level of education, family income and the number of children in the family, affect the caregiving burden and family well-being; and how these factors affect the mothers' perception of caregiving burden and family well-being. The results of this study could be used as guidelines for the development of nurses' capacity in assisting and promoting child care with relevance to these mothers' needs, especially those who live in upcountry. Moreover, the results could also help in giving support to mothers so that they be able to reduce their caregiving burdens, and lead to better family well-being.

Theoretical Framework

This study was based on Orem's nursing theory of within dependent care derived from Orem's theory of self-care, which focused on dependent care agency and dependent care demand. In addition, the concept of family well-being proposed by Caldwell (1988: 396) was also selected as a conceptual framework of the study.

Dependent Care Agency

Orem has proposed that individuals have limitations in taking care of themselves (Orem, 1986, cited in Somchit Hanucharunkul, B.E. 2536: 19), especially infants and children who require care from others. This is because they are in the early stage of physical, psychological, and psychosocial development, thus being dependent on parents or other family numbers (Orem, 1985: 84). Orem calls those responsible for caring "dependent-care agents." The dependent care agents must be dedicated to and trained for the task. Skills, knowledge and other potentials must be developed and improved so that they are able to continually respond to the dependent-care demand (Orem, 1991, cited in Somchit Hanucharunkul, B.E. 2540: 37). Whether autistic children will get good care or not depend on mothers' caring ability, since they have limitations in taking care of themselves. This is due to disorders in interacting with others, communication, activity performance, interests that are manifested in many

different forms, intelligence, movement and eating and sleeping, including response to the environment (Siriporn Suwanatos, B.E. 2535: 5). Autistic children could be classified as people with self-care limitations, who are not able to respond to the following self-care demands: universal self-care requisites, development self-care requisites, and health deviation self-care requisites (Somchit Hanucharurnkul, B.E. 2536: 27). Therefore, autistic children need help and attention from their mothers in responding to all these self-care demands so that their demands are continuously and sufficiently answered to, resulting in the maintenance of life, safety, and well-being of autistic children, as well as their families.

According to Orem, the dependent care agency consists of estimative, transitional, and productive ability. The caregivers should also have specific ability, which depends on their capacity and preliminary qualifications including the basic conditioning factors (Orem, 1991, cited in Somchit Hanucharurnkul, B.E. 2540: 37). Considering the required ability of caregivers, mothers of autistic children need to know and respond to the children's demands and to make necessary adjustments according to their health problems. Moreover, the mothers also need to provide care in relevance to the children's development and these caregiving activities must be integrated into their other daily activities.

Because autistic children have disorders in creating social interaction, speech, language use, communication and imagination, their mothers may feel that they have an excessive burden, especially when they have to take care of their other family members. Mothers of autistic children, therefore, might be easily stressed or bored of their caregiving task.

Caregiving Burden

Oberst and Hughes (1991: 71) have pointed out that an illness condition generates demands that requires time and effort of dependent care agents and these demands are perceived as caregiving burdens. The caregiving burdens for caregivers include implementation of medical care plans, surveillance and observation of abnormal symptoms, assessment of the illness outcomes and the side effects of medications, giving responses to general and developmental demands, and seeking medical consultation for recurrence symptoms or follow-up treatment.

Therefore, whether autistic children can have their demands satisfied or not depends on the capacity of their mothers who have to maintain other roles in the family, such as caring for other family members, or in some cases, earning family income.

If mothers can respond to autistic children's demands without considering the task as an excessive burden, the children will be able to develop capabilities for self-care and live with a happy life, leading to family well-being. On the contrary, if mothers view caregiving as an excessive burden, their physical and mental health may be adversely affected, even though they can fulfill all the demands of the autistic children. As a result, the mothers' other roles in the family may also be affected, leading to the violation of family well-being (Taylor, 1989: 131-137).

Family well-being

Orem (1991: 184) defines well-being as individuals' perception that they are satisfied, pleased, and happy since they have achieved their ideal and maintained their mature individuality. The perception of well-being is one of the most important aims in attending the dependants and it is a factor affecting other targets of self-care, as well as caring for the dependants. Hence, a mother's ability to respond to an autistic child's demands without regarding it as a burden, can lead to better family well-being.

According to Orem's nursing theory, the family is viewed as a crucial environment of the patient. It is a vital unit responsible for the patients and other family members with the functions to respond to physical, mental, emotional, and social demands. A balance between demands and the ability to fulfill the demands reflects that the dependent care agents are a useful source for their family members, especially when the agents do not view the caregiving task as a burden. This is consistent with Caldwell's concept that the family is obliged to create and maintain the balance between demands and resources for family members (Caldwell, 1988: 396). It is to be observed that the two concepts view persons and their families as an open system. Therefore, the well-being of each family member can have an effect on other members and on the whole family.

The concept of family well-being proposed by Caldwell (1988: 396) is a phenomenon which is closely related to family stress. It is the family's perception of

the situations shown in three aspects: family structure, family role process, and vulnerability.

Considering the caregiving burden of mothers of autistic children, it is apparent that mothers' ability in caring for and assisting autistic children efficiently can promote the autistic children's self-care ability to some extent. Furthermore, when mothers are able to adjust their roles and responsibilities in caring for the ill children, while performing other activities in their daily lives without viewing the caregiving task as a burden, they are less stressed, resulting in improved family well-being. On the other hand, if the mothers view the caregiving responsibility as a burden, the family stress will be elevated, resulting in poor family well-being. Thus, it could be concluded that caregiving burden has negative relationship with family well-being.

Orem (2001: 167) also states other basic conditioning factors that influence dependent care agency and the dependent care demand. These factors may contribute to the limitations in caregiving, thus inducing the perception of burdens, which in turn causes stress to individuals and their family. The factors under investigation in this study were selected based on the assumption that they are closely associated with caregiving burden and well-being in the family of mothers with autistic children, as described below.

Mothers' level of education

The mothers' level of education period plays an vital role in the development of skills, knowledge, and attitudes concerning the caring for dependants. It also helps individuals in solving problems in a reasonable way. The level of education is associated with the experience that generates the necessary learning to act and perform with care and discretion (Orem, 2001: 167). Well-educated persons are better able to apply their knowledge in looking after dependent persons, and they are equipped with information-searching skills and the skills for using that information (Muhlemkamp & Seyles, 1986: 336). Therefore, mothers with a higher level of education tend to be more capable of adjusting the caregiving burden in caring for autistic children and view it as a part of their daily life, resulting in good family well-being.

Family Income

Orem (1985: 122), stated that families have to be well proposed in regard to medication expenses for their autistic children and daily expenses for which the family has to be well prepared. If the family has a sufficient income, the caregiving burden will be decreased. Consequently, stress caused by financial problems is likely to be reduced, and decreasing stress means more family well-being. In contrast, if the family does not have a sufficient income to support members and autistic children, the demands are unlikely to be satisfied; thus, the family needs to seek more income to balance with the expenses. As such, mothers who have to earn family income are likely to create more burdens, leading to an increase in stress and a decrease in family well-being.

Number of children

According to Orem (1985: 221), the number of children indicates the mother's potential to attend to and help dependants. It can also condition the mother's ability to care for their autistic children. Mothers with many children are deprived of their full capability to fully respond to all the demands of their autistic children as they are overloaded with work. It is inevitable that they can easily get depressed and the family well-being is affected as a result.

In conclusion, mothers of autistic children may view caregiving responsibility as a burden and the family well-being may be adversely affected by such a view. The relationships of selected factors comprising the mother's educational period, family income and number of children and the caregiving burden to family well-being are summarized, as shown in Figure 1.

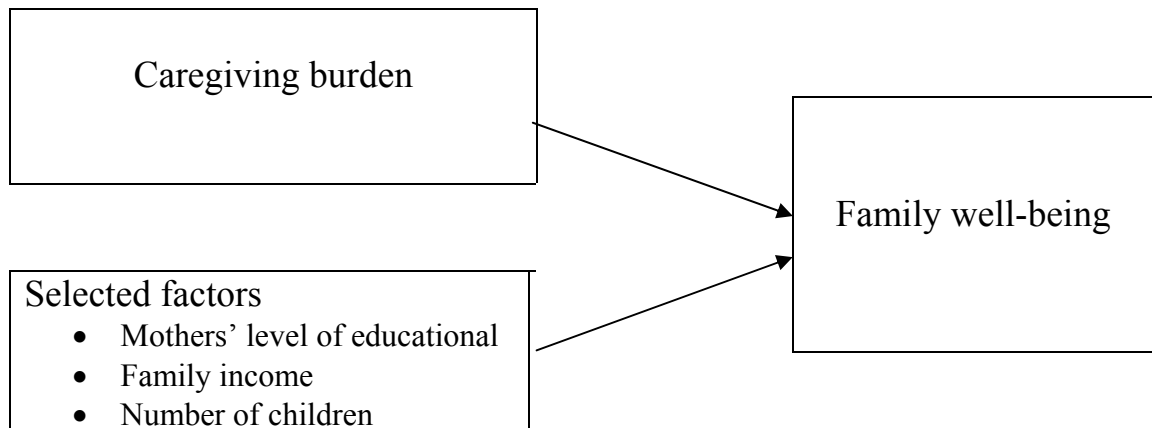


Figure 1: The relationships among Selected factors, Caregiving burden and Family well-being

Research Questions

1. What are the levels of caregiving burden, selected factors (mothers' level of educational, family income, and the number of children) and family well-being of the mothers with autistic children?
2. Can caregiving burden and selected factors (mothers' level of educational, family income and the number of children) predict family well-being of the mothers with autistic children?

Objectives of the research

1. To describe, the caregiving burden, selected factors (mothers' level of educational, family income and the number of children) and family well-being of the mothers with autistic children.
2. To identify the predictability of caregiving burden and selected factors (mothers' level of educational, family income and the number of children) and the number of children, on family well-being of the mothers with autistic children.

Research Hypothesis

Can caregiving burden and selected factors (mothers' level of educational, family income, and the number of children), predict family well-being of the mothers with autistic children.

Scope of the Study

The study was a survey of the caregiving burden of mothers whose children were diagnosed with Autistic disorders. Data were collected from the mothers of autistic children receiving treatment and behavioral therapy at the autistic clinic, speech therapy clinic, in the outpatient department of Sri Nakarin Hospital, Khon Kaen University, Ban Termtem, and the Special Educational Center, Zone 9 in Khon Kaen Province. The sample comprised of 107 mothers of autistic children. Data were collected from May to September 2003.

Benefits of the study

1. The results of this study can be used as guidelines for medical professionals in assessing the caregiving burden and well-being of mothers with autistic children.
2. The findings can provide information to help concerned professionals in making a plan to promote and sustain the well-being of autistic children and their families.
3. The results of this study can also be applied in further nursing research on other contributing factors regarding caregiving and family well-being of mothers with autistic children.

Definition of Variables

1. Caregiving burden refers to the mother's awareness of caring and difficulties in looking after autistic children. It includes direct care, interpersonal care and general care as measured by the caregiving assessment questionnaire created by McCubbin, Oberst, and Smith (1990). The researcher of this study translated and modified this questionnaire to suit the caregiving burden of the mothers of autistic children. Each question was divided into two parts: a) demand, which was assessed from the time spent in caring for the child in each activity; and b) difficulty, which was assessed from the difficulties in giving care in each activity. Each mother was asked to respond on a 5-point scale ranging from little or none (1) to a great deal (5), in order to describe both the amount of time and difficulty associated with each

caregiving task. The higher the total scores obtained from this questionnaire, the higher the level of awareness of caregiving as a burden.

2. Family well-being refers to the mother's awareness of family structure, family role process and vulnerability. These are measured with the Family Well-Being Assessment developed by Caldwell (1988: 396–422). The question was divided into two sections with were positive and negative items. It rated each item of family well-being on a 6 point Likert scale ranging from strong disagreement or almost never (1) and suggesting strong agreement or almost always (6). Positive items were 20 items and Negative items were 22 items. Low scores indicated good well-being or low stress.

3. Selected factors refer to mothers' educational background, family income, and the number of children, as defined below:

Mothers' level of educational means the number of years that a mother spent in an educational institute, starting from the compulsory elementary level to the highest level.

Family income means the average sum acquired per month from the career of parents or the net income of either father or mother in case not both the father and the mother earned an income.

Number of children means the number of children under the mother's responsibility including autistic children.

CHAPTER II

LITERATURE REVIEW

This research studied the predictability of caregiving burden and selected factors (comprising of mothers' level of education, family income, and the number of children) with family well-being in mothers of children with autistic disorders. This chapter presents an integrative review of relevant concepts and theories. The scope of the relevant literature review includes:

1. Caregiving burden of mothers with autistic children;
2. Family well-being of mothers with autistic children;
3. The relationship of caregiving burden and selected factors (mothers' level of education, family income, and the number of children) and family well-being of mothers with autistic children.

Caregiving burden of mothers with autistic children

Autistic disorder (also called autism and sometimes called classical autism) is one of five disorders coming under the umbrella of Pervasive Developmental Disorders (PDD). The five disorders under PDD are Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder (CDD), Rett's Disorder and PDD-Not Otherwise Specified (PDD-NOS). Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism impacts on the normal development of the brain in the areas of social interaction and communication skills (<http://www.autism-ociety.org/site/PageServer?pagename=whatisautism>). It is defined by symptoms that reflect delayed or abnormal development in Language, Social Skills and Behavioral Repertoire (http://www.psychnet-uk.com/dsm_iv/autistic_disorder.htm).

