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**MENTAL HEALTH AND CARING BEHAVIORS OF  
CAREGIVERS OF CHILDREN WITH AUTISM**

**PRAPAWADEE SUPUCKWANICH**

อธิปัทนการ  
จาก  
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The purposes of this descriptive study were to examine the mental health and caring behaviors of caregivers of children with autism. The subjects consisted of 100 caregivers of children with autism who brought their children to the outpatient clinic at Yuwaprasart Withayopathum Child Psychiatric Hospital. The General Health Questionnaire-28 (Thai-version), developed by Goldberg and translated into Thai language by Tana Nilchaigovit and his colleagues and the Caring Behaviors of Caregivers of Children with Autism Questionnaire, developed by the researcher, were used for data collection. The data were analyzed by mean and percentage and the relationship between mental health and caring behaviors was analyzed by the Chi-Square test.

The results showed that 73.0 percent of the subjects were persons who had a normal health. They were persons who did not have somatic symptoms, anxiety, insomnia, social dysfunction, or severe depression. Meanwhile 27.0 percent of the subjects were persons with potential psychiatric disorders. The subjects reported their caring behaviors at a high level with percentage of mean scores 82.56. The result also showed that mental health was related to caring behaviors of caregivers of children with autism at a significant level ( $\chi^2 = 15.16$ ,  $p < 0.001$ ). These findings suggested that nurses should promote mental health of the caregivers so that the children with autism would be cared appropriately.

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การศึกษาวิจัยครั้งนี้มีวัตถุประสงค์เพื่อ ประเมินสุขภาพจิต ศึกษาพฤติกรรมการดูแลเด็กออทิสติกของผู้ดูแล และศึกษาความสัมพันธ์ระหว่างสุขภาพจิต กับพฤติกรรมการดูแลเด็กออทิสติกของผู้ดูแล โดยศึกษาผู้ดูแลที่เป็นหลัก หรือมีหน้าที่โดยตรงในการดูแลเด็กออทิสติก ที่พาเด็กออทิสติกที่มีอายุระหว่าง 2-5 ปี มารับบริการที่แผนกผู้ป่วยนอกของโรงพยาบาลจุฬาลงกรณ์ จำนวน 100 ราย เพื่อตอบแบบสอบถามเพื่อคัดกรองปัญหาสุขภาพจิต ที่พัฒนามาจาก the General Health Questionnaire ของ Goldberg ได้รับการแปลและเรียบเรียงเป็นภาษาไทยโดย ธนา นิลชัยโกวิทย์ และคณะ และแบบสอบถามพฤติกรรมการดูแลเด็กออทิสติกของผู้ดูแล ที่ผู้วิจัยสร้างขึ้น ข้อมูลที่ได้ถูกวิเคราะห์ด้วยสถิติค่าเฉลี่ยและร้อยละ และหาความสัมพันธ์ระหว่างสุขภาพจิต และพฤติกรรมการดูแล โดยใช้ สถิติ Chi-square test

ผลการวิจัยพบว่า ผู้ดูแลเด็กออทิสติก ร้อยละ 73 เป็นผู้ที่ไม่มีความผิดปกติทางจิตเวช ซึ่งหมายความว่า เป็นผู้ที่ไม่มีความผิดปกติทางจิตเวชที่แสดงออกจากอาการทางกาย อาการวิตกกังวล และการนอนไม่หลับ ความบกพร่องทางสังคม และอาการซึมเศร้าที่รุนแรง และพบว่าผู้ดูแลเด็กออทิสติก ร้อยละ 27 เป็นผู้ที่มีแนวโน้มที่จะมีความผิดปกติทางจิตเวช และกลุ่มตัวอย่างมีพฤติกรรม การดูแลเด็กออทิสติก อยู่ในระดับมาก คิดคะแนนเป็นร้อยละ 82.56 แสดงว่ากลุ่มตัวอย่างมีพฤติกรรม การดูแลเด็กในด้านต่างๆ โดยรวมอยู่ในระดับมาก นอกจากนี้ยังพบว่าสุขภาพจิตมีความสัมพันธ์กับพฤติกรรม การดูแลเด็กออทิสติกของผู้ดูแล อย่างมีนัยสำคัญที่ระดับ 0.001 ผลการวิจัยนี้ชี้ให้เห็นว่า พยาบาลควรให้การส่งเสริมสุขภาพจิตของผู้ดูแลเด็กออทิสติก เพื่อเพิ่มพูนความสามารถในการดูแลเด็กออทิสติกของผู้ดูแล

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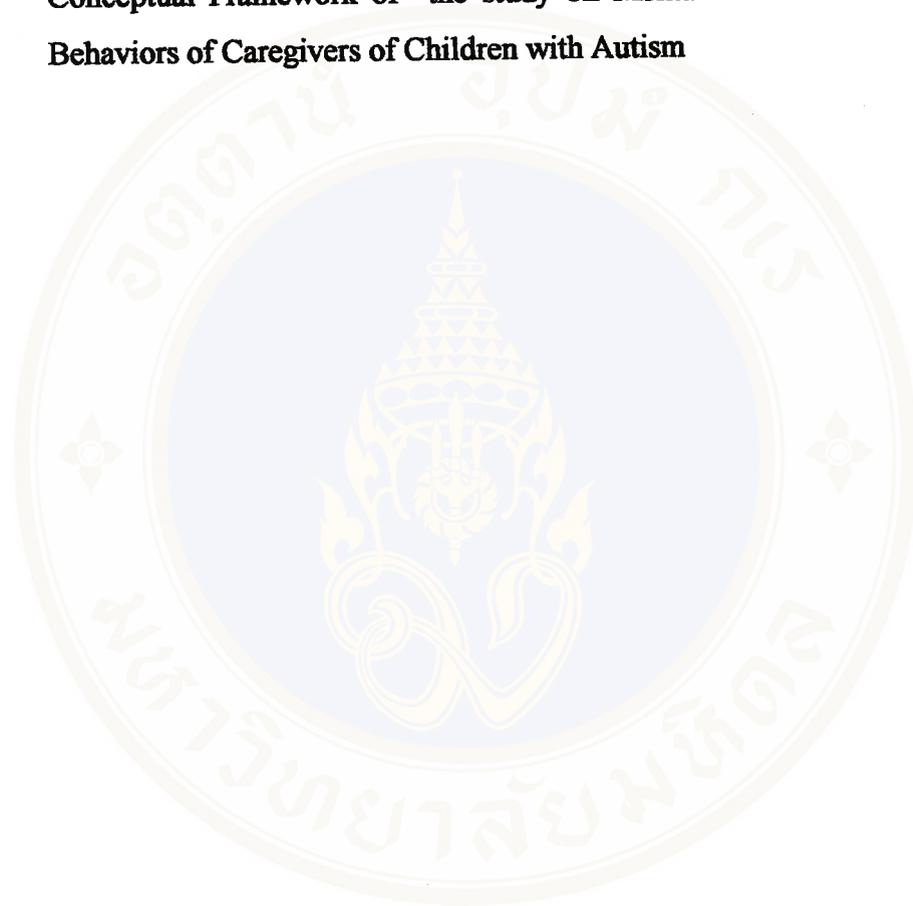
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## CHAPTER I

### INTRODUCTION

#### **Background and Significance of the Study**

Autism is a severe incapacitating lifelong developmental disability that typically appears during the first three years of life. In the U.S, autism and its associated behaviors have been estimated to occur in as many as 1 in 500 individuals (Autism Society of America, 1998: 1). In Thailand, no such large-scale surveys have been conducted. However, there is evidence suggesting that there is an increasing number of children with autism, as reported by the Yuwaprasart Withayopatum Child Psychiatric Hospital, which holds a position of national leadership in services for clients with autism and related disorders. It is reported that the number of out-patients was about 1,460 in 1995, increasing to 2,099 (a 43.77% increase over 1995) in 1996, and 3,022 (a 43.97% increase over 1996) in 1997 (Yuwaprasart Withayopatum Child Psychiatric Hospital Annual, 1997). These children with autism have severe impairment in their daily functioning and require long-term specialist care as well as involvement of the family. Since there is a limited number of health professionals who provide the special care for these children, the families have unavoidably become the primary caregiver for their ill child.

Autism is an illness that causes an impairment in language / communication, social interaction and behavioral response to the environment (Autism Society of America, 1998: 1). These deficits have created stress and tension for those who care for a child with autism. Though the impairments occur in the child with autism at birth, it is noticeable for their parents when their age is between 2-5 years. Many parents have sought out the professional help because of the difficulties in caring for the pre-school age children. These children with autism need special training programs in order to develop the appropriate skills such as self-care, expressing emotions, or communication skills (Phengkhae Limsila, 1998: 75-81). Caring for children with autism depends on the wholehearted performance and the

primary caregivers who have direct responsibility in caring for children for a long period of time are faced with complicated situations as they live with these children.