In a number of epidemiological studies of autistic disorder. It was found that the sex ratio is four-times more prevalent in boys than girls. However, girls with this disorder are prone to suffer the more severe debilitating effects. For many years

autism occurred in about 5 children per 10,000 live births. In England, Wing (1980: 6) investigated autistic spectrum in the south-eastern municipality of London and found 21 autistic children out of 1,000. The number of epidemiological studies of autism has increased in recent years, including in the United States, where investigators are now catching up in what has traditionally been a weak area of child psychiatric research in North America. In research reported by Fombonne (2003), Yeargin-Allsopp et al, reported the findings of their survey (which was funded by the Centers for Disease Control and Prevention) and found a rate of 34 per 10,000 for autism spectrum disorders ([http://www. Autisticsociety. org/modules.php?name=News &file =article&sid=130](http://www.Autisticsociety.org/modules.php?name=News&file=article&sid=130)). According to the U.S. Department of Education, autism is growing at a rate of 10 percent to 17 percent per year (<http://www. autisticociety. org/article414.html>). In addition, the estimate of children having autism varies considerably depending on the country, ranging from 2 out of 10,000 in Germany, to as high as 16 out of 10,000 in Japan (<http://www. autisticociety . org/modules.php? name=News&file=article&sid=91>). However, since the early 1990's, the rate of autism has increased enormously throughout the world with some studies reporting figures as high as 60 per 10,000 (<http://www. autismwebsite. com/ari/intro/autism. htm>).

At present, the cause of autism is unknown. However, research findings indicate a strong genetic component (<http://www.emedicinehealth.com/articles/29544-2.asp>) that it is caused by abnormalities in brain structure or function. Researchers are investigating a number of theories, including the link between heredity, genetics, medical problems and problems during pregnancy or delivery, in addition, environmental factors such as viral infections, metabolic imbalances, and exposure to environmental chemicals are also being investigated (<http://www.autism- society.org/site/PageServer? pagename= autismcauses>). Treatment of this disorder is very difficult and prolonged and presently there are no specific drugs for the treatment of autism. Treatment strategies for autistic disorder include biomedical and dietary therapies behavioral therapies, and complementary therapies. In general, a combination of biomedical and behavioral therapies, with or without complementary therapies, are the most effective in the majority of people with autism (<http://www.emedicinehealth. com/articles/29544-6.asp>).

The prognosis for individuals depends on the degree of their disabilities and on the level of therapy they receive (<http://health.allrefer.com><http://health.all.com/health/autism-> <http://health.a>). Autistic children whose language skills regress early in life, usually before the age of 3, appear to be more at risk of developing epilepsy or seizure-like brain activity (<http://www.ninds.nih.gov/disorders/autism/autism.htm>). However, for many children, autism symptoms improve with treatment and with age. Some children with autism even grow up to lead normal or near-normal lives (<http://www.ninds.nih.gov/disorders/autism/autism.htm>). Success in individual cases seems to be best with early recognition and intervention (<http://www.healthcentral.com/mhc/top/001526.cfm>).

Autistic children are in their childhood for a longer period than other normal children because of their behavioral and intellectual disorders. The condition is considered as a chronic illness that requires close and constant care from caregiving agents. The disorder also leads to disturbing behavior and has fairly severe effects on the caregiving agents, as well as all family members, in many aspects, especially family interaction (Morgan, 1988: 263-280). The lives of mothers who are the key caregiving agents of autistic children are the most adversely affected by the behaviors of their autistic children. A number of studies have reported physical, psychological, emotional impact and social impact on mothers of autistic children, as reviewed below.

Physical Impact: It has been found that the majority of mothers have declining health because they have to constantly care for autistic children, and have no time to rest. They get even more exhausted if autistic children have difficulty sleeping (Siriporn Suwanatos, B.E. 2535: 12-13). These mothers suffer from tiredness and exhaustion and do not have opportunities to develop their personality like other mothers of normal children (Kasama Uthaipatrakul, B.E. 2529).

Psychological Impact: Most mothers of autistic children are worried and stressed in the process of bringing up the children (Dunn et al., 2001: 39-51), as well as in training and modifying the children's behavior (Suparat Ekutsawin et al., B.E. 2539). In addition, they are concerned that autistic children who are hyperactive and have aggressive behavior may perform violent acts and cause harm to other family members who are weaker than themselves (Siriporn Suwanatos, B.E. 2535: 12-13;

Kasama Uthaiatrakul, B.E. 2529: 1-10). According to the study by Kanya Tunyamanta, (B.E. 2534), found that a family with autistic children was commonly concerned about the financial burden, as well as the upbringing and daily living of autistic children. This result is in accordance with a study conducted by Kasama Uthaiatrakul (B.E. 2529), who found that families with autistic children were confronted with several problems and difficulties such as financial problems. The mothers also expressed disappointment and concern over the behavior of their autistic children.

Emotional Impact: Mothers of autistic children felt depressed because of the children's behavior (Kasama Uthaiatrakul, B.E. 2529: 7-10). In her study with 41 mothers and 29 fathers of autistic children, Kanya Tunyamanta, (B.E. 2534) found that 14.63% of the parents were apparently depressed.

Social Impact: Caring for autistic children has a substantial impact on work performance. Mothers may have to resign from their full-time work if they cannot find caregiving agents for their autistic children, or they may be frequently absent from work (Kasama Uthaiatrakul, B.E. 2529: 7-10; Siriporn Suwanatos, B.E. 2535: 13). Furthermore, the pattern of social life also changes and the marriage life of couples with autistic children may be in distress, as exhaustion leads to sexual inactivity, especially in the mothers. Consequently, the couples are at high risk of divorce (Kasama Uthaiatrakul, B.E. 2529: 7-10; Dunn et al., 2001: 39-51). The conflicts among adult relatives are also likely to increase when autistic children conduct undesirable behavior. According to the study by Kanya Tunyamanta, (B.E. 2534), family atmosphere and interaction were most affected, followed by the interaction with relatives and neighbors, and parents' embarrassment in taking autistic children to public places.

According to the review of literature above, it is apparent that the majority of mothers are similarly affected physically, psychologically, emotionally, and socially. The only distinction lies in the degree of impact. Nevertheless, the Thai family pattern, coupled with the social and cultural system, has a characteristic of helping each other. Thus, the subsequent impacts are relatively less than the incidence in other countries. However, these impacts make the mothers less able to maintain their maternal roles and to satisfy all the demands of autistic children and other family

members, as expected by themselves or by the others. These mothers have to make an effort to be patient and spent a lot of time caring for their autistic children (Jaum Chumchuay, B.E. 2538: 6-10). The major cause of stress, which leads to lethargy and exhaustion, is the need to provide constant care to autistic children. Additional causes are unavailability of a suitable service in the society and lack of promotion for the caring of autistic children, this has lead to ignorance of the needs of parents of autistic children such as health care, and mental and social needs. As a result, families of autistic children may withdraw from the society with the sense of being isolated and lonely. The mothers may then be tired of being patient in caring for autistic children and they may view constant care for autistic children as an excessive burden.

Orem (1991: 175) defines the caregiving burden in terms of the outcomes of care arrangement for dependent persons. The family members who are responsible for answering to the demands of ill family members have to improve their knowledge, skills, and ability to establish interpersonal relationships and also to maintain the willingness to care for dependent persons. At the same time, the caregiving agents have to be responsible for their health condition and well-being. Many may consider

In caring for autistic children, the mothers have to conduct activities in response to all demands of the children. Their actions have to be systematic and effective and have to maintain a human functional structure in order to bring about development and well-being to autistic children and themselves. Therefore, the mothers have to learn how to combine and integrate caregiving activities into their daily living (Prakong Intarasombat, B.E. 2536: 133-164). If mothers cannot spare sufficient time for caregiving activities and have to make an effort in performing these activities, they will perceive the caregiving task as a burden.

Many scholars have made an attempt to explain the meaning of caregiving burden on the basis of their own beliefs and theoretical assumptions, especially the moral and ethical theory (Klein, 1989), and the stress theory of Lazarus & Folkman. Some proposed definitions are reviewed below.

Klein (1989) defines the caregiving burden as a confrontation with substantial burden and pressure. He views that the assessment of the level of caregiving burden depends on the intellectual level and moral and ethical development of individuals. He also considers caregiving as a form of stress assessed by the

caregiving agents. According to Lazarus & Folkman (1984), caregiving agents may view caregiving activities negatively, positively, or both and, as a result, the caregiving agents perceive the care for autistic children as a substantial burden, which leads to stress. Therefore, the caregiving burden should be a good indicator of stress. A study of the adjustment of parents of one-year-old children with congenital heart disease found a positive correlation between caregiving burden and mental stress at a statistically significant level ($r = .62, p < .01$) (Wanida Sanasutipun, et al B.E. 2544: 34).

A view similar to that of Klein (1989) can also be found in Oberst, 1990; Oberst et al., 1991; Wallhagen, 1992; Bull, 1990 who all state that “caregiving burden means the amount of caregiving demands and difficulties in giving care.” The amount of caregiving demands can be evaluated and measured and therefore, it is called an objective burden. Difficulty in caregiving, however, is not quantifiable or measurable, hence the name subjective burden. These two dimensions of caregiving burden are measured with the same set of questions but the queries are directed in two different ways. Firstly, the questions are focused on the amount of time needed for caregiving, which reflects the amount of caregiving demands that are the responsibilities of the caregiving agent. Secondly, the questions will focus on difficulties in caregiving, including the care required from caregiving agents. The caregiving activities included in measuring caregiving burden are the following: 1) personal hygiene care, e.g. having a shower, getting dressed, having a meal, and having excretion, etc.; 2) general regular activities such as receiving therapy, doing housework, or doing any other business; and 3) interpersonal interaction activities and/or activities concerning problematic behaviors such as preventing possible harm or modifying children’s behavior.

The caregiving activities for autistic children can be a substantial burden because autistic children cannot help themselves due to developmental impairments, as mentioned above. These children have to depend on their mothers to satisfy their demands.

According to Oberst (1990), caregiving burdens are perceived according to the care given to the children, as listed below.

1) Direct Care: the caregiving activities that directly respond to general demands, developmental demands, and healthcare demands of autistic children. Direct care consists of the following:

(1.1) Therapy—an activity to satisfy demands for essential care when there are health problems;

(1.2) Daily-activity—caregiving activities to satisfy the children's general demands; and

(1.3) Assistance—caregiving activities that help the children respond to their general demands.

2) Interpersonal Care: the caregiving activities concerning interpersonal relations. It consists of the following:

(2.1) Emotional support for patients;

(2.2) Surveillance against hazards or dangers;

(2.3) Dealing with behavior-related problems; and

(2.4) Communication with various persons.

3) Instrumental Care: general caregiving activities that may concern children or any general business, consisting of the following:

(3.1) Transferring the patients;

(3.2) Financial management;

(3.3) Dealing with increased household chores;

(3.4) Traveling to different places; and

(3.5) Planning various activities.

Oberst (1991) has developed a list of these activities to measure the caregiving burden. The concept is relevant to Orem's (1991) concept of caregiving demands assessment. Therefore, this study followed Oberst's (1990) concept in explaining and evaluating the caregiving burden in relevance with the total caregiving demands as proposed by Orem (1991).

In their study of caregiving demands and the assessment of the caregiving situation on family members who cared for 47 cancer patients who were exposed to radiation, Oberst et al. (1989) found that the activity that was the most demanding burden was arranging a journey for patients, followed by giving morale support and

doing increased domestic work. The study also found that the caregiving burden had a significant positive relationship with the dependence level of patients ($r = .53$, $P < .001$).

Fedewa and Oberst (1996) studied parents of 20 children receiving kidney transplants and found that the average score for caring demands were higher than those for caring difficulty. The scores were especially high in the demands concerning domestic work, patient transfer, and mental support. As for the caring difficulty, the scores were high in the aspects of domestic work, mental support, and dealing with difficult behaviors. The caregiving agents were aware that caregiving activities lead to an increase in all other activities for which they were responsible. Furthermore, they would have to conduct these activities throughout the rest of their life.

In Thailand, Wipawan Chaoum (B.E. 2536: 54) conducted a study of caregiving burden and well-being of relatives who looked after 100 senior dependants. The study findings revealed that the most demanding burden was monitoring symptoms for prevention of accidents. The following burdens were concerned with transport, morale support, and companionship. The score of time used in caregiving was higher than the score of caregiving difficulties. This finding was similar to that of the study conducted by Jariya Witayasuporn (B.E. 2539: 123), who examined a caustic model of caregiving burden in parents of 74 children with a chronic illness. She found that the perceived major burden was expenses, followed by prevention of danger, and transportation. This study also found that the average score for the amount of time used for caregiving was higher than the one regarding caregiving difficulty. Another study by Rosalin Eamyngpanich (B.E. 2539: 47), who investigated the caregiving burden and well-being in families of 100 mentally retarded children, found that the activity that the mothers perceived as the most demanding was managing the problematic behaviors of their children, followed by prevention of accidents and seeking sources of help. Time-consuming activities were providing mental support and seeking help from various sources. The activity perceived as less demanding was caring for the children's general actions, such as walking, sleeping, exercising, etc.

The aforementioned review of literature concerning caregiving burdens has revealed that the level of caregiving demands or the amount of time used in caregiving achieves higher scores than the caregiving difficulties in the aspects of health,

response to personal demands, and the response to general essential demands. This information indicates that although the amount of time used in caregiving cannot be reduced, the perception of caregiving difficulties can be modified to a lower level. This depends on several factors related to the patients and their caregiving agents. The perception of caregiving as a demanding task has direct impacts on both the patients and the caregiving agents, as well as on the quality of care and family well-being.

Caring for autistic children who are dependent persons, induces the sense of difficulty to the mothers and they have to make a great effort to overcome all the difficulties. Nevertheless, when the mothers feel confident in performing caregiving activities, they will no longer perceive the task as a difficult burden. As a result, the mothers will care for their autistic children with improved well-being, leading to an increase in potential to help and respond to the demands of autistic children and to maintain good relations among other family members. Finally, the whole family will live their lives with a higher level of well-being.