Many studies suggested that caregivers of children with autism were affected by finance, pattern of living, family relationship, family recreation, physical and the mental health problems (National Resource Center for Respite and Crisis Care Service, 1992 :1, Bebko et al., 1987: 566). For instance, Harris (1994: 162), in her integrated literatures review, indicated that caregivers of children with autism had physical illnesses resulting from stress, anxiety, depression, hopelessness, guilt, low self-esteem, role-play failure, social dysfunction and suffered from problems in caring for the child. This reflects the poor mental health state of the caregivers. O'Moore (1978 quoted in Koegel et al., 1992: 206) found that mothers of children with autism showed a high level of stress when involved with social activities. DeMyer (1979, quoted in Konstantareas and Homatidis, 1989: 459-460) suggested that mothers of children with autism had physical and psychological tension such as; guilt and uncertainty as to mothering ability. Fathers of children with autism were also affected, but they apparently were mainly influenced indirectly through their wives' reaction and pain at having a child with autism. Canwell and Baker (1984 quoted in Kanya Thanyamantha, 1991: 15) found that parents of children with autism had mental health problems, such as depression and anxiety. Gill (1990 quoted in Harris, 1994: 163) found that mothers of pre-school children with autism had stress, anxiety, physical-illness complaints and emotional fatigue.

Similarly in Thailand, Kanya Thanyamanta (1991), in her study of the effects of caring for children with autism on 70 parents, reported that 7.14% of parents had somatic symptoms, and 10% depression. Most of these parents had specific anxiety over their child's symptoms and the inadequate service facilities. Rungludee Wongchum (1996) studied stress in 138 parents of children with autism admitted in Yuwaprasart Withayopatum Child Psychiatric Hospital. The result showed that these parents experienced a high level of stress. The factors that caused stress were excessive attention in caring, a long treatment and being faced with their child's symptoms. More recently, Siriporn Suvuntod (1998) reported that the families of children with autism had hopelessness about the progression of their child,

discouragement, tension and burdens in caring. The results of these studies confirmed that caregivers of children with autism experienced stress, anxiety, depression which indicate they have poor mental health status.

The mental health state of the caregivers has an influence on their capability to care for themselves and for their ill child. It is suggested that a lack of understanding of their child's illness and poor mental health are related to caring behaviors. Chom Chumchuai (1996: 8) confirmed that the caregivers who lack an understanding of their child may force him/her to learn ,overprotect or reject him/her, and this may obstruct their child's learning. Kanlaya Wiriya (1996) studied perception and caring behaviors in 100 mothers of children with autism, and found that there was a relationship between perception of autism and caring behaviors of mothers of children with autism. Most of the mothers reported a high level of accurate perception and caring behaviors. These caring behaviors consisted of having their children vaccinated, following up the treatment, showing affection to their child by hugging, and calling their name gently, talking and playing with them. This study suggested that the mothers who were mentally healthy would provide better care for their child and develop his/her potential and self-reliability.

Up to date, the relationship between mental health and caring behaviors of caregivers of children with autism has not been studied. Mental health is concerned with competence, ability to solve problems realistically, decision-making and role functioning (Suwaniya Kiawkingkaw, 1985: 3). Mental health might relate to caring behaviors (Cavanagh & Ashman, 1985: 152; Moes et al., 1992: 1272-1274). Chom Chumchuai (1996: 6-11) stated that the caregivers of children with autism are extremely important to the child. When the caregivers could manage their emotions, thoughts, and attitudes, they show consistent caring which helps and enhanced appropriate development for their child.

The researcher as a psychiatric nurse has the responsibility to care for children with autism through their caregivers. Nurses first need to understand the mental health status of the primary caregivers of children with autism, as well as their caring behaviors. This information would help nurses to plan nursing intervention appropriate for these caregivers. The purposes of this study were to examine mental

health, caring behaviors and the relationship between them.

### **Research Question**

1. What was the status of mental health of caregivers of children with autism?
2. What caring behaviors did the caregivers perform with their children with autism?
3. Was there a relationship between the mental health and caring behaviors of caregivers of children with autism?

### **Purposes of the study**

The purposes of this study were to:

1. examine the mental health of caregivers of children with autism.
2. examine the caring behaviors of caregivers of children with autism.
3. examine the relationship between mental health and caring behaviors of caregivers of children with autism.

### **Conceptual Framework**

In this study, the mental health and caring behavior of caregivers of children with autism were based on Goldberg's framework, Meyeroff's Caring Concept, Watson's theory of Transpersonal Caring, and Leininger's theory of Cultural Care Diversity and Universality. The following were the details of these frameworks:

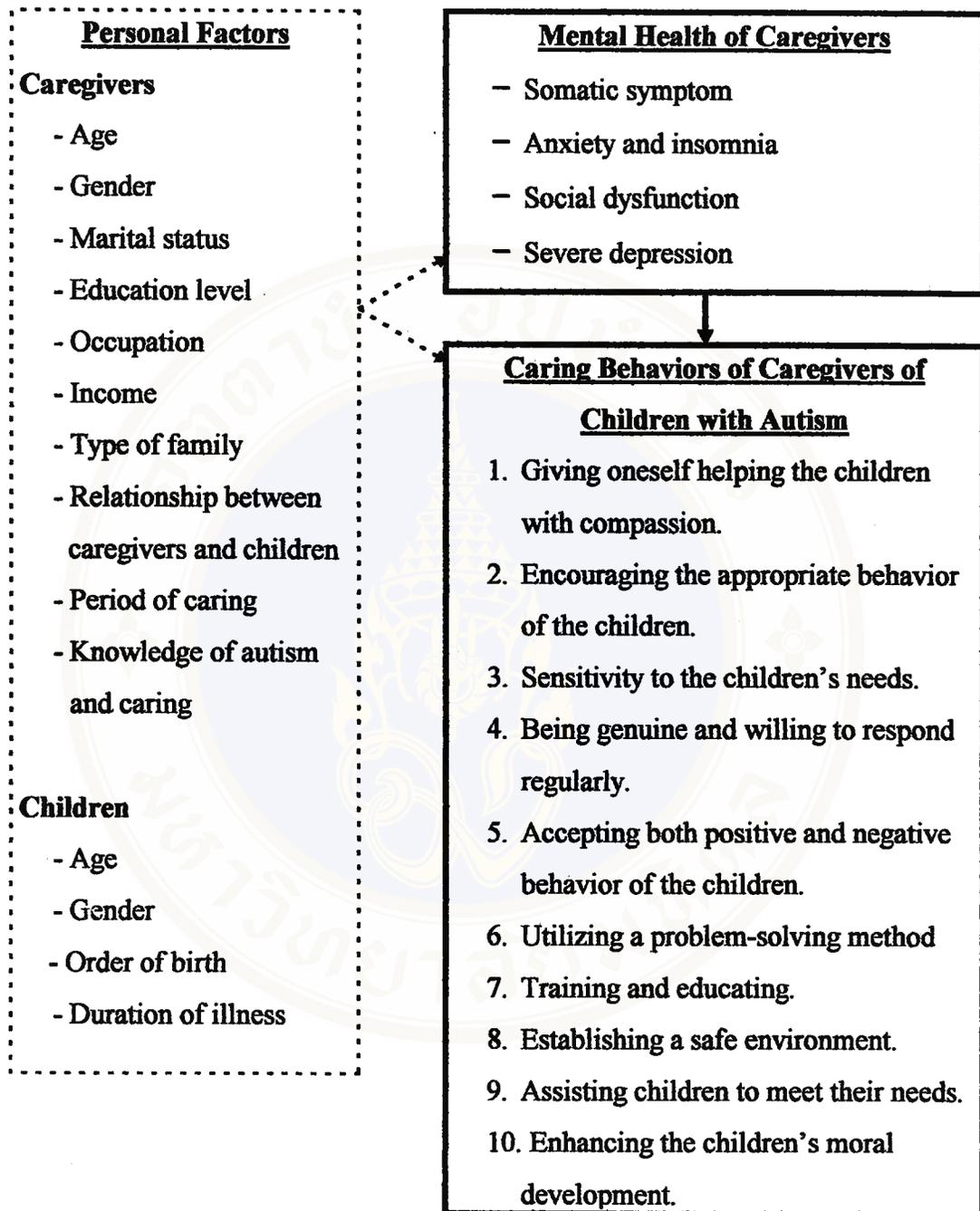
According to Goldberg's framework (Goldberg, 1979), mental health can be determined by two phenomena: (1) inability to carry out one's normal "healthy" functions, and (2) the appearance of new phenomena of a distressing nature. This manifestation is expressed in four ways. First is somatic symptom; second is anxiety or insomnia; third is social dysfunction; and fourth is severe depression.

In Mayeroff's concept (1971 quoted in Payom Euswas, 1996: 27), caring behaviors are the process of helping another grow, and live in society with integrity. Similarly, Watson (1985: 1-21; 1988: 29) stated that the goal of caring is gratification of certain human needs which is necessary for growth and development. According to

Leininger's theory of cultural care diversity and universality (1991: 46), human care is a universal phenomenon serving the human race. Care is action and activities directed toward assisting, supporting, or enabling another individual or group with anticipated needs to ameliorate or improve a human condition or life-way. Characteristics of care varies from culture to culture.