Family well-being of mothers with autistic children

Orem (1991: 184) states that well-being is a feeling experienced by those who know their demands are satisfied. They are pleased and happy that they have achieved their ideal and have attained their individuality as mature persons. Well-being is a factor that affects individuals' goals in caring for themselves and their dependents. Hence, when mothers can respond to caregiving demands, for both themselves and their autistic children without perceiving the task as a burden, family well-being should be subsequently achieved.

In Orem's nursing theory, family is important, because as the patients' environment, it is the basic factor responsible in caring for patients and other family members. A family functions in response to the physical, psychological, emotional, and social demands of all members. If the balance between demands and ability to fulfill them is well maintained, the persons who can satisfy the demands are regarded as beneficial sources of the family. Family well-being can be achieved if caregiving agents did not perceive their task as a burden. This concept is consistent with Caldwell (1988), who points out that the family has a responsibility to generate and maintain the balance between demands and resources for all members (Caldwell,

1988: 396-422). These two concepts also view individuals and family as open systems. The well-being of family members, therefore, impacts on each other and also on the overall family-well being.

According to Caldwell (1998: 396-422), family well-being is a family phenomenon that is a continuum with family stress. It is the perception of family members towards family situations in three directions: 1) family structure, 2) family role process, and 3) vulnerability. Family structure induces the sense of unity among all family members. A family with a pleasant atmosphere encourages family members to express their ideas freely with rationales and clarity in communication and to participate in solving family problems that are accountable for family well-being. The evaluation of family well-being in this direction involves five components, comprising family stress, satisfaction, support, cohesion and adaptation. Family role process is another significant factor that may lead to well-being or stress in the family. Good role performance, little or no conflict, no ambiguity in the role, no sense of overload, full participation, and readiness for implementation among family members, all contribute to family well-being. Thus, family well-being is evaluated from role conflict, role ambiguity, role overload, role non-participation and role preparation. Finally, vulnerability is another component for the evaluation of family well-being. It can be assessed from psychosomatic symptoms and life satisfaction.

The relationships among caregiving burden and selected factors, (comprising mothers' level of education, family income, and the number of children and family well-being) in mothers of autistic children.

The review of related literature found that there have been a number of studies on the relationship between burden from caring for dependent persons and family well-being in various groups of the population. However, there was not a study on the relationship between caregiving burden and family well-being in families of autistic children. Thus, the following review of related literature covers the issues of caregiving for dependent persons with a chronic illness.

Goldstein et al. (1981: 24-30) studied the role of 25 caregivers, aged between 35 and 87 years, who were mostly related to patients with chronic disease as spouses, sisters, mothers, and sons, respectively. They found that the time and energy

spent for caregiving conflicted and could not be integrated with other roles. For example, a caregiver who had the roles of a wife, a housewife, or a part-time worker whilst caring for her husband, reported that she could not completely perform all the roles. She had to resign from her part-time work and to take on the roles of caregiver and housewife. Nevertheless, this respondent could not reduce her stress from playing both roles. Instead, she became more stressed from financial problems in the family. The majority of the sample admitted that caregiving was a substantial burden and it induced stress.

These results demonstrate that conflicts regarding time and energy consumption between caregiving and other roles are related to family well-being. This finding is consistent with a study conducted by Wallhagen (1992: 111 - 127), who examined difficulties in caregiving and the impacts on well-being of caregivers older than 60 years of age who delivered care to patients with a chronic illness. The study indicated the difficulty in answering to personal needs was a predictor of satisfaction and depression of the caregivers and the caregivers tended to have stress. Similarly, a study conducted by Bull (1990: 758 - 776) found that caregiving burden is a predictor of mental health status among caregivers. This finding is also consistent with the result of a study conducted by Sexton and Munro (1985: 83 -90), who investigated the impact on the life of female caregivers whose husbands had chronic illness. The study, revealed that the wives of the patients experienced more life impact than the wives of patients no illness. Similarly, a study conducted by Findies et al (1994: 6-11), also found caregiving burden were stressful. They examined the outcomes of caregiving from the primary family caregivers to patients using a mechanical ventilator at home in aspects of activities, burden, and impact. They found that the caregivers perceived the care demands concerning food preparation, medication administration, showering, wound dressing, and bronchial suctioning as moderate-level burden. The caregivers reported that physical care was not complicated but time-consuming, while the activities that were both complicated and time-consuming were the utilization of equipment and coordination with health professionals who delivered home service. As for the impact of caregiving, the caregivers clearly perceived the negative impacts, as they reported inadequate sleep, limited traveling, increased anxiety concerning

financial problems, decrease in free time, reduction in social activities, social isolation, tiredness, and concerns about health, emotions, and the future of the patients.

In Thailand, Chuanruedee Kaewbud (B.E. 2535: 39) studied the relationship between mothers' deficiency in taking care of seizure children and family well-being. She found that mothers' errors had a significantly negative correlation with family well-being ($r = -.36$, $p < .01$) and it could predict family well-being by 6.63% of variance. Mothers who made less errors in caring for the children had better family well-being.

Wipawan Chaoum (B.E. 2536: 57) conducted a study on caregiving burden and general well-being of family caregivers of the dependent elderly. She found that caregiving burden had a significant negative correlation with general well-being ($r = -.40$, $p < .001$), and it could predicting general well-being by 21% of variance, meaning that the caregivers perceiving more caregiving burden tended to have poorer well-being.

The present research examined some selected factors, comprising the mothers' educational background, family income, and number of children in the family. These factors should have an effect on and can predict family well-being in mothers of autistic children, as discussed in the details below.

Mothers' Level of Educational Period

According to Orem (1985: 175), education enhances individuals' abilities to seek knowledge and help from various sources and to understand about health and illness, thus leading to capacity for self-care and care for other dependent persons. Individuals with a higher education can comprehend obtained information and can apply their knowledge and skills to solve problems better than those with lower education.

As for the family well-being, Oberst et al. (1989: 209-215) studied the assessment of caregiving circumstances among members of families of patients receiving radiotherapy and found a negative correlation between the education of family caregivers and the assessment of caregiving as stress. This finding indicated that family caregivers with a low education level are more likely to assess the caregiving circumstance as stress or poor well-being. This finding is consistent with

the result of a study by Strauss and Monton (1985: 371-375), which revealed that parents with high education could cope with stress from the children's delayed development better than the parents with a lower education.

Wipawan Chaoum (B.E. 2536: 57) studied general well-being of relatives delivering care to the dependent elderly and found that the caregivers' education had a positive correlation with their general well-being and could predict general well-being. The study by Chuanruedee Kaewbud (B.E. 2535: 39) revealed similar finding, as it found a positive correlation between mothers' education and family well-being in the families of children with seizure symptoms, indicating that mothers who had a higher education level tended to have better well-being. Thus, it was assumed in the present study that mothers' educational background should have a positive correlation with family well-being in mothers of autistic children.

Family Income

Income enables mothers to seek resources for better care of their autistic children. It is a significant component contributing to individuals' potentiality for caring of dependents and for answering to individuals' basic needs. People with high income, therefore, have many resources that can help them to care for the dependent persons as needed. Income is also a significant variable in determining persons' satisfaction toward different lifestyles and in providing them with sufficient resources, leading to better family well-being (Orem, 1985: 122).

Oberst et al. (1989: 209-215) examined the correlation between family income and the assessment of caregiving circumstance of the family caregivers of patients receiving radiotherapy. They found that family income had a negative correlation with the assessment of caregiving circumstance as severe stress. Thus, the caregivers who had a low family income tended to assess caregiving circumstance as severe stress.

This was consistent with a study by Wipawan Chaoum (B.E.2536: 57), who examined the correlation between problems of medical expenses and general well-being and found that problems concerning medical expenses had a negative correlation with general well-being. This finding indicated that the families with low income tended to have more problems concerning medical expenses, leading to poorer

well-being of the caregivers. Therefore, it could be concluded that income has a positive correlation with family well-being because it could answer humans' basic needs. However, a study by Chuanruedee Kaewbud (B.E. 2535: 39) found no correlation between family income and family well-being. Thus, the relationship between these two variables is not ascertained.

Number of Children

According to Orem (1985: 221), the number of children is an indicator of family potential for caring for dependent children. Hass (1990 cited by Chuanruedee Kaewbud (B.E. 2535: 18) states that the number of children in a family is a variable that can predict mothers' potential. Nevertheless, studies by Autchareeya Patoomwan (B.E.2534: 50), regarding the number of children and the family well-being and a study by Chuanruedee Kaewbud (B.E. 2535: 40) did not find a correlation between these two variables. These results may be due to the characteristics of the families being studied, which were small families with a few children. These results showed that the correlation between the number of children and family well-being is not yet ascertained. However, mothers of several children who were highly experienced in caring for their children, developed additional skills and capability for taking care of their children (Orem, 2001: 372-379). Thus, the mothers who have many children may induce their families need for more caring demands. This situation can increase the burdens to the mothers who look after their autistic children increase. Therefore, the mothers have to play many roles and status and others in their families can create additional conflicts in their active role, which has an effect on family well-being.

In conclusion, there are several factors relating to the development of abilities in caring for dependent children. If mothers have insufficient capability in responding to the needs of dependent children, they may perceive the caregiving for autistic children as a substantial burden. Even though mothers can answer to the caregiving demands of their dependent autistic children with maternal love and bonding, they cannot help feeling bitter and frustrated, which may also have impact on the perceived caregiving burden. These feelings have a direct impact on mothers' performance of her maternal role and other family roles, thus threatening the well-being of the entire family, including extended family members.

CHAPTER III

MATERIALS AND METHODS

This descriptive research was designed to study the predictability of caregiving burden and selected factors, conducted to describe the relationship between selected factors (mothers' level of education, family income and number of children) and family well-being in mothers of children with autistic disorders.

Population and sampling

The population of this study were the mothers with autistic children whose children had been receiving and/or had received behavioral therapy at the autistic clinic and speech therapy clinic in the outpatient department of Sri Nakarin Hospital, Khon Kaen University, Ban Termtem Khon Kaen Province and the Special Educational Center, Zone 9 in Khon Kaen Province. The total population consisted of autistic children and their mothers who received medical treatment and follow up treatment at the autistic clinic outpatient's department of Sri Nakarin Hospital, Khon Kaen University Khon Kaen Province.

Purposive sampling was used. The inclusion criteria of the samples were mothers of autistic children.

They were primary caregivers of autistic children who had been providing care to autistic children for at least three months after being informed of the medical diagnosis.

1. They were able to read, write, speak, and understand Thai language.
2. They were willing to participate in this study

A sample size was calculated using, the Cohen and Cohen formula. Cohen and Cohen (1983: 116-132) proposed a formula for determining the sample size for a multiple regression analysis called the method of power analysis. The data in this study were initially collected from a total 120 cases, but thirteen of these cases did not

completely fill out the questionnaire. Therefore, the final sample size of this predictive study was 107 cases (Appendix A).

Research setting

The settings of this study consisted of four sites.

The first site was the autistic clinic of the outpatient department of Sri Nakarin Hospital, Khon Kaen University, Khon Kaen Province. The Autistic Clinic is a public service clinic where autistic children received medical treatment and follow up treatment including counseling for their caregiver, primarily the mother. The second site was the speech therapy clinic located at the outpatient department of Sri Nakarin Hospital, Khon Kaen University, Khon Kaen Province. The speech therapy clinic is also a public service clinic for speech training of autistic patients who have problems with voice and speech. The third site was Ban Termtem. Ban Termtem is a clinic providing services to train and adjust behavior for the delayed developmental child. The last site was the Special Educational Center, Zone 9 in Khon Kaen Province. The Special Educational Center, Zone 9, is a public service clinic which provides developmental stimulation to children with disabilities.

The visiting hours were from 08:00 a.m. to 04:00 p.m., Monday to Friday. The study was conducted between the months of May and September, 2003.

Instruments

Three questionnaires were used to elicit data for this study including, (1) the Demographic Data Form, (2) the Autistic Caregiving Burden Scale, and (3) the Family Well-Being Scale, each of which was elaborated on in the subsequent sections.

1. Demographic Data Form

This form was constructed by the researcher with the aim to collect information related to the characteristics of the autistic children and their mothers. It included information about 1) age, sex, mother's educational background of autistic children, normal school attendance, and the treatment/therapy received by autistic children; 2) age, educational background, family income, number of children, religion,

occupation, adequacy of income, assistance received in caring for autistic children, and number of other children with a chronic illness in the family.

2. The Autistic Caregiving Burden Scale

Caregiving demands are defined as the amount of time consumed and difficulty associated with autistic caregiving tasks perceived by the mother. The variable of caregiving demands was quantified by the Autistic Caregiving Burden Scale.

The Autistic Caregiving Burden Scale was translated and modified from The Care of my Child instrument (McCubbin, Oberst, & Smith, 1990) which had been modified from the Caregiving Burden Scale (Oberst, 1988).

This questionnaire was aimed at measuring the awareness of the caregiving burden of parents who took care of their children who suffered from congenital heart disease. Each question was divided into two parts: a) demand, which was assessed from the time spent in caring for the child in each activity; and b) difficulty, which was assessed from the difficulties in giving care in each activity.

The Care of my child (McCubbin, Oberst, & Smith, 1990) was modified from the Caregiving Burden scale (Oberst, 1988) into 17 items. In this study, The Autistic Caregiving Burden Scale was translated and modified from the Care of my Child instrument (McCubbin, Oberst, & Smith, 1990) from 17 items into 20 item instruments which were then divided into three parts:

- 1) direct care: Item 1,2,3,4,5,6,7,8 and 9
- 2) interpersonal care: Item 14,15,16 and 17
- 3) instrumental care: Item 10,11,12,13,18,19 and 20

Each item was further divided into two scales: the time scale and the difficulty scale.