Meyeroff's caring concept, Watson's theory of transpersonal caring, and Leininger's theory of cultural care diversity were used to study the caring behaviors of caregivers of children with autism (Mayeroff, 1971, Watson, 1985 & Leininger, 1991). However, Watson (1985) emphasized that caring behavior could meet the psychological, physical, societal, and spiritual / environmental needs of the children with autism. Caregivers should care for the children with respect to their value, dignity and rights, and with love, mercy, willingness and intention. Relationships between caregivers and children are an important factor to build children's trust. It is most important that caregivers should accept the children not only as they are now but for what they will become.

In this study, the researcher derived 10 aspects of caring behaviors according to Watson's concepts of caring behaviors as follows; giving oneself helping the children with compassion, encouraging the appropriate behavior of the children, sensitivity to the children's needs, being genuine and willing to respond regularly, accepting both positive and negative behavior of the children, utilizing a problem-solving method, training and educating, establishing a safe environment, assisting children to meet their needs and enhancing the children's moral development.



**Diagram I:** Conceptual Framework of the study on Mental Health and Caring Behaviors of Caregivers of Children with Autism.



:

Factors studied



:

Factors not studied, but involved

## **Hypotheses**

Mental health was related to the caring behaviors of caregivers of children with autism.

## **Scope of the study**

This study was to explore the mental health and caring behaviors of caregivers of children with autism who brought their children with autism to the outpatient clinic at Yuwaprasart Withayopatum Child Psychiatric Hospital, Samutprakan. The data were collected between April to June, 1999.

## **Definition of Terms**

**1. Mental health of caregivers of children with autism.** It is defined as the capacity of caregivers of children with autism to adapt to function comfortably within society and the environment. In this study, the General Health Questionnaire-28 (GHQ-28) was used to measure the mental health of caregivers of children with autism. The GHQ-28 was developed by Goldberg and translated by Tana Nilchaikovit and his colleagues (1996: 2-17). The mental health was evaluated by using 4 sub-scale, as follow:

**1.1 Somatic symptom :** the caregivers have feelings of being perfectly well or ill, run down, having pains in the head, tightness in the head and hot and cold spells.

**1.2 Anxiety and insomnia :** the caregivers lost much sleep over worry, have difficulty in staying asleep, and are bad tempered, scared, and panicky.

**1.3 Social dysfunction :** the caregivers were keeping busy, doing things well, being capable of making decisions, and able to enjoy normal activities.

**1.4 Severe depression :** the caregivers have feelings of worthlessness, hopelessness, wish to die and think of suicide.

**2. Caring behaviors of caregivers of children with autism.** Caring behaviors are activities that caregivers do for their children in order to meet their needs that include physical, psychosocial, and spiritual needs, and to protect and maintain their children's values, honor and human rights. Such caring behaviors are based on the consistent and sincere relationship between caregivers and their children. Caring behavior was measured by the Caring Behaviors of Caregivers of Children with Autism Questionnaire, developed by the researcher. The scale was developed by using caring concept of Watson (1985) and related literature review. The scale consisted of 10 dimensions which are the following:

**2.1 Giving oneself helping the children with compassion**

The caregivers demonstrate their care for children with autism with love, mercy, and great attention. They take care of the child wholeheartedly.

**2.2 Encouraging appropriate behavior of the children**

The caregivers encourage their children with autism to behave appropriately by praising them with verbal and nonverbal communication.

**2.3 Sensitivity to the children's needs**

The caregivers observe any change that occurs in their children with autism in physical, emotional, social and spiritual ways, and respond to that change immediately.

**2.4 Being genuine and willing to respond regularly**

The caregivers show spontaneity in their relationship with their children with autism. The caregivers use clear and understandable language when talking to their child.

### **2.5 Accepting both positive and negative behavior of the children**

The caregivers show an understanding of the meaning of behaviors of children with autism. They try not to judge whether the child's behaviors are right or wrong.

### **2.6 Utilizing problem-solving methods**

The caregivers seek more information to understand the cause of the problems that occurred with their children with autism, and to find ways to help them solve the problems.

### **2.7 Training and educating**

The caregivers teach their children with autism to be able to self-care. The children are trained about communication, social skills, and all-round environments.

### **2.8 Establishing a safe environment**

The caregivers establish a home environment to make their children with autism feel safe and secure. The caregivers arrange the home to be clean, and cozy with good ventilation.

### **2.9 Assisting children with autism to meet their needs**

The caregivers help their children with autism to meet their needs including physiological needs (food, water, personal hygiene, elimination, rest and exercise), and psychosocial needs (security, safety and sense of belonging).

### **2.10 Enhancing the children's moral development**

The caregivers enhance their children with autism to learn how to give and care for others by guiding them or being a model for them.

**Benefits and Expected outcomes of the study**

It is expected that the results of this study will be useful for nurses and related health professionals as follows:

1. increasing awareness of the importance of promoting mental health and caring behaviors of caregivers of children with autism, simultaneously.
2. planning the intervention to promote mental health of caregivers of children with autism.
3. planning the intervention to promote and improve appropriate caring behaviors of caregivers of children with autism.

**Limitations**

This study was only to examine the mental health and caring behaviors of caregivers of children with autism who brought the children with autism ranging in age between 2 to 5 years to the outpatient clinic at Yuwaprasart Withayopatum Child Psychiatric Hospital. Most of them attended the parent training groups. These training groups provided the caregivers with knowledge of guidelines of caring for their children with autism. Therefore the subjects had willingness and wished to care for their child. They were interested in bringing their child to follow up, and were interested in participating in the parent training groups, continuously. Therefore the results of this study can not be generalized to other caregivers.

## **CHAPTER II**

### **LITERATURE REVIEW**

In this study, the researcher reviewed the relevant literatures and investigated several research findings, in the following areas:

1. **Mental health of caregivers of children with autism.**
  - 1.1 **Children with autism and care-giving demands.**
  - 1.2 **Caregivers.**
  - 1.3 **Mental health of caregivers of children with autism.**
  - 1.4 **The assessment of mental health of caregivers of children with autism.**
2. **Caring behaviors of caregivers of children with autism.**
  - 2.1 **The concept of caring.**
  - 2.2 **Caring behaviors of caregivers of children with autism.**
3. **The relationship between mental health and caring behaviors of caregivers of children with autism.**

#### **1. Mental Health of Caregivers of Children with Autism.**

##### **1.1 Children with Autism and Care-giving demands**

###### **1.1.1 Children with Autism**

Autism is a developmental disability that typically appears during the first three years of life and continues throughout life, the result of a neurological disorder that affects functioning of the brain. Children with autism have deficiencies in verbal and non-verbal communication, social interactions and leisure or play activities (Autism Society of America, 1998: 1). Autism has been known for a long time. In the beginning, Bleuler (1934 quoted in Phenkhae Limsila, 1995: 754) found a child who showed some schizophrenia-like behaviors such as; impaired social

interaction, self-centered and restricted patterns of interests. He named it “*Autism*” which comes from the old Greek language “*Auto*” which mean “*Self*”. Since then, there have been many studies seeking to increase knowledge of autism. At present, The Diagnostic and Statistical Manual, 4<sup>th</sup> Edition [DSM IV] criteria for children with autism consists of 3 parts as follows: 1) Qualitative impairments in reciprocal social interaction; marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture and gestures to regulate social interaction, etc. 2) Qualitative impairments in communication; a delay in, or total lack of the development of spoken language, etc. and 3) Restricted, repetitive and stereotyped patterns of behaviors, interests or activity; stereotyped and repetitive motor mannerisms such as hand or finger flapping or twisting or complex whole body movements, etc (American Psychiatric Association, 1994 quoted in Siegel, 1996: 19).

The impairments appear in children with autism 2-3 months after birth. The children with autism are extremely unresponsive when their caregivers are playing or talking with them. It is noticeable for their parents when their age is between 2-5 years old. Normally, preschool age children can achieve self care in daily life in activities such as eating, bathing, dressing, and personal hygiene. They are able to speak, understand language and all-round environments, and are able to live with others. Meanwhile, the children with autism exhibit behaviors such as social withdrawal (isolation in their own world), little interest in social interaction, bizarre greetings and behaviors, instrumental relation, failure to learn about dangerous situations, language develops slowly or not at all, unusual use of words, repeating the question without listening for the answer, through sight, less responsiveness to social cues (such as eye contact, or a smile), difficulties in changing daily routines, lack of spontaneous or imaginative play, stereotype, so the children with autism lack awareness of the emotions of others. Therefore the parents have extreme difficulty in caring for the children and begin to seek help from health professionals. This is why they bring their child to see a doctor (Chatri Withunchat, 1997: 119; Phenkhae Limsila, 1998: 28; Siriphon Suwanthot, 1994: 84; Wing, et al., quoted in Phenkhae Limsila, 1998: 11-13).

In the past, it was believed that autism was caused by bad rearing: the children was brought up by parents who were cold, hard, and rejected their child.

These parents felt they were being blamed (Wing, 1980: 32-33). Nowadays, medical researchers are exploring different explanations for the various forms of autism. Although a specific cause of autism is not known, current research links autism to biological or neurological differences in the brain (Autism Society of America, 1998: 3). First, one of the most important findings indicates **abnormalities of the brain: damage in the limbic system**, particularly the area of amygdala and hippocampus. The neurons in these areas of children with autism are densely packed, smaller than normal persons, and the damage appears to occur during the prenatal stage of development. The result is that the children with autism have abnormalities of the emotions, learning, memory and behaviors (Center for the Study of Autism, 1995b). *Damage in the cerebellum*, the neurons in this area decrease and are thinly packed. It shows that the abnormalities occur before birth similar to damage in the limbic system. The result is children with autism have abnormalities of movement, posture, and strength of muscles (Phengkhae Limsila, 1998: 31-33).

Second, **abnormalities of neurotransmitters**: It was found that three neurotransmitters, including Serotonin, Catecholamine, and Endorphin increase in blood level. Abnormalities of Serotonin are causes of hyperactivity and restlessness. Abnormalities of Endorphin cause compulsive behaviors, lack of interest, and aggression (Chatri Withunchat, 1997: 118; Phengkhae Limsila, 1998: 19). Abnormalities of Catecholamine cause impairment in social interaction, short attention span, and repetitive behavior (Phengkhae Limsila, 1998: 19). These three neurotransmitters are related to pain control, and children with autism are under responsive to pain, have increased tolerance to pain and may injure themselves (Phengkhae Limsila, 1998: 19; Ratri Sutthruang, 1996: 185-192; Romanczyk, et al., 1992: 36-37).

Third, **Genetic factor**: The prevalence of autism is 50 times as great in siblings of children with autism. At this time no one gene has been directly linked to autism. Other factors that cause autism are environmental factors (such as virus and chemicals), physical disorders (such as fragile X syndrome, maternal rubella, encephalitis, meningitis, tuberous sclerosis, untreated phenylketonuria [PKU], and congenital rubella), and infection during pregnancy and delivery.

There is no cure for autism at present. To cure means “to restore to health, soundness, or normality”. In the medical sense, there is no cure for the differences in the brain which results in autism. Interventions for autism take a continuous and long period of time. Because of the spectrum nature of autism and the many behavioral combinations which can occur, no one approach is effective in alleviating symptoms of autism in all cases. The interventions normally are designed to remedy specific symptoms in each individual. Various types of interventions for children with autism include the medication treatments, improvement in self-care skills, improvement in developments, and caregivers training, etc. The medication treatments (such as CNS stimulant, neuroleptic, antidepressant, etc.) have been used in treating specific medication-responsive symptoms such as self injurious behavior, aggression, concentration and learning problems, and epilepsy (Autism Society of America, 1998: 6-7; Phenkhae Limsila, 1998: 20-21; Waldinger, 1990: 309). Self-care skills are essential skills that children with autism must learn to be able to self care in daily life. The skills include eating, dressing, bathing, and personal hygiene (Sansani Sutprasoet, 1996b: 66-74). Improvement in developments consists of emotional factors, communication and language, intellect and learning, and using muscle development (Sansani Sutprasoet, 1996a). It is also crucial for the intervention to educate the caregiver with knowledge of autism and train them how to care for their ill child and solve the problem behaviors. It is suggested that children with autism who have been treated before the age of 5 years have an improvement in their development, and are capable of speaking, learning and studying with normal children. (Phenkhae Limsila, 1998: 19-20, Winadda Piyasin, 1994: 5).

In summary, *autism* is a developmental disability, the result of neurological disorders that affects the functioning of the brain. Autism causes delay or impairment of development in social, emotional, verbal and non-verbal communication, and intellectual and learning development. The cause of autism is not known now, but the original point is biological and in the brain namely: abnormalities of the brain, abnormalities of neurotransmitters, genetic factors including other factors that cause autism such as environmental factors, disorders, and infection during pregnancy and

delivery. Therefore children with autism should be cared for and treated by health professionals and their family in order that they may have appropriate development and self-care according to their potential.

### **1.1.2 Care-giving demands of Children with Autism**

However, like other children, children with autism have care-giving demands for psychological and physiological support and enhancement of developments. They also need enhancement in communication and social developments according to their impairments. Caring for children with autism depends on competence in learning by the child. But in fact, children with autism have impairments that hinder their learning ability such as little and slow learning, having a short attention span, being under responsive, or hyperactive being, resistant to changes, having deficient perception and lack of understanding of the meaning of words, commands, or anything that they see, hear and touch, etc. (Phenkhae Limsila, 1998: 67-69).

The children with autism have care-giving demands for psychological and physiological support, potential enhancement, and enhancement of developments. They need psychological support such as love, warmth, understanding, and attention from their caregivers (Sriruan Kaekangwan, 1995: 242). They need physiological support such as food, water, exercise, and rest (Phunni Chuchaichenjit, 1996: 132). They need potential enhancement; that is training to be able to self care for themselves in their daily routine such as eating, personal hygiene, dressing, etc. Also the children with autism need enhancing developments in communication, cognition, social relationship, and moral behavior so that they are able to speak, understand in language and all-round environments, and are able to live with others (Praphaiphuan Phumwuttisan, 1983: 94-100).

Moral development is related to the intellect of the children. Preschool children only understand the meaning of "goodness" and "badness" in that goodness is anything they do for which they are not punished. Although the children incapably understand about right, wrong, goodness and badness, the caregivers should explain, guide, train them and be a good model for their child to imitate. The children should

learn about giving, helping, and apportionment, etc (Lakha Piyaatchariya, 1987: 121-133; Sriruan Kaekangwan, 1995: 250).

In summary, preschool children with autism have care-giving demands for psychological support, physiological support, potential enhancement, enhancement of developments in communication, intellectual, emotional, social, and moral behavior. These will improve their child's competence in order to prepare them to go to school and to live in community.

## 1.2 Caregivers

In the general meaning, *caregiver* is anyone who provides assistance to someone else who needs it. *Family caregiver* or *informal caregiver* refers to a relative or person who provides assistance to the recipient at home. The majority of caregivers are family members such as father, mother, husband, wife, a relative, or someone close such as friends, or neighbors, etc. The caring aims to assist without payment or reward. The term of caregiver is separated into responsibility levels. *Primary caregiver* is the person who has direct and consistent responsibilities in caring, while a *secondary caregiver* is a person who has non-direct responsibilities in caring and does so part-time such as officers or persons who intend to get paid (Family Caregiver Alliance and The State of California's Caregivers Resource Center, 1998b: 1; Yupapin Sirapo-ngam, 1996: 86).

Caregivers acquire functions, responsibilities, and tasks in caring, for instance helping in the activities of daily live (ADLs), coping with problem behaviors, giving emotional and psychological support, and helping with decision making in health status, such as seeking a place for treatment and choosing different methods of treatment for the recipient (Chuchun Chiwaphunphon, 1998: 18-19; U.S. General Accounting Office, 1996: 1; Yupapin Sirapo-ngam, 1996: 87-88).

In this study, caregivers of children with autism are people who have direct and consistent responsibilities in caring and are family members, such as father, mother or a relative. The caring aims to assist without payment or reward. The

caregivers have functions in caring such as helping in activities of daily life, coping with problem behaviors, giving emotional and psychological support, and helping with decision making in health status.

### **1.3 Mental Health of Caregivers of Children with Autism**

#### **1.3.1 Mental Health**

Although there are many definitions of mental health they seem to be similar. For instance, the World Health Organization (WHO) defined mental health as the capacity of a person to adapt to functions comfortably within society and the environment, having satisfying and spontaneous relationships with others, and living with a balance between the integrated body, mind, spirit and the environment which includes meeting their needs, not merely the absence of disease or infirmity (Johnson, 1993: 4). Similarly, the Department of Medical Service, Ministry of Public Health (1993: 32) adds to the meaning of mental health defined by WHO that it includes persons who have normal emotions, intellects, and can solve problems. Also the American Psychiatric Association (1980 quoted in Shives, 1994: 4) adds to the meaning of mental health that it includes simultaneous success at working, loving, and creating with the capacity for mature and flexible resolution of conflicts between instincts, conscience, and important other factors and reality.

In summary, mental health is the capacity of a person to adapt to function comfortably within society and the environment, having a satisfying and spontaneous relationship with others and living with a balance between physiological and psychological needs.

### 1.3.2 Mental Health of Caregivers of Children with Autism

Autism is an illness that causes an impairment in language / communication, social interaction, perception, and behavioral response to the environment. Caring for children with autism is difficult for a long period of time, so caregivers of children with autism are persons who are at risk of getting mental health problems (McAdoo & DeMyer, 1978 quoted in Miligram & Atzil, 1998: 415; Siriphon Suwannathot, 1994: 84-87).

Many previous studies showed that caregivers of children with autism suffered from restrictions on their personal time and freedom, and endured a loss of self-esteem because they viewed themselves as having “failed” in their role. They had physical illnesses resulting from stress, depression, anger, fatigue, anxiety, hopelessness, guilt, and tension (Bebko, et al., 1987: 565-566; DeMyer, 1979; Holroyd, 1974; Wolf, et al., 1989 quoted in Harris, 1994: 162). Canwell and Baker (1984 quoted in Kanya Thanyamantha, 1991: 15) found that parents of children with autism had mental health problems, such as depression and anxiety, resulting from the difficulty in the management of their child, finances and their child’s future. Most importantly, caregivers particularly those who are the parents of children with autism have the risk of psychiatric illness (Chom Chumchuai, 1996: 9).