The items were arranged in a five-point rating scale, ranging from little or none (1), to a great deal (5), in order to describe both amount of time and difficulty associated with each caregiving task. Scoring was done by adding points for each item within a scale (e.g., the time scale, the difficulty scale). The scores gained were calculated by multiplying the points from both parts and then squaring them. The scores from each part were then added to the derived scores. The scores ranged from

20 to 100. Higher scores indicate a greater time consuming and difficulty related to caregiving tasks. Also, the researcher separated the level of the caregiving burden score by class interval which were then divided into levels. The researcher set criteria for interpretation, calculated from mean score, are presented as follows:

<u>Mean score</u>	<u>Interpretation</u>
75-100	High caregiving burden
50-74.9	Moderate caregiving burden
25-49.9	Less caregiving burden

Validity and reliability of the Caregiving Burden Scale

In studying validity, Svavasdottir & McCubbin (1996) used the pattern of “The Care of My Child” to study parenthood transition for parents of an infant who was diagnosed with a congenital condition. The content validity was examined by nurses who specialized in the pediatric cardiology clinic and parents of an infant who suffered from a congenital heart condition. By doing that, the questions became more specific for parents of a child with congenital heart disease (CHD). In addition, Reliability, Svavasdottir & McCubbin used the pattern of “The Care of My Child” to test the internal consistence reliability. Cronbach’s alpha coefficient of time spent in giving care was equivalent to .80.

Wanida Sanasutipun (B.E. 2544: 25-26) used the same pattern to study the adjustment by parents of children with a congenital heart disease. The internal consistency reliability of the instrument was tested. Cronbach’s alpha coefficient was equivalent to .95.

In this study, the researcher tested content validity by four qualified experts: one nursing instructor who was an expert in looking after sick children, two nursing instructors who were experts in caring for autistic children and one nurse who was an expert in developing and taking care of autistic children. Then, the researcher revised the instrument for better clarification and language suitability as recommended by the experts. The researcher undertook the study by applying the pattern of the caregiving burden with 25 mothers who were similar to the subjects of the main study. Scores derived were used to calculate the reliability of the pattern. Cronbach’s alpha

coefficient was equivalent to .91. In the current study of 107 mothers, the Cronbach's alpha coefficient was equivalent to .92.

3. The Family Well-Being Assessment

The Family Well-being Assessment is an instrument designed to measure various aspects of family life on a continuum from well-being to stress by Caldwell (1983) and was used in an investigative study in 1983 (Caldwell, 1988). The questionnaire was translated into Thai by Bu-Hgar Phuchacram (B.E.2533) and used in an investigative study in B.E.2533.

The family well-being awareness questionnaire assessed the awareness of family well-being as perceived by the mothers. The questionnaire is comprised of three following parts:

1. Family structure of 16 items comprised:

Family Stress	3 items:	5, 14, and 25
Family Satisfaction	3 items:	6, 15, and 21
Family Support	6 items:	27, 29, 33, 35, 36, and 37
Family Cohesion	4 items:	12, 19, 23, and 38

2. Family role process of 16 items comprised:

Role Conflict	3 items:	1, 8, and 17
Role Overload	2 items:	3 and 10
Role Ambiguity	5 items:	2, 9, 18, 24, and 42
Role Nonparticipation	4 items:	4, 11, 39, and 41
Role Preparedness	2 items:	22 and 40

3. Vulnerability of 10 items comprised:

Psychosomatic Symptoms	6 items:	26, 28, 30, 31, 33, and 34
Life Satisfaction	4 items:	7, 13, 16, and 20

The entire set of questionnaires consisted of 42 items:

Positive items were 2, 4, 6, 7, 9, 11, 12, 13, 15, 18, 19, 21, 22, 23, 27, 29, 32, 35, 36, 37, 39, and 41.

Negative items were 1, 3, 5, 8, 10, 14, 16, 17, 20, 24, 25, 26, 28, 30, 31, 33, 34, 38, 40 and 42.

There are two sections in this questionnaire. Individual mothers rated each item of family well-being on a 6 point Likert scale, ranging from 1 to 6 (with 1 representing total disagreement, and 6 suggesting total agreement and 1 representing total, almost always and 6 suggesting total, almost never).

The scoring was divided into two sections:

The first section covered items 1 to 25 and featured comment-related scores. The statements were divided into positive and negative items.

Scoring criteria:

Statements with a positive meaning		Statements with a negative meaning
1	Strong agreement	6
2	Moderate agreement	5
3	Slight agreement	4
4	Slight disagreement	3
5	Moderate disagreement	2
6	Strong disagreement	1

The second section covered items 26 to 42. Points were given according to the frequency of the incidents. The questions were divided into positive and negative items.

Scoring criteria:

Statements with a positive meaning		Statements with a negative meaning
1	Almost always	6
2	Very often	5
3	Frequently	4
4	Occasionally	3
5	Not very often	2
6	Almost never	1

The total well being score obtained by the scores of the negative items had to be reversed first, and then the scores in all items were combined. The total possible score rang was 42 to 252. A low score indicated well-being or low stress. Also, the researcher separated level of the family well-being score by class interval which were then divided into levels. The researcher set criteria for interpretation, calculated from mean score, are presented as follows:

<u>Mean score</u>	<u>Interpretation</u>
182-252	Good family well-being
112-181.9	Moderate family well-being
42-111.9	Poor family well-being

Validity and Reliability of the Family Well-Being Assessment

The Family Well-Being Assessment was developed by Caldwell (1988). The Family Well-Being Assessment had to face validity, because the instrument was developed from a conceptual framework. Each of the items for the subscales was developed from the definition and was tested for content validity by two family research experts: Stickland from the university of Maryland and Cronenwett and the head of the medical research department of Dartmouth Hitchcock Medical Center. The Content Validity Index for each of the subscales ranged from 0.9 to 1. Construct Validity testing found that the instrument was able to separate high- stress persons from low-stress persons and high-stress families from low-stress families. Support for construct validity was further validated when data from families without a chronically ill child that had low stress, were compared to data from families with a chronically ill child. It showed a significant ($p < .01$) difference. In addition, Caldwell (1985) used the Family Well-Being Assessment to test a correlation matrix which supported the reliability of family well-being assessment. Caldwell (1985 cited in Caldwell, 1988) using the revised instrument and the data from the increased sample size of 185 parents. The results showed that Cronbach's alpha reliability of subscales of the Family Well-Being Assessment ranged from .55 to .80. The number of items per subscale varied from 3 to 8, so the subscales were considered worthwhile for stage instrument development. Overall instrument reliability was .90. Also, coefficient of

stability and recommended for determining the reliability of affective measures was administered to 11 families. It was found to be .88.

Bu-Hgar Phuchacram (B.E. 2533) translated the instrument into Thai and had the content validity examined by three experts who specialized in psychiatry, social psychology and nursing with specialization in mothers and children. After modification, the tool was used with ten mothers of children who had leukemia. Cronbach's alpha coefficient in terms was equivalent to .93. In a real trial with 60 mothers of children with leukemia, Cronbach's alpha coefficient was equivalent to .88.

For this study, the reliability of the questionnaire was tested with 25 subjects who shared similar characteristics with the subject of the main study. It was found that Cronbach's alpha coefficient of family structure, family role process, family vulnerability, and a family well-being awareness was equivalent to .85. In the current study of 107 mothers, the Cronbach's alpha coefficient of structure, role process, vulnerability, and a family well-being awareness was equivalent to .77.

Protection of Human Rights of the Subjects

This study was conducted with regard to the protection of human rights. More importantly, it was carried out after the approval of ethical clearance was granted from the Institution Review Board (IRB) of Sri Nakarin Hospital, Khon Kaen University. Eligible subjects were asked to participate in the study. The researcher explained the purposes of the study, the research procedures, benefits, and the duration of the study. The subjects who agreed to participate were informed and assured that the data would be kept strictly confidential and reported only as group data. In addition, they were also informed that they had the right to withdraw at any time without having to specify the reason and without causing any effect on the treatment and nursing care their children would receive.

Data Collection

Data was collected through the following procedures:

1. The permission letters were obtained from the Faculty of Graduate Studies, Mahidol University, and were sent to the Director of Sri Nakarin Hospital,

Khon Kaen University, the Manager of Ban Termtem and the Director of Special Educational Center, Zone 9 in Khon Kaen Province.

2. After obtaining the approval and permission from the Director of Sri Nakarin Hospital, Khon Kaen University, and the Institution Review Board (IRB) of Sri Nakarin Hospital, Khon Kaen University, the researcher contacted the head of the autistic clinic and the speech therapy clinic, at the outpatient's department of Sri Nakarin Hospital, Khon Kaen University, as well as the Manager of Ban Termtem and the Director of Special Educational Center, Zone 9 in Khon Kaen Province to introduce herself and explain the study procedures.

3. Subjects were then selected based on the inclusion criteria previously set by the trainer nurse of the autistic clinic and the trainer nurse of the speech therapy clinic, at the outpatient's department of Sri Nakarin Hospital, Khon Kaen University, as well as the trainer of Ban Termtem and the trainer of Special Educational Center, Zone 9 in Khon Kaen Province. Data was collected Monday to Friday from 08:00 a.m. to 04:00 p.m. Furthermore, prior to subjects answering the questions, the researcher set up an appropriate area for the subjects to feel at ease and in some instances questioning was conducted in conference room.

4. All eligible subjects were approached by the researcher prior to the start of the data collection process and the study objectives were explained along with expected outcomes, data collection processes and the subjects' right to participate in the study. The required consent form was signed by all subjects participating in the study. Data was collected while the participating subjects (mothers) were waiting for a doctor and/or a trainer. The completion of the questionnaires lasted approximately 15 to 20 minutes.

5. The researcher examined the questionnaires to ensure completeness.

Data Analysis

The computer package for Windows Program was used to analyze the data. The following statistics were applied:

1. Number, percentage, mean, and standard deviation were used to analyze the demographic characteristics of the mothers and autistic children.

2. Mean and standard deviation were used to analyze the overall and detailed aspect of caregiving burden of the mothers of autistic children and family well-being.

3. The relationships between the selected factors, namely, educational background, family income and care-giving burden, with family well-being of mothers with autistic children were examined by using Pearson's correlative coefficient.

4. Stepwise multiple regression analysis was carried out to predict family well-being of the mothers of autistic children.

CHAPTER IV

RESULTS

The objective of this study was to describe the predictability of caregiving burden and selected factors with family well-beings in mothers of children with autistic disorders. The results of this study are presented as follow:

Demographic Data of Mothers

The total number of samples in this study amounted to 107 mothers with autistic children. The autistic children who were part of this study were: A) Ninety-eight subjects from the autistic clinic and speech therapy clinic at the out-patient department of Sri Nakarin Hospital, Khon Kaen University; B) Six subjects from the Ban Termtem; and C) Three subjects from the Special Educational Center, Zone 9. Khon Kaen Province. Their demographic characteristics of the subjects in this study are presented in Table 1.

The mothers ages ranged from 20 to 47 years (mean = 36.05, SD = 5.46), with the largest group being between 20 and 40 years of age (80.4%). Their educational background ranged from 6 to 18 years of formal education, (mean =13.84, SD = 3.29). The lowest level of education was elementary education and the highest was a master's degree. More than half of the sample (50.5%) held a bachelors degree. In addition, 35.5% worked as government employees. Family incomes ranged from 2,000 to 100,000 Baht per month (mean 23,742, SD = 19,208). The majority of subjects had family incomes between 10,001 and 20,000 Baht per month (31.8%), had adequate income but did not have savings (67.3%). In caring for their autistic children, 10.3% of the mother subjects took care of their autistic children by themselves. 89.7% had an assistant with the main assistance being from their husbands (52.3%). Only one subject had a child with a chronic illness (0.9%). The subjects number of children in the family ranged from 1 to 3 (mean =1.80, SD = 0.71). Most of them had two children (46.7%).

Table 1: Demographic characteristics of the subjects: range, mean, standard deviation, frequency and percentage (n=107)

Mothers' Characteristics	Frequency	Percentage
Age (years)		
20-40	86	80.4
41-60	21	19.6
Range = 20-47, Mean = 36.05, S.D. = 5.46		
Level of Educational		
Elementary	10	9.3
Early secondary	7	6.5
High school	10	9.3
Vocational education	20	18.7
Diploma	2	1.9
Bachelor's degree	54	50.5
Master's degree	4	3.8
(years) Range = 6-18, Mean = 13.84, S.D. = 3.29		
Occupation		
Housewife or unemployed	32	29.9
Trader	17	15.9
Laborer	13	12.2
Government official / public enterprise employee	38	35.5
Private business	7	6.5
Family income (baht/month)		
< 6,001-10,000	31	29
10,001-20,000	34	31.8
20,001-30,000	27	25.2
30,001-40,000	4	3.7
> 40,000	11	10.3
Range = 2,000 –100,000, Mean = 23742.06, S.D. = 19208.52		

Table 1: Demographic characteristics of the subjects: range, mean, standard deviation, frequency and percentage (n=107) (Cont.)

Mothers' Characteristics	Frequency	Percentage
Adequacy of income		
Inadequate	15	14
Adequate without savings	72	67.3
Adequate with savings	20	18.7
Assistance in caring for autistic children		
No	11	10.3
Yes	96	89.7
Husband	56	52.3
Relative/sibling	43	40.2
Baby sitter	22	20.6
Daycare center	24	22.4
Nursery school	5	4.7
Other Special Educational Centers	29	27.1
Number of children in the family		
One	39	36.5
Two	50	46.7
Three	18	16.8
Range = 1 - 3, Mean = 1.80, S.D. = 0.71		
Other children with chronic illness		
No	106	99.1
Yes	1	0.9

Demographic Data of Autistic Children

The age of the autistic children ranged from 2 to 14 years old (mean = 6.25, SD = 2.815), with the largest group being between the ages of 4 and 6 years of age (41.1%). There were more males (85.0%) than females. In regards to the educational background of autistic children, they ranged from having no education to elementary education, with the majority of them (75.7%) being formally educated. Furthermore, more than half (52.3%) could attend school everyday. Therapy provided for the autistic children, most of them were given language and communicational motivation (81.3%) were shown in Table 2.