Kanya Thanyamanta (1991) studied the effects of caring for children with autism on 70 parents. She reported that 7.14% of parents had somatic symptoms, 10% were depressed. Most of them had specific anxiety over their child’s symptoms and the inadequate service facilities. Rungludee Wongchum (1996) studied stress in 138 parents of children with autism who were admitted to Yuwaprasart Withayopatum Child Psychiatric Hospital. The parents experienced a high level of stress. The factors that caused stress of these parents were excessive attention in caring, a long treatment and recognition of their child’s symptoms. Similarly the study of O’Moore (1978 quoted in Koegel et al., 1992: 206) found that mothers of children with autism showed a higher level of stress in activities that involved social contact. DeMyer (1979, quoted in Konstantareas and Homatidis, 1989: 459-460) found that mothers of children with autism had physical and psychological tension such as; guilt and uncertainty as to their mothering ability. Fathers of children with autism were also

affected, but they apparently were mainly influenced indirectly through their wives' reaction and pain at having child with autism.

Holroyd and McArthur (1976 quoted in Gallagher, et al., 1983:11) compared the level of stress reported by parents of children with autism to those of children with Down's syndrome, and those children who were attending the patient psychiatric clinic. They found that these families revealed different patterns of parental responses, and families of children with autism reported the most overall stress. The parents of children with autism had physical illnesses, depression, and negative attitudes toward their child. Similarly, the study of Wolf and his colleague (1989 quoted in Harris, 1994: 162) reported that mothers of children with autism experienced depression more than mothers of children with mental retardation and mothers of children with normal development. Gill (1990 quoted in Harris, 1994: 163) found that mothers of pre-school children with autism experienced significantly greater stress, compared with mothers of children with mental retardation and mothers of children with normal development. More recently, Siriporn Suvuntod (1998) reported that the families of children with autism had feelings of hopelessness about the progress of their child, discouragement, tension and were burdened in caring.

Studies about mental health related to demographic data are, as follows; mental health is related to caregivers' demographic data such as age, occupation, income, socioeconomic class, intelligence, past experience, and marital relationship. It was found that marital relationship is the best support of the caregivers (Gallagher, 1983: 12-15). Mental health of the caregivers is related to children with autism's symptoms and behaviors (Bebko, et al, 1987: 565-577; Bristol, 1979 quoted in Gallagher, 1983: 11; Konstantareas & Homatidis, 1987: 459-470). The children's age is also important because mothers of an older child have somewhat more stress than mothers of younger children (Bristol, 1979, Demyer & Goldberg, 1983 quoted in Bebko, et al., 1987: 566). Caregivers of male children with autism were also associated with having greater stress than those with female children (Bristol & Schopler, 1984 quoted in Bebko, et al., 1987: 566).

In summary, the mental health of caregivers of children with autism is the capacity of caregivers to adapt in order to function effectively within society and the environment. The caregivers who have good mental health demonstrate satisfying and spontaneous relationships with others, and meet their needs, both physical and psychological. Caregivers of children with autism who are mentally healthy also demonstrate effective management of stress, anxiety, depression, and the ability to fulfil their role functions.

#### **1.4 The Assessment of Mental Health of Caregivers of Children with Autism.**

There are a great number of questionnaires which assess mental health status. These include the Mental Health Index, Symptom Distress 90 (SCL.90), and the General Health Questionnaire (GHQ). *The Mental Health Index*, was developed by the Rand Corporation, California. This questionnaire evaluates mental health using both positive and negative criteria. Positive criteria consists of emotional ties and general positive effects, and negative criteria consists of anxiety, depression and loss of control (Veit & Ware, 1983: 740). The Symptom Distress 90 (SCL.90), developed by Leonard and Lipman, consists of 90 items, rated in 9 sub-scales, as follows: feeling about physical illnesses, obsessive-compulsive symptoms, lack of communication with others, depression, anxiety, hostility, panic, paranoia, and psychiatric disorders. The General Health Questionnaire (GHQ), developed by Goldberg (1972), is a self-administered screening questionnaire. It is to aid in the detection of non-psychotic psychiatric illness. It is concerned with 2 major classes of phenomena: inability to carry out one's normal "healthy" functions, and the appearance of new phenomena of a distressing nature. The GHQ consisted of 60 items that cover physical symptoms and overt psychiatric disturbance. The GHQ was found to be a good questionnaire for screening psychiatric morbidity in the general population, particularly in the community. Up to date, the GHQ is highly accepted and it has been translated into more than 36 languages.

In Thailand, the questionnaire that evaluates mental health status is the Psychological Questionnaire. This questionnaire was translated from Symptom

Distress 90 (SCL.90) by a group of psychologists at Somdedchaopraya Hospital. Another questionnaire is the General Health Questionnaire-28 (GHQ-28) in the Thai-version was translated by Tana Nilchaigovit, Chakkrit Sukying and Chatchawan Silpakit from The General Health Questionnaire of Goldberg (1972), as above-mentioned. The GHQ-28 is a screening test for psychiatric disorders, and it has 28 items. The GHQ-28 is concerned with the psychological distress of altered behaviors, which is rated in 4 sub-scales of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression with 7 items in each sub-scale. GHQ-28 consists of 7 items in sub-scales of somatic symptom, and 2 items of somatic symptom inserted in other sub-scales (Goldberg, 1979:139-145). Most importantly, it can be used as a self-administrated screening instrument to detect psychiatric disorders in the Thai population (Tana Nilchaigovit et al., 1996: 2-3). The GHQ-28 has good effectiveness, reliability, validity, a high level of sensitivity and specificity and a low misclassification rate (Bank, 1983 quoted in Jintana Singkhornard, 1998: 4; Nawanant Piyavhatkul, et al., 1998: 325-335; Tana Nilchaigovit et al., 2539: 2-3).

In this study, the GHQ-28 Thai-version was chosen to assess the mental health status of caregivers of children with autism. The first reason is because the GHQ-28 takes a short period of time for data collection. Second, the GHQ-28 has been translated into a Thai version and has been widely used with the Thai population. Third, the GHQ-28 showed good efficiency, reliability, and validity, and fourth, the GHQ-28 could screen psychiatric morbidity.

## 2. Caring Behaviors of Caregivers of a Child with Autism.

### 2.1 The Concept of Caring and Caring Behaviors.

*Caring* means sense of ownership, attachment, interest, concern, love, and protection (Webster's Dictionary, 1988: 212). The word *Caring* is widely used in everyday life. *Caring* is used in a positive sense to describe relationships, love, involvement, and attention (Benner & Wrubel, 1989: 1). *Caring* is an interaction between caregivers and caring recipients with understanding, and trust (Blattner, 1981 quoted in Rangthip Wirakun, 1996: 18). Mayeroff (1971 quoted in Euswas, 1991: 9) stated that caring is the process of helping another grow and actualize. This process is the common basic pattern of caring in any context in which it occurs. Through the caring process the caregiver participates in the reality of the others. The caregiver sees the others as having potentialities which are expressed through the latter's need to grow. According to Leininger (1991: 46), human care is a universal phenomenon of survival in the human race. Care is action and activities directed toward assisting, supporting, or enabling another individual or group with evident or anticipated needs to ameliorate or improve a human condition or way of life. Watson (1985: 1-21, 1988: 29) believed that "caring" is concerned with consistency between acceptance of human value, willingness, intention, knowledge, and performance. Watson stated that caring is a moral ideal rather than a task-oriented behavior and includes such elusive aspects of the actual caring occasion as the transpersonal caring relationship between the caregiver and caring recipient. The goal is the preservation of human dignity and humanity in the health care system. The underlying aim is gratification of certain human needs, that are necessary for growth and development. According to Watson, caring behaviors consist of 10 curative factors, as following:

1. *Formation of a humanistic-altruistic system of values.* This factor emphasizes the respect for humanistic and altruistic values of the recipient, and caring with love, and mercy. This factor can be defined as satisfaction through giving and extension of the sense of self.

2. *Instillation of faith-hope.* This factor, incorporating humanistic and altruistic values, facilitates the promotion of holistic care and positive health. It also describes the role in developing an effective relationship between the caregiver and the recipient.

3. *Cultivation of sensitivity to one's self and to others.* The recognition of feelings leads to self-actualization through self-acceptance for both the caregiver and the recipient. As caregivers acknowledge their sensitivity and feelings, they become more genuine, authentic, and sensitive to others.

4. *Development of a helping-trust relationship.* The development of a helping-trust relationship between the caregiver and the recipient is crucial for transpersonal caring. A trusting relationship promotes and accepts the expression of both positive and negative feelings. It involves congruence, empathy, nonpossessive warmth, and effective communication. Congruence involves being real, honest, genuine, and authentic. Empathy is the ability to experience and thereby understand the other person's perceptions and feelings and to communicate those understandings. Nonpossessive warmth is demonstrated by moderate speaking volume; a relaxed, open posture; and facial expressions that are congruent with other communications. Effective communication has cognitive, affective, and behavior response components.

5. *Promotion and acceptance of the expression of positive and negative feelings.* The sharing of feelings is a risk-taking experience for both the caregiver and the recipient. The caregiver must be prepared for either positive or negative feelings. The caregivers must recognize that intellectual and emotional understandings of a situation differ.

6. *Systematic use of the scientific problem-solving method for decision making.* Use of the process brings a scientific problem-solving approach to care.

7. *Promotion of interpersonal teaching-learning.* This factor is an important concept that separates caring from curing. It allows the recipient to be informed and thus shifts the responsibility for one's wellness and health to the recipient. The caregiver facilitates this process with teaching-learning techniques that are designed to enable the recipient to provide self-care to determine personal needs, and to provide opportunities for their personal growth.

8. *Provision for supportive, protective, and/or corrective mental, physical, sociocultural, and spiritual environment.* Caregivers must recognize the influence that internal and external environments have on the health and illness of individuals. Concepts relevant to the internal environment include the mental spiritual well-being and sociocultural beliefs of an individual. In addition to epidemiological variables, other external variables include comfort, privacy, safety, and clean, aesthetic surroundings.

9. *Assistance with gratification of human needs.* The caregiver recognizes the biophysical, psychophysical, psychosocial, and intrapersonal needs of self and the recipient. Recipients must satisfy lower-order needs before attempting to attain higher-order ones. Food, elimination, and ventilation are examples of lower-order biophysical needs, whereas activity/inactivity and sexuality are considered lower-order psychophysical needs. Achievement and affiliation are higher-order psychosocial needs. Self-actualization is a higher order intrapersonal-interpersonal need.

10. *Allowance for existential-phenomenological forces.* Phenomenology describes the data of the immediate situation that helps people understand the phenomena in question. Existential psychology is a science of human existence that uses phenomenological analysis. Watson considers this factor to be difficult to understand. It is included to provide a thought provoking experience leading to a better understanding of ourselves and others.

In summary, caring behaviors are activities directed toward assisting, supporting, or enabling another individual or group. The goal is the preservation of human values, human dignity and human rights. Caring behaviors is based on the consistent and sincere relationship between a caregiver and a caring recipient. Caring is concerned with consistency between the acceptance of human value, willingness, intention, knowledge, and performance for helping another grow and actualize.

### **2.3 Caring Behaviors of Caregivers of Children with Autism.**

The fundamental goal of child-rearing for most parents is basically the same, namely, how to cope with day to day events in a way that will enhance rather than hinder family members' growth and development. However, families having a handicapped child are faced with complicated problems (Cavanagh & Ashman, 1985: 151). Particularly, families having a autistic child with severe impairments are facing a severe burden as they become the primary caregiver of their ill child for a long period of time.

From the related literature review about caring behaviors for children with autism, it was found that caring behaviors for children with autism aimed to encourage their development, to improve appropriate skills, and to reduce problem behaviors. Caring behaviors for children with autism was based on love, mercy, warmth, attention, willingness, sincerity, consistency in caring and particularly acceptance and understanding of their behaviors and their emotions (Penkhae Limsila, 1990: 12-13; Supharut Ekatsawin, 1996c: 12-13). Caring behaviors for children with autism can be classified into 3 parts, as follows

1. **Improvement in self-care skills.** These are essential skills that children with autism must learn in order to be able to self care in daily life. The skills include eating, dressing, bathing, and personal hygiene (Sansani Sutprasoet, 1996b: 66-74).

2. **Improvement in development consists of emotional factors,** communication and language, intellect and learning, and using muscle development (Sansani Sutprasoet, 1996a: 54-56; Supharut Ekatsawin, 1996c: 18).

3. **Improvement in solving problem behaviors consists of behavior modification and medication.** Children with autism have many problematic behaviors such as screaming, aggression, destruction, self injury or injury to others, aloofness and social withdrawal, resistance to change, and special fears, etc. Behavior modification aims to reduce problem behaviors, and enhance and encourage appropriate behaviors. Medication (such as CNS stimulant, neuroleptic, antidepressant, etc.) has been used in treating specific medication-responsive symptoms, such as self injurious behavior, aggression, concentration and learning problems, as well as associated conditions; epilepsy, etc (Autism Society of America,

1998: 6-7; Phengkhae Limsila, 1998: 20-21; Waldinger, 1990: 309). Caregivers ensure their child have appropriate medicines according to the order of physicians.

In summary, caring behaviors of caregivers of children with autism are activities that caregivers do for their children in order to help their children meet needs including physical, psychosocial, and spiritual, and to protect and maintain their child's values, honor and human rights. Such caring behaviors are based on the consistent and sincere relationship between caregivers and their child. Therefore in this study, the concept of caring behaviors was based on Watson's curative factors (1985) and the review of related literature, define the caring behaviors of caregivers of children with autism. These caring behaviors include: 10 aspects as follows:

*1. Giving oneself helping the children with compassion*

Children with autism need psychological support such as love, warmth, understanding, and attention like normal children, This is the most important factor that helps the child's growth, both physiological and psychological, and may hinder emotional and mental problems. The caregivers demonstrate their care for children with autism with love and great attention. They take care of the child wholeheartedly. They provide time for the child to talk, play and train them in development.

*2. Encouraging the appropriate behavior of the children*

The caregivers should not ignore the important role of encouraging the appropriate behaviors as well as the curative processes. Although autism is not curable, and it is a lifelong disability, encouraging their child with autism to behave appropriately by praising with verbal and nonverbal communication, may reduce undesirable behaviors.

*3. Sensitivity to the children's needs*

Children with autism live in their own world. The caregivers observe any change that occurs in their children, either physical, emotional, social or spiritual, and try to understand and respond to changes immediately.

*4. Being genuine and willing to respond regularly*

The caregivers show spontaneity in their relationship with their children with autism. Although it is difficult because children with autism have impairment in

making a relationship; they have social self-isolation, atypical attachment, lack of interest in friendship and lack of awareness of emotions and feelings of others. The caregivers use clear and understandable language when talking to their child because children with autism have an impairment with communication, slow comprehension or can not understand at all.

#### *5. Accepting both positive and negative behavior of the children*

Children with autism have many problem behaviors such as screaming, aggression, destruction, injury to themselves and others, making their caregivers suffer and have shame, aloofness and social withdrawal, resistance to change, and special fears. It is important that caregivers understand the limitations, competence, and ability of their child, and the caregivers show an understanding of the meaning of behaviors of the children. They should not try to judge whether the child's behaviors are right or wrong.

#### *6. Utilizing problem-solving method*

Utilizing a problem-solving method is the process that depends on the omniscience of the caregivers. First, the caregivers seek more information to understand the cause of problems that occur with their child by asking and observing, and finding ways to help them solve the problems. If the caregivers lack understanding of the problems of their children, caring will proceed with difficulty.

#### *7. Training and Educating*

Children with autism have care-giving demands to enhance their potential, enhance developments in communication, intellectual, emotional, and social. The caregivers teach their child to be able to self-care. They provide the opportunity in learning for their child even if the child has impairments in intellectual and learning developments. However, if the children acquire the appropriate teaching, training, and support, they will develop their competence.

#### *8. Establishing a safe environment*

The children with autism lack the ability to protect themselves; they do not show fear in dangerous situations. Therefore the caregivers should establish a home environment to make their children feel safe, secure and they should not leave their

child alone. And they should arrange the home to be cleaned, and cozy with good ventilation.

*9. Assisting the children to meet his / her needs*

Because children with autism have care-giving demands both psychological, and physiological, the caregivers should help their children to meet their needs including physiological needs (food, water, personal hygiene, elimination, rest and exercise), and psycho- social needs (security, safety and sense of belonging).

*10. Enhancing the children's moral development*

The caregivers enhance and support their children with autism to learn how to give, accept apportionment and care for others. Although the children are incapable of understanding about right, wrong, goodness and badness, caregivers should explain, guide, teach, train and be good models for imitation. These positive teaching methods will show results quickly.

### **3. The Relationship between Mental Health and Caring Behaviors of Caregivers of Children with Autism.**

Generally, a *person with a normal healthy function* refers to a person who has competence in reality orientation; distinguishes fact from fantasy, manages stress. The person can manage his/her own inappropriate mood such as depression, anxiety, and can tolerate high levels of that stress, knowing that the feeling is not going to last forever. The person is flexible and can experience failure without self-castigation and acceptance of responsibility for action (Beckingham, & Baumann, 1990:2; Johnson, 1993:5). Johnson, 1993:5). Mental health is concerned with competence, potential and decision-making and role-play (Suwaniya Kiawkingkaw, 1984: 3). This includes a person who has not only the ability to love, but also the ability to care for others, or to work productively (Pasquali, et al.,1985: 9). That is, mental health is related to the behaviors of a person, including caring behaviors.

The caregiver's physical and psychological well- being can be affected by care-giving demands from someone whom they care for (Yupapin Sirapo-ngam, 1996: 94). Cavanagh and Ashman (1985: 152) found that mental health was related to caring behaviors of caregivers of handicapped children. And Rosenberg (1977 quoted in

Gallagher, et al., 1983: 12) stated that mental health problems negatively influenced the parent's abilities to care for a handicapped child. The mental health problem not only impacts on the caregivers, but also the behaviors that caregivers perform with their child. Caregivers' behaviors are the child's environment that directly and influentially affects the developments of the children (Chamrut Pin-ngoan, 1993: 14).