Table 2: Demographic characteristics of the autistic children: range, mean, standard deviation, frequency and percentage (n=107)

Autistic children's characteristics	Frequency	Percentage
Age (years)		
1-3	20	18.7
4-6	44	41.1
7-9	27	25.2
10-12	12	11.2
13-15	4	3.8
Range = 2 - 4, Mean = 6.25, S.D. = 2.815		
Gender		
Male	91	85.0
Female	16	15.0
Level of Educational		
None	26	24.3
Yes	81	75.7
Pre-nursery School	21	19.6
Nursery School	26	24.3
Elementary school	26	24.3
Other Special Educational Centers	8	7.5
Normal School Attendance		
Yes	56	52.3
No	51	47.7
Treatment/therapy for autistic children*		
Behavioral therapy	82	76.6
Language and communicational motivation	87	81.3
Activation of brain, muscles, and senses	56	52.3
Use of medicine and other substances	62	57.9
Nutrition-based therapy	20	18.7
Mental therapy	32	29.9

* more than one treatment

Caregiving Burden

The mean score of the caregiving burden was 60.98, ranging from 26.66 to 90.46 with a standard deviation of 11.77. The total time-consuming scores ranged from 26 to 95, with mean scores and standard deviation was 64.89 and 12.27, respectively. The total difficulty scores ranged from 28 to 91, with mean scores and standard deviation 59.47 and 14.14, respectively. These scores indicated that mothers with autistic children in the study had a moderate level of burden in giving care. When considering each subscale, the direct care subscale ranged from 13-45, with a mean of 28.31 and a standard deviation of 6.36. The interpersonal care subscale ranged from 9.24-30.88, with a mean of 20.58 and a standard deviation of 4.26. The instrumental care subscale ranged from 5-100, with a mean of 40.31 and a standard deviation of 18.31, as shown in Table 3. When considering the highest to the lowest items of each subscale in caregiving burden, the mean scores findings revealed that, on the instrumental care subscale, the highest caregiving task was additional task outside the home (mean = 3.13). The lowest caregiving task was structuring and planning activities for the child and family (mean = 2.90). In the direct care subscale, the highest caregiving task was helping with speech (mean = 3.76). The lowest caregiving task was toileting the child (mean = 2.90). In the interpersonal care subscale, the highest caregiving task was managing discipline and any behavior problems (mean = 3.37). The lowest caregiving task was providing emotional support for the spouse (mean = 2.63), as shown in, Table 7 appendix B.

Table 3: Range, mean, and standard deviation of the caregiving burden classified by overall and each subscale (n = 107)

Caregiving burden	Time-Consuming			Difficulty			Caregiving burden		
	Range	Mean	S.D.	Range	Mean	S.D.	Range	Mean	S.D.
Overall	26-95	64.89	12.27	28-91	59.47	14.14	26.66	60.98	11.77
							-		
							90.46		
Subscale									
Direct care	13-45	29.94	6.47	13-45	27.60	7.31	13-45	28.31	6.36
Interpersonal Care	8-33	21.91	4.61	11-32	20.21	5.22	9-30	20.58	4.26
Instrumental Care	5-20	13.04	3.18	4-20	11.66	3.49	5-100	40.31	18.31

Family Well-Being

The mean score for the family well-being variable was 158.21, ranging from 65 to 207 with a standard deviation of 19.67. This score indicated that mothers with autistic children in the study had a moderate level of well-being in their family. When considering each subscale, the highest to the lowest subscale of family well-being were the family structure scores, the role process scores and the vulnerability scores with mean scores of 65.01, 62.33 and 30.87, respectively, as shown in Table 4.

When considering the highest to the lowest items of each subscale in family well-being the mean scores findings revealed that, the family structure subscale, the highest item was family support (mean = 4.59), and the lowest was family stress (mean = 2.60). In the role process subscale, the highest was non-participatory (mean = 4.14), and the lowest was role conflict (mean = 3.14). The vulnerability subscale, the highest item was Problems of body and mind relationships (mean = 3.12), and the lowest was role conflict (mean = 2.27). As shown in Table 9, Appendix B.

Table 4. Range, mean, and standard deviation of family well-being classified by overall and each subscale (n = 107)

Family Well-Being	Range	Mean	S.D.
Overall	65-207	158.21	19.67
Subscale			
Family structure	23-86	65.01	10.94
Role Process	21-81	62.33	9.44
Vulnerability	16-49	30.87	7.12

The relationships of the studied variables

The relationship among caregiving burden and selected factors with family well-being was computed by using Pearson's product moment correlation as shown in Table 5. The findings indicated that caregiving burden has a significant negative correlation with family well being ($r = -.29, p < .01$). This indicated that mothers of autistic children perceive that an outcome of the high burden of caring for autistic children is low family well-being. The mothers' level of education was significant positively correlated with family well-being ($r = .27, p < .01$). Therefore it suggests that mothers of children with autistic disorder who had obtained a higher education would have increased good family well-being as compared to mothers who were lower educated. However, there was no significant relationship between family income ($r = .11, p > .05$) and number of children ($r = .07, p > .05$) in relationship to family well-being.

Table 5: Pearson's product moment correlation of the studied variables with family well-being (n = 107)

Variables	X1	X2	X3	X4	X5
1. Mothers' educational period	1.00				
2. Family income	.11	1.00			
3. Number of children	.07	.14	1.00		
4. Caregiving burden	-.24*	-.002	-.003	1.00	
5. Family well-being	0.27**	-0.01	0.06	-0.29**	1.00

**p < .01, *p < .05

Hypothesis: Caregiving burden and selected factors (mothers' level of education, family income and the number of children) can predict family well-being of the mothers with autistic children.

Stepwise multiple regression analysis was used to identify the predictability of caregiving burden and selected factors with family well-being in mothers of autistic children, as shown in Table 6. There were two independent variables being caregiving burden and mothers' level of education that entered into the regression equation. Two variables together could explain 12.7 percent of variance in family well-being (Overall, $F_{(2, 104)} = 7.56, p < .01$). The first variable was caregiving burden which could explain 8.4 percent of variance in family well-being with statistical significance ($\beta = .24, t = 2.53, p < .05$). The second variable was the mother's educational period, which could explain 4.2 percent of variance in family well-being with statistical significance ($\beta = .21, t = 2.25, p < .05$). As shown in Table 6.

Thus this hypothesis was partially supported.

Table 6: Stepwise multiple regression for predicting family well-being (n = 107)

Variables	R ²	R ² Change	F Change	β	t	p
Caregiving burden	.084	.084	9.68	.24	2.53	< .05
Mothers' educational period	.127	.042	5.06	.21	2.25	< .05

(Overall $F_{(2,104)} = 7.56, p < .01$)

CHAPTER V

DISCUSSION

The discussion of the results associated with the research questionnaire and the hypothesis testing is presented in this chapter. This is followed by a discussion of the demographic characteristics of the subjects, caregiving burden and selected factors of family well-being. The relationships among studied variables and the research hypothesis testing that demonstrated the predictability of the studied variable family well-being in mothers of children with autistic disorders are also discussed.

Demographic characteristics of the subjects

The findings of the present study revealed that the mean age of the mothers was 36.05 years, with more than three-quarters (80.4%) ranging in ages from 20 to 40 years old. More than half of the sample (50.5%) held a bachelors degree. In addition, 35.5% worked as government employees. The family income of the majority of subjects was between 10,001 and 20,000 Baht per month (31.8%) this was considered an adequate income but without savings (67.3%). In addition, the majority of the subjects (89.7%) had an assistant for caring of autistic children who was primarily their husbands (52.3%). The number of children in the family ranged from 1 to 3 children and the majority of the mothers had two children (46.7%.) There was only one subject who had a child with a chronic illness (0.9 %.)

The ages of the autistic children ranged from 2 to 14 years of age, with an average age of 6.25 years. The largest group (41.1%) were aged between 4 and 6 years. The majority of them (85.0%) were boys. The majority of the autistic children (75.7%) had a formal education. Furthermore, more than half (52.3%) could attend school on a daily basis and the majority of them (81.3%) received language treatment along with communicational motivation.

Caregiving burden

The results showed that the mean caregiving burden score for the sample was 60.98 (S.D. =11.77) This finding indicated that these mothers of autistic children had a moderate degree of caregiving burden. This may be due to the majority of subjects assessing time consuming (mean= 64.89, S.D.= 12.27) and difficulty (mean= 59.47, S.D.= 14.14) in caring for autistic children as moderate. There results are higher than that of previous studies (Chuanruedee Kaewbud, B.E.2535: 29; Rosalin Eamyngpanich, B.E.2539: 41; Jariya Wittayasuporn, B.E.2539: 94 and Orathai Thongpetch, B.E. 2545: 37), which may be because that different studies used different assessment techniques and instruments.

The moderate caregiving burden might be due to many factors of mothers and factors of autistic children. In this study, the majority of the subjects were in their early adulthood (20 to 40 years of age.) This is generally the period when they have undergone some life experiences and so they are able to make their own decisions when confronting problems. They also have more skills to take care of themselves and their family members. Consequently, the more maturity the mothers have, the better they are able to adapt and develop appropriate capabilities to take care of their children. Orem (1985: 226) has proposed that age is a basic factor which can influence the ability to take care of one self and others. Additionally, a study of Autchareeya Patoomwan (B.E. 2534) found that the older caregivers of children with acute lymphoblastic leukemia could take better care of the children, which was in congruence with the dependent care concept of Orem (1980). This concept stated that patients require family members' assistance and family members have to satisfactorily accept and develop caregiving ability for patients (Orem, 1980) Moreover, the bond between mothers and children can influence mothers to take care of their behaviorally ill children with love, affection and patience, and they can accept the difficulties in taking them to receive therapy. In this study, 52.3% of the subjects had their husbands and relatives as the persons they trusted. Family generally plays a crucial role in providing mental support to mothers and other family members (Ruja Phuphaibul, B.E. 2541). As a result, mothers had satisfaction and motivation, which is one of the ten power components in caring for their children (Somchit Hanucharunkul, B.E. 2536: 34).

In addition to this, the many of the subjects held a bachelor's degree and they were government officials who earned regular incomes. Thus, they were able to pay for the therapy expenses and they could also ask for reimbursement from the government. As a result, the subjects reported that they did not have any financial problems. The present study showed even though the subjects had one to three children in their family, they still had sufficient time to take care of their autistic child without having to quit their job. They were able to continuously take them to receive their therapy. Likewise, Rosalin Eamyngpanich (B.E. 2539: 54) found that caregiving burden of mothers with mentally retarded children who had a small number of children did not spend too much time taking care of their normal children and they were able to fully take care of their children with mental retardation.

Furthermore, the present study showed that the majority of autistic children (75.7%) were being formally educated and more than half (52.3%) could attend school everyday. Their mothers had an increase in short periods of free time for relaxation from caring for autistic children. Therefore, they could spend time for their daily living and self-care for themselves and the extended family. Autistic children have behavioral and intellectual disorders which are difficult and time-consuming to treat. This result reported that most of them were given language and communicational motivation (81.3%). Additionally, it takes a long time for them to learn how to perform daily living activities which is a major factor indicating the self-care abilities of autistic children. Therefore, perceived caregiving burden may reflect this limitation of autistic children. Hence, mothers perceive the time as moderate consumption related to the difficulties of caregiving burden when caring for their autistic children.

When considering each subscale of caregiving burden in regards to instrumental care, the mothers who had the highest caregiving burden score had additional tasks outside the home such as receiving treatment, follow up treatment, and behavior therapy (Table 7, appendix B.) Upon interviewing the mothers, one possible explanation is that the majority of mothers spent too much time traveling because the hospitals and places providing services which were very far from their homes. In terms of direct care, the highest helping therapies to the mothers was in the area of speech. Speech training of autistic children is difficult and time-consuming to treat. It consumes a lot of time for caregivers to continuously transport their child to speech

therapy sessions. As for interpersonal care, the highest degree of perceived problems for mothers was managing discipline and other behavioral problems such as disciplining autistic children, when they exhibited aggressive behavior, own self harm damage or harm to others (Table 7, appendix B). One possible explanation is that behavioral modification required parents to spend a lot of time and energy getting the necessary help for this issue and lacked experience for helping their children because they were unable to control the aggressive behavior by themselves.

When considering activities of time-consumption, difficulty and caregiving burden, the data suggests that mothers perceived as highly burdensome these assisting their autistic child with their speech, assisting their autistic child with their social interaction and managing the discipline of their autistic child and other behavioral related problems related to aggressive and self-harm behavior (Table 8 appendix B).

As autistic children have severe impairment in development regarding social interaction, speech, language, communication, imitation, imagination, sensory perception, coordination of organs, as well as other behavioral and emotional impairments (agitation, inertness, and indifference to pain), mothers have to dedicate a lot of time and endure difficulties in managing these behavioral problems. In this study, it was found that although taking care of autistic children was very difficult and time-consuming most mothers had their husbands and other relatives as their support system. Additionally, sufficient family income and a small number of children also helped decrease the stress levels of these mothers. Thus, these factors were assumed to have an important influence on overall perceived caregiving burden of mothers of autistic children.

Family well-Being

The results show that the mean score of family well-being of the mothers was 158.21 (S.D. = 19.67) These scores indicate that mothers with autistic children in the study had a moderate level of family well-being. This result is contrary with the previous studies such of Bu-Hgar Phuchacram (B.E. 2533: 41), who studied 60 mothers of lymphoblastic leukemia children, Chuanruedee Kaewbud (B.E. 2535: 38), who studied 80 mothers of children who suffered from seizures, and Rosalin

Eamyngpanich (B.E. 2539: 50) who investigated 100 mothers of mentally retarded children. These studies found that the mean score of family well-being was higher.

It could be argued that autistic children in these families that affected the stress levels that subsequently had an adverse effect on the family member's adaptation in their roles to bring balance to the family as a whole. Moreover, the mothers and family members had additional burdens in taking care and protecting the autistic family member, plus the financial burden for treatment and therapy. These situations consequently resulted in a higher level of stress in the family unit and impacted their maintenance and self-care in everyone's daily life and routine. However, mothers who had high stress levels in the caring of their autistic children but had physical and emotional support from family members, perceived a moderate level of family well-being as compared to mothers who didn't have a support system in place.

In considering each subscale of family well-being, it was found that the families' well-being regarding family structure rated the highest, followed by family roles, process and vulnerability, respectively.

In regards to family structure, the subjects who had the highest family well-being were the ones who had a strong family support system. (Table 9, Appendix B). This finding was consistent with those of previous research such as Bu-Hgar Phuchacram (B.E. 2533: 41), Chuanruedee Kaewbud (B.E. 2535: 38), Rosalin Eamyngpanich (B.E. 2539: 50) and Caldwell (1988). Most of the mothers had their husbands and relatives to help take care of autistic children and give each other spiritual, emotional, physical support and encouragement. Thus, the data from this study infers that the family becomes a primary and critical source of social support, which enables mothers to continue their different roles and lessens the stress levels in their ability to accomplish their daily tasks.

In terms of family roles and processes, the mothers who had the highest family well-being scores were in the non-participatory roles (Table 9, Appendix B). One possible explanation is that good family relationships result in less family stress. As a result, mothers perceived their importance and had motivation to proceed with their roles and responsibilities.

In the area of vulnerability, many mothers who had low perceived family well-being scores in the area of problems of body and mind relationships (Table 9, Appendix B.) This may have resulted from the time and difficulties mothers endured in caring for their autistic children. In addition, there were additional responsibilities that mothers had to accomplish, including housework and taking care of other family members. Thus, these could lead to stress and subsequent illness due to lack of rest and appropriate self-care.

The relationships among the studied variables

In this study, caregiving burden had a significant negative correlation with family well being in mothers of autistic children ($r = -.29, p < .01$). This indicates that mothers of autistic children feel that the by-product of the high burden of caring for autistic children would produce low family well-being. Similarly, Chuanruedee Kaewbud (B.E. 2535: 39) reported that there was a significant negative correlation between mothers' deficiencies in taking care of children who suffered from seizures and family well-being ($r = -.36, p < .01$.) This is contrary with Rosalin Eamyngpanich (B.E. 2539: 51) whose study of mentally retarded children found that there was not a significant negative correlation between mother's caregiving burden and family well-being. Autistic children require a higher level dependence and care than those of mentally retarded children. Mothers have to continuously satisfy autistic children needs, which involves both time and energy. The limitations of autistic children indicates that the mothers have to endure difficulties in performing their caregiving duties while also having to care for other members of the family, thus increasing her level of stress. Subsequently, the additional stress translates into a decrease in family well-being. For this reason, caregiving burden was found to be negatively correlated with family well-being in mothers of autistic children.

When considering the relationships among the selected factors of mothers' educational background, family income, number of children and the families' well-being of mothers of autistic children, the following result were found.

Mothers' educational period. The findings indicated that there was a significant positive relationship between mothers' level of education and family well-being in mothers of autistic children ($r = .27, p < .01$). This revealed that educated

mothers had a higher level of family well-being. This finding is supported by Orem's theory (1985).

According to Orem (1985), education can promote individuals' ability to seek out knowledge and resources which can lead to a higher level of capabilities when caring for dependent persons. Therefore, higher level educated persons can solve the problems they confront by using their knowledge and skills in better ways than those with a lower level of education. Oberst et al. (1989: 209-215) studied the caring situation assessment of family members in radiotherapy patients' families and discovered that there was a negative correlation between educational level of family members who served as caregivers and stressful caring situations which indicated lower levels of family well-being. The report was in agreement with the results of a study conducted by Strauss & Monton (1985: 371-375) which found that higher educated parents of delayed developmental children could confront stress better than those with lower levels of education. Furthermore, Chuanruedee Kaewbud (B.E. 2535: 39) also found a positive relationship between mothers' education and family well-being of families with seizure-patients. Consequently, these findings led to a conclusion that the more educated the mothers were the higher the families' well-being levels would be. As a consequence, it is assumed that education may play an important role as a resource by which individuals can strengthen their families. This favorably affects the problem-solving process of the families and brings about adaptation of both mothers and their families (McCubbin et al., 1987: 14-25). Thus, in conclusion, the more highly educated mothers have a higher family well-being.

Family income. There was no significant correlation between family income and family well-being of mothers of autistic children. These findings supported the findings of a previous study by Chuanruedee Kaewbud, (B.E.2535: 39) which found no correlation between family income and family well-being. This is contrary with Rosalin Eamyngpanich (B.E. 2539: 53) who found that there was a significant positive correlation between family income and family well-being ($r = .24$, $p < .05$). It may be that the subjects in the present study had adequate of income which was sufficient to cover their living expenses and so there was no statistical significant correlation between these variables.

Number of children. The number of children was also not significantly correlated with family well-being of mothers with autistic children. Furthermore, the number of children could not describe the variability of family well-being. This finding was in agreement with previous studies by Chuanruedee Kaewbud (B.E. 2535: 39) and Rosalin Eamyngpanich (B.E. 2539: 53), which reported that the number of children was not correlated with family well-being. It is perhaps due to the fact that most subjects who had a small number of children in the household were rather homogenous.

The Predictability of studied Variables on Family Well-Being

Stepwise multiple regressions was used to analyze the predictability of independent variables on family well-being. The findings indicated that there were two variables which could predict family well-being. These predictors were caregiving burden and mothers' educational period. The combination of the predictors significantly accounted for 12.7 percent of variance in family well-being (Table 6). In addition, it was found that the first variable was caregiving burden which could explain 8.4 percent of variance in family well-being with statistical significance ($\beta = .24$, $t = 2.53$, $p < .05$). When considered at its coefficient value, the Pearson correlation value between caregiving burden and family well being was negative ($r = -.29$, $p < .01$), as shown in Table 5. The results showed that caregiving burden directly influences the families well being. Similarly, Chuanruedee Kaewbud (B.E. 2535: 39) reported that there was a significant negative correlation between mothers' deficiencies in taking care of children who suffered from seizures and family well-being. Therefore, family well-being could be predicted. This is contrary with Rosalin Eamyngpanich (B.E. 2539: 51) whose study of mentally retarded children found that there was not a significant negative correlation between mother's caregiving burden and family well-being and predict family well-being could not be predicted. The degree of caregiving burden depends upon the perceived burden of mothers in caring for their autistic children. Therefore, impact is particularly strong for mothers and families of autistic children that require long term treatment. It effects on time management, work responsibilities, social tasks, free time, self-care and the personal life of mothers (Hoyert & Seltzer, 1992: 74- 81). However, the mothers have to give

care and respond to the autistic children's demands, while at the same time the mothers have to maintain other roles within the family unit. Hence, the mothers can not respond to all her autistic children's demands and cannot play her other roles in family. For this reason, mothers had perceived burden and higher stress levels when caring for their autistic children. Subsequently, this resulted in higher levels of stress on her family and resulted in decreased family well-being. Thus, caregiving burden could significant predict levels of family well-being.

The mothers' level of education was the second variable that entered into the regression equation and accounted for 8.4 percent of variance in family well-being ($\beta = .24$, $t = 2.53$, $p < .05$). It indicated that there was a significant positive relationship between mothers' educational period and family well-being ($r = .27$, $p < .01$). Similarly, Chuanruedee Kaewbud (B.E. 2535: 39) reported that there was a significant positive correlation between mothers' education and family well-being and also could predict family well-being This is contrary with Rosalin Eamyngpanich (B.E. 2539: 51) whose study of mentally retarded children found that there was not a significant correlation between mothers' education and family well-being and could not predict family well-being could not be predicted. The mothers' level of education was the last predictor influencing family well-being in this study. Mothers of autistic children who had a greater education level were more likely to show higher levels of family well-being. It revealed that mothers' education was directly associated with family well-being. It might be explained that the education helps in the development of skill, knowledge and attitudes concerning the caring for dependants, and also helps individuals in solving problem in a reasonable way. This includes the association on experience that generates the necessary learning to act and perform with care and exhibit discretion (Orem, 2001: 167). Therefore, mothers who have a higher level of education are better equipped to apply their knowledge and tend to be more capable of adjusting the burdens in caring for autistic children and view it as a part of their daily life. they also experience decreased stress levels when caring for their autistic children. Thus, mothers' level of education could statistically predict significant family well-being.

In this study, other variables that were not indicators of family well-being were the family income and the number of children. Family income didn't indicate a

significant correlation in relationship to the families well-being and could not be a predictor influencing family well-being. These findings supported the findings of a previous study by Chuanruedee Kaewbud, (B.E.2535: 39) which found no correlation between family income and family well-being and family income could not predict family well-being. This is contrary with Rosalin Eamyngpanich (B.E. 2539: 53), who found that there was a significant positive correlation between family income and family well-being and income also could predict family well-being. It might be explained that the mothers of autistic children in this study had adequate family balance and income to handle expenses. Many were government employees who could get medical expenses reimbursed. As such, mothers of autistic children had reduced stress levels, resulting in a lesser perceived burden on the families' income.

The number of children in the family it could not be a predictor of family well-being. and had no effect on family well-being. This finding corresponds with studies by Chuanruedee Kaewbud (B.E. 2535: 39) and Rosalin Eamyngpanich (B.E. 2539: 53), which reported that the number of children was not correlated with family well-being and could not predict family well-being. The participants in this study reported that they had only a few children in their family which may explore the result in this current study. Subsequently it was easier for mothers to take care of their autistic children and other family members.

In summary, the two primary factors highlighted in this study were caregiving burden and the mothers' level of education which infers that they are the major predictors of the families' well-being in mothers of autistic children. The combinations of these factors accounted for 12.7 percent of variance in family well-being (Overall, $F_{(2, 104)} = 7.56, p < .01$).

Research Limitations

Some limitations of the present study were identified in the following areas:

1. The subjects were recruited by means of purposive sampling at the outpatient department of Sri Namarin Hospital of Khon Kaen University, Ban Termtem, and the Special Educational Center, Zone 9 in Khon Kaen Province. The

sample was less than the calculated sample size. Thus, the results of the study could not be generalized to other groups of the population.

2. During data collection, 92 % of the data was collected in a conference room. The researcher was unable to offer explanations and clarifications to the subjects who might have had trouble understanding the questionnaires. This might have affected the final outcomes of this study.

3. Some subjects might have been disturbed and or distracted by their autistic children while responding to the questionnaire. Again, this might have had an adverse affect on the final outcome of this study.

CHAPTER VI

CONCLUSION

In this chapter, the conclusion and recommendations are presented in terms of involving implications for nursing practice, nursing education, and nursing research.

Conclusion

This descriptive research was designed to examine the relationships and predict the caregiving burden, selected factors (mother's educational background, family income and the number of children) with family well-being in mothers of autistic children. The research framework was based on the concept of dependent care derived from Orem's theory (1989) of self-care, which focuses on dependent care agencies. In addition, the concept of family well-being proposed by Caldwell (1988) was also selected as part of the conceptual framework of the study.

The total number of subjects in this study was 107 mothers of autistic children, who had received treatment or were receiving treatment and behavioral therapy at the autistic clinic, speech therapy clinic at the outpatient department of Sri Nakin Hospital, Khon Kaen University, Ban Termtem, and the Special Educational Center, Zone 9 in Khon Kaen Province, Thailand. Data was collected from May to September 2003 and the subjects were selected by purposive sampling. The inclusion criteria was that the subjects had been principle caregivers of autistic children for at least three months after being informed of the medical diagnosis; they had the ability to read, write, and speak Thai and could answer the questionnaires; and that they agreed to participate in this study. The researcher collected data in respect to individual human rights and using a three-part questionnaire which included the Demographic Data Form, the Autistic Caregiving Burden Scale (ACBS), and the Family Well-being Assessment (FWA). The reliability of ACBS and FWA were analyzed by using Cronbach's alpha coefficient, and the overall value of the coefficient was 0.92 and 0.77, respectively, for all subjects (n = 107). Data were

analyzed using the Statistical Package for Social Science for Windows Program (SPSS/ FW) version 10.0.

The result of the study can be summarized follows:

The researcher collected data from 107 mothers of autistic children. Most of the subjects (80.4 %) were 20 to 40 years of age. More than half of the mothers (50.5%) held a bachelors degree. The majority of mothers (31.8%) had family incomes between 10,001 and 20,000 Baht per month and adequate incomes but without savings (67.3%). The average number of children in the family was two (46.7%).

The mean score of the overall caregiving burden as perceived by mothers of autistic children was at a moderate level (mean = 60.98, S.D. = 11.77). Family well-being of mothers of autistic children was moderate (mean = 158.21, S.D. = 19.67).

Stepwise multiple regression indicates that there are only two significant variables, caregiving burden and mothers' educational background, which together accounted for 12.7 percent of variance in family well-being (Overall, $F_{(2, 104)} = 7.56$, $p < .01$).

Implication and Recommendation

The finding of this study indicated that caregiving burden and mothers' educational background could explain the variance of family well-being scores in mothers of autistic children. This provides several important implications for the nursing profession, nursing education, and future research.

Nursing Practice

The results of this study could be used as a guideline for the development and promoting nursing care for mothers and autistic children as follows:

1. Increasing numbers of nurses should be trained for taking care of autistic children. Nurses lacking said skills should be further educated and develop additional trained for taking care of autistic children. Increasing the number of trained nurses and helping to provide them with information and training skills for taking care of autistic children will also assist them in their ability to provide consultation for mothers and caregivers.

2. Promoting and providing continuing group support as an exchange of knowledge and techniques to solve behavior problem of autistic children for mothers and caregiver.