Mental health related to caring behaviors of caregivers of children with autism has not been studied. However, Moes and his colleague (1992: 1272-1274) stated that mental health may be related to caring behaviors of caregivers of children with autism. This was supported by Wing (1980: 133-140) who stated that although caring for children with autism is difficult because of the severe impairments of children with autism, the caregivers wanted to live with their child, because of the occurrence of attachment. When they see their child better, the caregivers will have hope, and a sense of belonging in that progression. And when they see the result of their performance for a long time, they will have a normal healthy function that will make them satisfied with their caring behaviors. Chom Chumchuai (1996: 6-11) stated that the caregivers of children with autism were extremely important to the child. When the caregivers effectively managed their emotions, thoughts, and attitudes, they provided consistent caring, to enhance the appropriate development for their child. Milgram and Atzil (1988: 415-424) found that mental health is related to tasks in caring by parents of children with autism.

In summary, this section provided the related literature review on autism, the nature of and care-giving demands of children with autism, the mental health of caregivers of children with autism, caring behaviors of caregivers of children with autism, and the relationship between mental health and caring behaviors of caregivers of children with autism. Caring for children with autism is difficult for a long period of time, so caregivers of children with autism are persons who are at risk of getting mental health problems. The caregivers of children with autism suffered from restrictions on their personal time and freedom, and endured a loss of self-esteem because they viewed themselves as having "failed" in their role. They had physical illnesses resulting from stress, depression, anger, fatigue, anxiety, hopelessness, guilt,

and tension. Mental health may be related to the caring behaviors of caregivers of children with autism. When the caregivers effectively managed their emotions, thoughts, and attitudes, they provided consistent caring, to enhance the appropriate development for their child.



## CHAPTER III

### METHODOLOGY

#### Research Design

In this chapter, population and sampling, setting, instrumentation, data collection procedure, protection of human subjects and data analysis were presented.

#### Population and Sampling

##### 1. Population

The population of this study were caregivers of children with autism who brought their children to the outpatient clinic at Yuwaprasart Withayopatum Child Psychiatric Hospital, Samutprakan. The inclusion criteria for the samples in this study were:

- 1.1 A father, a mother, or a significant family member who had lived with an autistic child with an age between 2 to 5 years, and had the responsibility to give direct care for the child,
- 1.2 Caregivers of children with autism who had been diagnosed as autistic for at least 3 months, and
- 1.3 Caregivers who cared for the children without payment or reward.

##### 2. Sampling

The subjects in this study consisted of 100 caregivers of children with autism who met the above criteria. The number of subjects required was calculated by the formula below:

$$n = \frac{Z^2 S^2}{d^2}$$

where

n	=	The number of subjects
Z	=	The value of standard errors in the standard errors in the normal distribution at the 95% confidence interval ( $\alpha = 0.05$ ) which was equal to 1.96

$$S^2 = \text{Variance of questionnaire}$$

$$d = \text{Number of errors that are acceptable}$$

when the variance of questionnaire was 241.73 therefore

$$n = 3.8416 \times 241.73 / 13.24$$

$$n = 70.138$$

### Setting

The setting of this study was the outpatient clinic, Yuwaprasart Withayopatum Child Psychiatric Hospital, Samutprakan. The hospital provides treatments for children and teenagers with psychiatric disorders. It consists of 150 beds. Health professionals consist of psychiatrists, nurses, psychologists, speech tutors, special teachers, and social welfare staff. The hospital's services consist of in and out-patients service for children and teenagers with psychiatric disorders. The services for children with autism are behavior modification, social skill development, speech/ language therapy, special education, and caregivers training. In this study, the data were collected at the outpatient clinic at Yuwaprasart Withayopatum Child Psychiatric Hospital.

### Instrumentation

The instruments used for data collection in this study comprised the demographic data questionnaire, the General Health Questionnaire-28 (Thai-version), and the Caring Behaviors of Caregivers of Children with Autism Questionnaire, as follows:

**1. The demographic data questionnaire** was developed by the researcher to provide general information of both caregivers and children with autism; it consisted of 2 parts as follow:

**1.1 Data of caregivers** included age, gender, marital status, education level, income, type of family, relationship between caregivers and children, period of caring, and knowledge of autism and caring.

**1.2 Data of children with autism** included age, gender, order of birth, duration of illness, frequency of hospitalization, and a history of seizures.

## 2. The General Health Questionnaire-28 [Thai-version]

The General Health Questionnaire-28 (GHQ-28) in the Thai-version was translated by Tana Nilchaigovit, Chakkrit Sukying and Chatchawan Silpakit from the General Health Questionnaire of Goldberg (1972).

GHQ-28 is a self-administered screening instrument for psychiatric morbidity and to detect non-psychotic psychiatric illness. It consists of 28 items that were concerned with psychological distress of altered behaviors, which were rated in 4 sub-scales of somatic symptom, anxiety and insomnia, social dysfunction and severe depression with 7 items in each sub-scale. Each item compared the recent state with the usual state, and the item is only counted as being present if it is being experienced "more than usual". The scores were calculated by using GHQ score (0-0-1-1 / bimodal response scale), the meaning of scores were: 0 = absent, 1 = present. The criterion of six or more positive responses were used to predict a person who had potential psychiatric disorders (Goldberg et al., 1976: 61-67). The result of GHQ score was not different from a Likert score (0-1-2-3), and the correlation of them is 0.92-0.94.

GHQ-28 had an internal consistency (Cronbach's alpha coefficient) of 0.90, sensitivity of 81.3 and specificity of 88.2; that showed its reliability and validity. Thus GHQ-28 can be used as a self-administrated screening instrument to detect psychiatric disorders in the Thai population (Tana Nilchaigovit, et al., 1996: 2-3).

The reliabilities of the General Health Questionnaire- 28 (GHQ-28) was tested on 30 caregivers of children with autism who were similar to the study sample. Cronbach's alpha was used to examine the reliabilities of the instrument.

$$\alpha = \frac{n}{n-1} [1 - \frac{S_1^2}{S_t^2}]$$

where

- $\alpha$  = Cronbach's alpha
- $n$  = The number of items in the questionnaire
- $S_1^2$  = Variance of each item score
- $S_t^2$  = Variance of total score

The reliabilities of the General Health Questionnaire- 28 was 0.92.

### **3. The Caring Behaviors of Caregivers of Children with Autism Questionnaire.**

The Caring Behaviors of Caregivers of Children with Autism Questionnaire was developed by the researcher, and was based on caring concepts of Watson (1985) and concepts from the related literature review as well as the data from the interviews and observation of the caregivers of children with autism, at Yuwapasart Withayopatum Child Psychiatric Hospital. The findings of the interviews with caregivers of children with autism were interesting and there were real experiences that illustrated their caring behaviors. The details were explained, as follows:

The caregivers gave love, mercy, attention, and provided time in caring for their child, more than they cared for themselves. They enhanced their child to do the activities in order to improve their skills, by praising, hugging, kissing the cheeks and giving rewards such as sweets and toys. Some caregivers said that their child had limited learning ability, therefore they had to spend more time. Some said that their child had a short attention span, so they worked hard to encourage and help their child to do the activities.

The caregivers said that they were playing and talking even though their children could not speak at all. They were hugging even without response. They attempted to understand abnormal behaviors and the world of their child, through step by step training with endurance. Many caregivers faced problems when their child was going to school such as playing badly, having problems about elimination, or injuring friends, etc. These were reasons the caregivers decided not to send their child to school. They suffered from fear that teachers would lack understanding and might punish their child. Moreover, many caregivers did not accept the illnesses of their child, they were shopping around and then they only halfheartedly accepted it. One of the caregivers said that having a child with autism caused her to keep the child out of sight of others, even family members such as grandfathers, grandmothers, etc. The mother was ashamed and hurt because of her child's disability.

The caregivers solved the problem behaviors of their child such as screaming, naughtiness, self-centeredness, destruction, repeated play, and problems

about sleeping and elimination. These were difficult to care for, and made caregivers discouraged. They solved problems by observing, modifying, and evaluating problem behaviors. They learned how to care for their child from books, other caregivers, health professionals, and their own experiences.

The caregivers taught their child to learn about the all-round environment even though the child could not speak. They realized the importance of a dangerous environment because their child could not protect themselves. They kept razor-sharp things, iron, glass, etc. far from their child. The caregivers established a home environment to make their child feel safe and they did not leave their child alone.

The caregivers helped their child to meet needs, such as food, water, elimination, and personal hygiene. They trained them in skills according to the impairments that their child had. Some children acquired gaze training first, while some acquired speech training first. After the children progressed in their competence, they acquired self-care skills training such as eating, bathing, dressing in order that their children could go to school. They insisted that their child can progress in social skills, and would be able to live in society like normal children. They allowed their child to wander out side the home but they were closely watched.

Furthermore, many caregivers resigned from their occupation in order to spend more time with their child. This impacted them in many ways, such as financial problems, and spouse relationships. Some caregivers were separated and divorced. These problems affected their mental health.