3. Encouraging family members to share in taking care of autistic children and household work with mothers. This would increase healthy relationships with all family members and also decrease stress and burden levels of the mother.

4. Nurses should provide advice about various resources closer to the family's home thereby decreasing transportation time. These resources should be highly beneficial and relevant to the demands and problems of mothers and children in uncertain situations.

5. Nurses should provide special services to families of autistic children by providing home visits and giving help to the mothers and their autistic children with consideration of personal factors that affect perceived caregiving burdens. The services should be relevant to the demands and problems of mothers and children so that the mothers can deliver appropriate care to autistic children.

Nursing Education

1. Nursing students should be taught to acknowledge the importance of family, taught to promote family relationships, and taught to encourage family members to develop their potential and abilities in caring for dependent children efficiently and effectively. In making a plan to help mothers who have to spend a lot of time and endure considerable difficulties in caring for autistic children, nurses need to take into account basic factors and resources that can help reduce the burden and enhance family well-being of the mothers and caregivers.

2. There should be training courses for nurses and other professionals working with autistic children in order to enhance their ability to teach and to develop the potentiality of mothers and caregivers of autistic children. Moreover, the general public should receive knowledge and information about autistic children so that they will have better understanding about autism and give autistic children more opportunities to develop in various aspects of their lives.

Nursing Research

1. A further study with difficult samples should be undertaken that comparative data can be obtained on parents who care for autistic children.

2. It was also found in this study that some of the subject were being disturbed when attempting to answer questionnaires by their autistic children. Therefore, in further research, the research should be let to allow the subject to take questionnaires and fill them out at their home. This may decrease the possibility of being disturbed by their children during the answering of the questionnaire.

3. Further research should increase the number of subjects and caregiving burdens should be studied in various institutions throughout the country.

4. Future research should also be concerned with other basic conditioning factors which can assist in predicting caregiving burden and family well-being in mother of autistic children.

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APPENDIX

APPENDIX A

Calculation of sample size

A sample size was calculated using Cohen and Cohen formula. Cohen and Cohen (1983: 116-132) propose a formula for determining the sample size for a multiple regression analysis called the method of power analysis. The formula was as follow:

$$N = \frac{L + k + 1}{f^2}$$
$$N = \frac{11.94 + 4 + 1}{.11} = 113$$

when N = total sample size
L = effect size index
k = number of independent variables
 f^2 = the population effect size

For this study, the smallest sample size was 113, [power = 0.80; small effect size = .01 and α = .05], which was determined to be adequate to statistically discriminate significant differences among the independent variables. The data were initially collected from a total 120 cases, but thirteen of these cases did not completely fill out the questionnaire. Therefore, the final sample size of this predictive study was 107.

APPENDIX B

Table 7. The highest to lowest mean score of Caregiving burden classified by each subscale and each items (n = 107)

Caregiving burden	Time-Consuming			Difficulty			Caregiving burden		
	Range	Mean	S.D.	Range	Mean	S.D.	Range	Mean	S.D.
Instrumental Care	1.25 - 5	3.26	0.80	1-5	2.92	0.87	1.10-5	3.02	0.75
16 Additional task outside the home	1-5	3.40	1.12	1-5	2.99	1.14	1-5	3.13	1.00
14 Managing finance, bills, and forms related to a child condition	1-5	3.27	1.14	1-5	3.01	1.18	1-5	3.08	1.06
15 Additional household tasks beyond the usual responsibilities	1-5	3.21	1.09	1-5	2.87	1.00	1-5	2.99	0.91
17 Structuring and planning activities for the child and family	1-5	3.16	1.06	1-5	2.79	1.06	1-5	2.90	0.89
Direct care	1.44-5	3.33	0.72	1.44-5	3.07	0.81	1.44-5	3.15	0.71
6 Helping to speech	1-5	3.90	1.04	1-5	3.71	1.21	1-5	3.76	1.05
7 Helping to social interaction	1-5	3.72	1.04	1-5	3.47	1.18	1-5	3.55	1.04
9 Teaching how to play	1-5	3.37	1.02	1-5	2.81	1.20	1-5	3.29	0.93
8 Helping to Practicing concentration	1-5	3.28	1.11	1-5	3.17	1.12	1-5	3.18	1.03

Table 7. The highest to lowest mean score of Caregiving burden classified by each subscale and each items (n = 107) (Cont.)

Caregiving burden	Time-Consuming				Difficulty				Caregiving burden			
	Range	Mean	S.D.	Range	Mean	S.D.	Range	Mean	S.D.	Range	Mean	S.D.
2 Bathing and dressing the child	1-5	3.40	1.01	1-5	2.86	1.12	1-5	2.86	1.12	1-5	3.07	0.95
4 Feeding the child	1-5	3.12	1.21	1-5	2.84	1.29	1-5	2.84	1.29	1-5	2.94	1.17
1 Medical and nursing treatments	1-5	3.05	1.06	1-5	2.87	1.16	1-5	2.87	1.16	1-5	2.89	0.94
5 Helping to movement of body and sensory	1-5	3.03	1.19	1-5	2.57	1.24	1-5	2.57	1.24	1-5	2.73	1.09
3 Toileting the child	1-5	3.07	1.23	1-5	2.81	1.20	1-5	2.81	1.20	1-5	2.90	1.13
Interpersonal care	1.14-4.71	3.13	0.66	1.57-4.57	2.89	0.75	1.32-4.41	2.89	0.75	1.32-4.41	2.94	0.61
18 Managing discipline and any behavior problems	1-5	3.51	1.01	1-5	3.31	1.21	1-5	3.31	1.21	1-5	3.37	1.03
10 Providing emotional support for the child	1-5	3.44	1.12	1-5	3.07	1.21	1-5	3.07	1.21	1-5	3.18	1.02
20 Coordinating arranging and managing and services resources	1-5	3.06	1.12	1-5	2.97	1.05	1-5	2.97	1.05	1-5	2.93	0.90
13 Observing and reporting symptoms and progress	1-5	3.16	1.03	1-5	2.78	0.90	1-5	2.78	0.90	1-5	2.90	0.78
11 Providing emotional support for any other children in the family	1-5	3.06	1.25	1-5	2.71	1.21	1-5	2.71	1.21	1-5	2.83	1.12

Table 7. The highest to lowest mean score of Caregiving burden classified by each subscale and each items (n = 107) (Cont.)

Caregiving burden	Time-Consuming			Difficulty			Caregiving burden		
	Range	Mean	S.D.	Range	Mean	S.D.	Range	Mean	S.D.
19 Obtaining child care and babysitting help or respite care	1-5	2.86	1.35	1-5	2.79	1.30	1-5	2.73	1.12
12 Providing emotional support for the spouse	1-5	2.82	1.18	1-5	2.58	1.17	1-5	2.63	1.01

Table 8. Range, mean, and standard deviation of the caregiving burden classified by overall and each items (n = 107)

	Time			Difficulty			Caregiving burden		
	Range	Mean	S.D.	Range	Mean	S.D.	Range	Mean	S.D.
Overall	26-95	64.89	12.27	28-91	59.47	14.14	26.66-94	60.98	11.77
1 Medical and nursing treatments	1-5	3.05	1.06	1-5	2.87	1.16	1-5	2.89	0.94
2 Bathing and dressing the child	1-5	3.40	1.01	1-5	2.86	1.12	1-5	3.07	0.95
3 Toileting the child	1-5	3.07	1.23	1-5	2.81	1.20	1-5	2.90	1.13
4 Feeding the child	1-5	3.12	1.21	1-5	2.84	1.29	1-5	2.94	1.17
5 Helping to movement of body and sensory	1-5	3.03	1.19	1-5	2.57	1.24	1-5	2.73	1.09
6 Helping to speech	1-5	3.90	1.04	1-5	3.71	1.21	1-5	3.76	1.05
7 Helping to social interaction	1-5	3.72	1.04	1-5	3.47	1.18	1-5	3.55	1.04
8 Helping to Practicing concentration	1-5	3.28	1.11	1-5	3.17	1.12	1-5	3.18	1.03
9 Teaching how to play	1-5	3.37	1.02	1-5	3.30	1.05	1-5	3.29	0.93
10 Providing emotional support for the child	1-5	3.44	1.12	1-5	3.07	1.21	1-5	3.18	1.02
11 Providing emotional support for any other children in the family	1-5	3.06	1.25	1-5	2.71	1.21	1-5	2.83	1.12

Table 8. Range, mean, and standard deviation of the caregiving burden classified by overall and each items (n = 107) (Cont.)

Caregiving Task	Time			Difficulty			Caregiving burden		
	Range	Mean	S.D.	Range	Mean	S.D.	Range	Mean	S.D.
12 Providing emotional support for the spouse	1-5	2.82	1.18	1-5	2.58	1.17	1-5	2.63	1.01
13 Observing and reporting symptoms and progress	1-5	3.16	1.03	1-5	2.78	0.90	1-5	2.90	0.78
14 Managing finance, bills, and forms related to a child condition	1-5	3.27	1.14	1-5	3.01	1.18	1-5	3.08	1.06
15 Additional household tasks beyond the usual responsibilities	1-5	3.21	1.09	1-5	2.87	1.00	1-5	2.99	0.91
16 Additional task outside the home	1-5	3.40	1.12	1-5	2.99	1.14	1-5	3.13	1.00
17 Structuring and planning activities for the child and family	1-5	3.16	1.06	1-5	2.79	1.06	1-5	2.90	0.89
18 Managing discipline and any behavior problems	1-5	3.51	1.01	1-5	3.31	1.21	1-5	3.37	1.03
19 Obtaining child care and babysitting help or respite care	1-5	2.86	1.35	1-5	2.79	1.30	1-5	2.73	1.12
20 Coordinating arranging and managing and services resources	1-5	3.06	1.12	1-5	2.97	1.05	1-5	2.93	0.90

APPENDIX B**Table 9.** Range, mean and standard deviation of a family well-being classified by each subscale (n = 107)

Family Well-being	Range	Mean	S.D.
Family structure	1.44-5.38	4.06	0.68
Family support	1-6	4.59	1.13
Family satisfaction	1-6	4.36	1.02
Family harmony	1-5	3.64	0.92
Family stress	1-6	2.60	1.28
Role Process	1.31 -5.06	3.90	0.59
Non-participatory	2-6	4.14	0.92
Too many roles	1-6	3.53	1.45
Role ambiguity	1-5	3.43	0.79
Role preparation	1-6	3.16	0.98
Role conflict	1-6	3.14	1.15
Vulnerability	1.6-4.9	3.09	0.71
Problems of body and mind relationships	1-6	3.12	1.28
Life satisfaction	1-4	2.72	0.80

APPENDIX C



มหาวิทยาลัยขอนแก่น

หนังสือฉบับนี้ให้ไว้ เพื่อแสดงว่า

โครงการวิจัยเรื่อง: ความสัมพันธ์ระหว่างปัจจัยคัดสรรภาระการดูแล และความผาสุกในครอบครัว
ของมารดาที่มีบุตรออทิสติก
(The relationship among selected factors, caregiving burden and family
well-being in mothers of children with autistic disorder)

ผู้วิจัย: นางชยมน บุญลักษณ์ และคณะฯ

หน่วยงานที่สังกัด: นักศึกษาหลักสูตรปริญญาโท สาขาจิต ภาควิชาพยาบาลศาสตร์
คณะแพทยศาสตร์ โรงพยาบาลรามาริบัติ มหาวิทยาลัยมหิดล

ได้ผ่านการพิจารณาของคณะกรรมการจริยธรรมการวิจัยในมนุษย์มหาวิทยาลัยขอนแก่น แล้ว
โดยยึดหลักเกณฑ์ตามคำประกาศเฮลซิงกิ (Helsinki's Declaration)

ให้ไว้ ณ วันที่ 24 เมษายน พ.ศ. 2546

(รองศาสตราจารย์วีระชัย ไควสุวรรณ)

ประธานคณะกรรมการจริยธรรมการวิจัยในมนุษย์มหาวิทยาลัยขอนแก่น

ลำดับที่ 4.1.13 : 4/2546

เลขที่: HE 460417

คณะกรรมการจริยธรรมการวิจัยในมนุษย์มหาวิทยาลัยขอนแก่น 123 ถนนมิตรภาพ อ.เมือง จ.ขอนแก่น 40002

โทร. (043) 348360-9 ต่อ 3723 สายตรง 348373

โทรสาร (043) 243064, 348373 ,01-2625055

APPENDIX C

Informed Consent Form

แบบฟอร์มใบยินยอมให้ทำการวิจัยโดยได้รับการบอกกล่าวและเต็มใจ

การวิจัยเรื่อง ความสัมพันธ์ระหว่างปัจจัยคัดสรร ภาระการดูแล และความผาสุกในครอบครัว
ของมารดาที่มีบุตรออทิสติก

วันที่ให้คำยินยอม วันที่.....เดือน.....พ.ศ.....

ก่อนที่จะลงนามในใบยินยอมให้ทำการวิจัยนี้ ข้าพเจ้าได้รับการอธิบายจากผู้วิจัยถึง
วัตถุประสงค์ของการวิจัย วิธีการวิจัย และประโยชน์ที่จะเกิดขึ้นจากการวิจัยอย่างละเอียด และมีความ
เข้าใจดีแล้ว

ผู้วิจัยรับรองว่าจะตอบคำถามต่างๆที่ข้าพเจ้าสงสัยด้วยความเต็มใจ ไม่ปิดบังซ่อนเร้น จน
ข้าพเจ้าพอใจ

ข้าพเจ้ามีสิทธิที่จะบอกเลิกการเข้าร่วมในโครงการวิจัยนี้เมื่อใดก็ได้ และเข้าร่วม
โครงการวิจัยนี้โดยสมัครใจ และการบอกเลิกการเข้าร่วมการวิจัยนี้จะไม่ผลต่อการรักษาที่บุตรของ
ข้าพเจ้าพึงได้รับต่อไป

ผู้วิจัยรับรองว่าจะเก็บข้อมูลเฉพาะเกี่ยวกับตัวข้าพเจ้าเป็นความลับ และจะเปิดเผยได้เฉพาะ
ในรูปที่เป็นผลสรุปการวิจัย การเปิดเผยข้อมูลเกี่ยวกับตัวข้าพเจ้าต่อหน่วยงานต่างๆที่เกี่ยวข้อง
กระทำได้เฉพาะกรณีจำเป็นด้วยเหตุผลทางวิชาการเท่านั้น

ผู้วิจัยรับรองว่าหากมีข้อมูลเพิ่มเติมที่ส่งผลกระทบต่อการศึกษา ข้าพเจ้าจะได้รับการแจ้งให้
ทราบโดยไม่ปิดบังซ่อนเร้น

ข้าพเจ้าได้อ่านข้อความข้างต้นแล้วและมีความเข้าใจดีทุกประการ และได้ลงนามในใบ
ยินยอมนี้ด้วยความเต็มใจ

ลงนาม.....ผู้ยินยอม

ลงนาม.....พยาน

ลงนาม.....พยาน

APPENDIX D

Demographic Data Form

คำชี้แจง: กรุณาตอบแบบสอบถามโดยทำเครื่องหมาย \surd ลงในช่องว่าง () หรือเติมข้อความลงในช่องว่าง

ส่วนที่ 1 ข้อมูลทั่วไปของบุตรออทิสติก

1. อายุบุตรปีเดือน
2. เพศ () ชาย
() หญิง
3. เป็นบุตรคนที่ ในจำนวนพี่น้องทั้งหมด.....คน (รวมบุตรออทิสติก)
4. มีผู้ช่วยเหลือดูแลบุตรออทิสติกหรือไม่
() ไม่มี
() มี คือ (ตอบได้มากกว่า 1 ข้อ) () สามี
() ญาติ ไปรตระบุญ.....
() พี่เลี้ยงเด็ก
() สถานรับเลี้ยงเด็กกลางวัน (daycare)
() โรงเรียนเตรียมอนุบาล
() อื่นๆ ไปรตระบุญ.....
5. ในครอบครัวมีบุตรคนอื่นป่วยเรื้อรังหรือไม่
() ไม่มี () มี ไปรตระบุญ ป่วยเป็น.....
6. การบำบัดที่บุตรออทิสติกได้รับ (ตอบได้มากกว่า 1 ข้อ)
() การบำบัดทางพฤติกรรม
() การกระตุ้นภาษาและการสื่อสาร
() การกระตุ้นสมอง กล้ามเนื้อและประสาทสัมผัสต่างๆ
() การใช้ยาหรือสารบางอย่าง
() การบำบัดทางโภชนาการ
() การบำบัดทางจิตใจ

7. ระดับการศึกษาของบุตรออสติก
- ยังไม่เข้ารับการศึกษ
 - เตรียมอนุบาล
 - อนุบาล
 - ประถมศึกษา
 - อื่นๆ ระบุ.....
8. บุตรออสติกสามารถไปโรงเรียนได้ตามปกติหรือไม่
- ได้
 - ไม่ได้ เพราะ.....

ส่วนที่ 2 ข้อมูลทั่วไปของมารดา

1. อายุมารดาปี
2. ศาสนา
- พุทธ
 - คริสต์
 - อิสลาม
 - อื่นๆ โปรดระบุ
3. ระดับการศึกษา (ระยะเวลาในการศึกษา)
- ไม่ได้เรียนหนังสือ
 - ประถมศึกษาชั้นปีที่.....
 - มัธยมศึกษาชั้นปีที่.....
 - อาชีวศึกษา / ประกาศนียบัตร
 - ปริญญาตรี
 - ปริญญาโท
 - ปริญญาเอก
 - อื่นๆ โปรดระบุ.....
4. อาชีพ
- แม่บ้าน หรือ ไม่ได้ประกอบอาชีพ
 - ค้าขาย โปรดระบุ.....
 - รับจ้าง โปรดระบุ.....
 - รับราชการ โปรดระบุ.....
 - อื่นๆ โปรดระบุ.....
5. รายได้ของครอบครัวเฉลี่ยต่อเดือน บาท
- เพียงพอต่อค่าใช้จ่ายหรือไม่ ไม่เพียงพอ
- เพียงพอแต่ไม่เหลือเก็บ
 - เพียงพอและมีเหลือเก็บ

APPENDIX D

The Autistic Caregiving Burden Scale

คำชี้แจง

ข้อความต่อไปนี้ เป็นกิจกรรมต่างๆ ที่มารดาช่วยเหลือบุตรออทิสติกในการปฏิบัติกิจวัตรประจำวัน โปรดระบุระยะเวลาและความยุ่งยากในการดูแลลูกตามกิจกรรมนั้นๆ โดยการทำเครื่องหมายถูก (✓) ในช่องว่างที่ตรงกับประสบการณ์จริงของท่านมากที่สุดในแต่ละข้อและโปรดตอบคำถามให้ครบทุกข้อ ดังนี้

1. ระยะเวลาที่ใช้ในการปฏิบัติกิจกรรมการดูแลบุตรออทิสติกในแต่ละกิจกรรม

- น้อยมากหรือแทบจะไม่ใช่เวลาเลย = ใช้เวลาน้อยมากหรือแทบจะไม่ใช่เวลาในการทำกิจกรรมนั้นๆ เลย
- น้อย = ใช้เวลาน้อยในการทำกิจกรรมนั้นๆ
- ปานกลาง = ใช้เวลาปานกลางในการทำกิจกรรมนั้นๆ
- มาก = ใช้เวลามากในการทำกิจกรรมนั้นๆ
- มากที่สุด = ใช้เวลามากที่สุดในการทำกิจกรรมนั้นๆ

2. ความยุ่งยากในการปฏิบัติกิจกรรมการดูแลบุตรออทิสติกในแต่ละกิจกรรม

- น้อยมากหรือไม่ยากเลย = เกิดความยุ่งยากน้อยมากหรือไม่ได้เกิดความยุ่งยากในการทำกิจกรรมนั้นๆเลย
- น้อย = เกิดความยุ่งยากน้อยในการทำกิจกรรมนั้นๆ
- ปานกลาง = เกิดความยุ่งยากปานกลางในการทำกิจกรรมนั้นๆ
- มาก = เกิดความยุ่งยากมากในการทำกิจกรรมนั้นๆ
- มากที่สุด = เกิดความยุ่งยากมากที่สุดในการทำกิจกรรมนั้นๆ

กิจกรรม	ระยะเวลาที่ใช้				ความยุ่งยากในการดูแล					
	น้อยมากหรือแทบจะไม่ใช้เวลาเลย	น้อย	ปานกลาง	มาก	มากที่สุด	น้อยมากหรือ	น้อย	ปานกลาง	มาก	มากที่สุด
1. การดูแลเกี่ยวกับการรักษาพยาบาล เช่น การให้ยา การเจ็บป่วยทางกาย การดูแลสุขภาพทั่วไป และการออกกำลังกาย เป็นต้น			√				√			

หมายถึง มารดาต้องใช้เวลาในการดูแลเกี่ยวกับการรักษาพยาบาลมาก แต่มีความยุ่งยากในการทำกิจกรรมในการดูแลเกี่ยวกับการรักษาพยาบาลน้อย

APPENDIX D

The Family Well-Being Scale

คำถามต่อไปนี้จะเกี่ยวข้องกับการทำงานร่วมกันของสมาชิกในครอบครัวท่าน และบทบาทของท่าน กรุณาตอบตรงตามความเป็นจริงที่เกิดขึ้นในครอบครัวของท่านให้มากที่สุด คำตอบทุกคำตอบจะถือเป็นความลับ

คำชี้แจง

แบบสอบถามนี้แบ่งเป็น 2 ส่วน ส่วนที่ 1 มี 25 ข้อ คือ ข้อ 1- 25 ส่วนที่ 2 มี 17 ข้อ คือข้อ 26- 42 กรุณาอ่านคำตอบที่ได้อธิบายไว้อย่างรอบครอบก่อนตอบคำถามในแต่ละส่วน แล้วทำเครื่องหมาย \surd ลงในช่องว่าง () ที่ตรงกับความรู้สึกของท่านมากที่สุดเพียง 1 ตัวเลือก

ตัวอย่าง ส่วนที่ 1 เป็นคำถามเกี่ยวกับความคิดเห็นของท่านในข้อคำถามนั้น

ข้อความ	เห็นด้วยอย่างยิ่ง	เห็นด้วยปานกลาง	เห็นด้วยเล็กน้อย	ไม่เห็นด้วยเล็กน้อย	ไม่เห็นด้วยปานกลาง	ไม่เห็นด้วยอย่างยิ่ง
1. งานใดก็ตามถ้าสามีไม่เห็นด้วย ฉันก็ไม่สามารถทำให้สำเร็จลุล่วงได้						\surd

หมายถึง ฉันสามารถทำงานหรือกิจกรรมต่างๆให้สำเร็จลุล่วงได้ เมื่อสามีของฉัน ไม่เห็นด้วยอย่างยิ่ง

APPENDIX D
The Family Well-Being Scale

ส่วนที่ 1 เป็นคำถามเกี่ยวกับความคิดเห็นของท่านในข้อคำถามนั้น

ข้อความ	เห็นด้วยอย่างยิ่ง	เห็นด้วยปานกลาง	เห็นด้วยเล็กน้อย	ไม่เห็นด้วยเล็กน้อย	ไม่เห็นด้วยปานกลาง	ไม่เห็นด้วยอย่างยิ่ง
1.งานใดก็ตามถ้าสามีไม่เห็นด้วย ฉันก็ไม่สามารถทำให้สำเร็จลงได้						
2.ฉันรู้ว่าครอบครัวของฉันคาดหวังให้ฉันทำอะไรในบทบาทแม่ในแต่ละวันและวันต่อไป						
3.สมาชิกในครอบครัวคาดหวังให้ฉันเป็นแม่ที่ดีกว่าที่เป็นอยู่เกือบตลอดเวลา						
.....						
.....						
.....						
.....						
.....						
25.บ้านของฉันเปรียบเสมือนบาดแผลดั่งเปรี๊ยะพร้อมที่จะระเบิด						

APPENDIX D

The Family Well-Being Scale

ตัวอย่าง ส่วนที่ 2 เป็นคำถามที่อธิบายปฏิกิริยาของท่านและครอบครัวของท่านที่เกี่ยวข้องกับ
สถานการณ์ในบ้าน กรุณาทำเครื่องหมาย (✓) ในช่องคำตอบที่แสดงได้
เหมาะสมที่สุดว่าสถานการณ์นั้นเกิดขึ้นมากน้อยเพียงใด ในครอบครัวของท่าน

ข้อความ	เกือบ ตลอดเวลา	บ่อยมาก	บ่อยครั้ง	เป็นครั้งคราว	ไม่เคยเป็น ส่วนมาก	เกือบจะ ไม่เคยเลย
26. ฉันรู้สึกปั่นป่วนในกระเพาะอาหาร หรือ คลื่นไส้ อาเจียน				✓		

หมายถึง ฉันรู้สึกปั่นป่วนในกระเพาะอาหารหรือคลื่นไส้ อาเจียนบ้างเป็นครั้งคราว

APPENDIX D

The Family Well-Being Scale

ส่วนที่ 2 เป็นคำถามที่อธิบายปฏิกิริยาของท่านและครอบครัวของท่านที่เกี่ยวข้องกับสถานการณ์ในบ้าน กรุณาทำเครื่องหมาย (✓) ในช่องคำตอบที่แสดงได้เหมาะสมที่สุดว่าสถานการณ์นั้นเกิดขึ้นมากน้อยเพียงใด ในครอบครัวของท่าน

ข้อความ	เกือบตลอดเวลา	บ่อยมาก	บ่อยครั้ง	เป็นครั้งคราว	ไม่เคยเป็นส่วนมาก	เกือบจะไม่เคย
26. ฉันรู้สึกปั่นป่วนในกระเพาะอาหารหรือคลื่นไส้อาเจียน						
27. สามีให้การสนับสนุนฉันและการตัดสินใจของฉัน เมื่ออยู่ต่อหน้าสมาชิกในครอบครัวและเพื่อนๆ						
28. ฉันมีปัญหาหลับยากหรือนอนไม่หลับ						
.....						
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.....						
.....						
42. ฉันไม่แน่ใจว่าในฐานะที่เป็นแม่ฉันต้องรับผิดชอบอะไรบ้าง						

APPENDIX E

List of expert for questionnaires validity

1. Chamaiporn Pongpanich Registered Nurse of Yuwaprasatwithayopatom Hospital, Samut Prakan Province.
2. Udorn Jitjaruen, MSN.
Registered Nurse of Developmental Child Unit, Faculty of Medicine
Ramathibody Hospital, Mahidol University
3. Supapak Phetrasuwan, Ph.D
Instructor, Department of Psychiatric Nursing, Faculty of Nursing,
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4. Patraboorn Pudtharaksa
Head of Department of Psychiatric Mental Health Nursing, Faculty of Nursing,
Assumption University
5. Wanida Sanasutipun
Assistant Professor, Department of Pediatric Nursing, Faculty of Nursing,
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BIOGRAPHY

NAME	Mrs. Chayamon Boonluk
DATE OF BIRTH	18 November, 1974
PLACE OF BIRTH	Udon Thani, Thailand
INSTITUTION ATTEND	Burapha University, 1993-1997 Bachelor of Nursing Science Mahidol University, 2001-2004 Master of Nursing Science (Pediatric Nursing)
POSITION AND OFFICE	1999-Present:, Faculty of Nursing, Ratchathani University, Ubonratchathani, Thailand Position: Nurse Instructor