Based on the data from interviews and Watson's caring behaviors; the Caring Behaviors of Caregivers of Children with Autism Questionnaire scale were developed which of 34 items and covered 10 aspects as follows: giving oneself helping the children with compassion (3 items; 1-3), encouraging the appropriate behavior of the children (3 items; 4-6), sensitivity to the children's needs (4 items; 7-10), being genuine and willing to respond regularly (3 items; 11-13), accepting both positive and negative behavior of the children (3 items; 14-16), utilizing a problem-solving method (3 items; 17-19), training and educating (3 items; 20-22), establishing a safe environment (3 items; 23-25), assisting children to meet their needs (6 items; 26-31)

and enhancing the children's moral development (3 items; 32-34). All items were positive.

Four open-ended questions were also included. These questions were,

1. In addition to the above-mentioned items, how do you have especial caring for your child with autism or different caring from other children ?
2. In your thought and actual situations, what supports you in caring for your child with autism ?
3. In your thought and actual situations, what obstructs you in caring for your child with autism ?
4. Please tell what you need more from health professional teams so that you can give better care for your child with autism.

A 4-point rating scale was used that presented frequency of performance of caring behaviors for children with autism; usually, often, sometimes, and rarely/ never.

#### ***Meanings of scales***

Usually	means the caregivers performed according to the item, usually or when the situation of the item occurred, they performed every time.
Often	means the caregivers performed according to the item often, or when the situation of the item occurred, they performed several time.
Sometimes	means the caregivers performed according to the item sometimes
Rarely/Never	means the caregivers rarely performed according to the item or the caregivers never performed although the situation of the item occurred.

#### ***The meaning of the scores***

Usually	=	4
Often	=	3
Sometimes	=	2
Rarely/Never	=	1.

Therefore the total score of caring behaviors was 136. These criteria were used to evaluate the percentage of total scores of caring behavior and each aspect. Scores below 60%, 60-80%, and above 80% were set as low, moderate, and high level of caring behaviors, respectively.

The content validity of the Caring Behaviors of Caregivers of Children with Autism Questionnaire was evaluated by five experts: a child psychiatrist, a nurse instructor who is an expert in caring behaviors, a nurse instructor who is an expert on caregivers, a nurse instructor who is an expert in pediatric nursing and a nurse who is a clinical expert in caring for children with autism. Then the researcher revised the questionnaire according to the experts' recommendations.

The reliabilities of the Caring Behaviors of Caregivers of Children with Autism Questionnaire was tested on 30 caregivers of children with autism who were similar to the study sample. Cronbach's alpha was used to examine the reliabilities of the instrument.

$$\alpha = \frac{n}{n-1} [1 - \frac{S_1^2}{S_t^2}]$$

where  $\alpha$  = Cronbach's alpha

$n$  = The number of items in the questionnaire

$S_1^2$  = Variance of each item score

$S_t^2$  = Variance of total score

The reliabilities of the Caring Behaviors of Caregivers of Children with Autism Questionnaire was 0.93.

### Data collection procedure

In this study, the researcher collected data from the caregivers who brought children with autism, ranging in age between 2 to 5 years, to the outpatient clinic at Yuwaprasart Withayopatum Child Psychiatric Hospital. The procedures of data collection were as follows:

1. The researcher sent a letter to the director of Yuwaprasart Withayopatum Child Psychiatric Hospital requesting permission for data collection. Then the researcher met the head of the outpatient clinic to explain the details, the purposes of this study and data collection procedures in order to ask for permission to

collect data from April to June, 1999 on Monday and Wednesday -Friday at 8:00-12:00 am.

2. The researcher selected the caregivers who met the study's criteria by using a chart and the suggestions of nursing staff.

3. After introducing, the researcher built a good relationship with subjects and explained the purposes of this study. The researcher asked for their permission to collect data and used an informed consent form to ensure that the subjects had volunteered.

4. The researcher explained how to complete the demographic data questionnaire and the Caring Behaviors of Caregivers of Children with Autism Questionnaire. Then the researcher read each item, both question and answer for each subject, and recorded their answers. When the answer was rarely/never, the researcher then asked about their reasons for this response.

5. With the GHQ-28, the subjects were allowed to complete the instrument by themselves. The researcher would not interfere with them during their completion. In the meantime, the researcher stayed close to the subjects in order to respond to any questions the subjects might have.

6. In the case of subjects who expressed depression or were crying, these subjects were supported by the researcher until they felt better. The researcher asked whether they wanted to continue or discontinue to complete the data entry form. The researcher quitted the data collection process if the subjects refused to continue

7. The researcher prepared the data analysis.

### **Protection of Human Subjects**

The data collection procedure in this study certainly compassed the protection of human subjects. The researcher explained the purposes of this study for the subjects and asked for their permission to collect data and used an informed consent form to ensure that the subjects had volunteered. The subjects were assured that all of the responses and the information from the hospital record would remain confidential, their identity would not be revealed, there were no known risks in participation and the subjects had the right to participate or not participate and the

right to withdraw from this study at any time, even after they started to answer the questions, and this would not affect them and the caring for their child in any way.

### **Data Analysis**

Analysis of data was completed by a computer using the Statistical Package for Social Science (SPSS/PC) and the analysis was divided into 4 parts, as follows:

1. Frequency distribution, and percentage were used to describe the demographic data profile.
2. Frequency distribution, and percentage were used to describe the mental health in caregivers of children with autism both for each sub-scale and for the total according to the criteria.
3. Frequency distribution, and percentage were used to describe the caring behaviors in caregivers of children with autism both for each aspect and for the total according to the criteria.
4. Chi- Square test was used to calculate and identify the relationship between mental health, and caring behaviors of caregivers of children with autism.

## CHAPTER IV

### RESULTS

In this chapter, the results of this study were presented in tables as follows;

- Part 1. The demographic data of the caregivers and the children with autism**
- Part 2. Mental health of caregivers of children with autism data**
- Part 3. Caring behaviors of caregivers of children with autism data**
- Part 4. The relationship of mental health and caring behaviors of caregivers of children with autism data**

**Results**

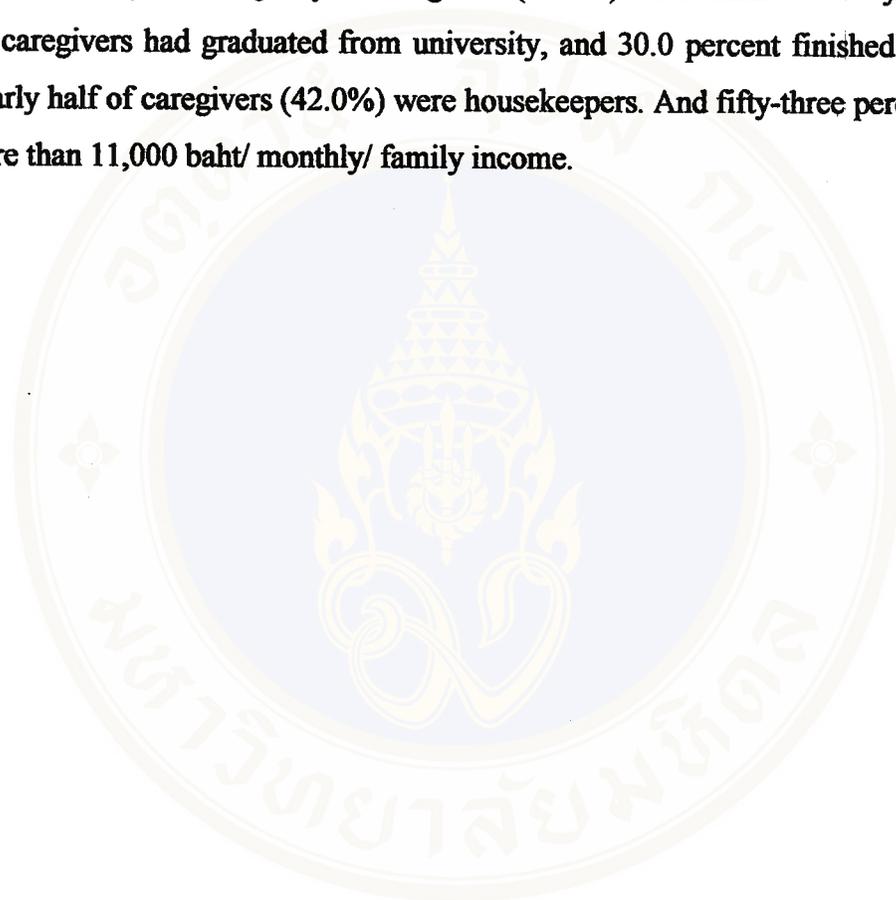
**Part 1. Demographic Data of Caregivers and Children with Autism.**

The demographic data of caregivers and children with autism were presented in tables 1-3.

**Table 1** Frequency and Percentage of Caregivers' Characteristics According to Gender, Age, Marital Status, Education level, Occupation, and Income.

<b>Characteristics</b>	<b>Frequency (N=100)</b>	<b>Percentage (%)</b>	<b>Characteristics</b>	<b>Frequency (N=100)</b>	<b>Percentage (%)</b>
<b>Age (years old)</b>			<b>Occupation</b>		
< 20	2	2.0	Housekeepers	42	42.0
20 - 30	22	22.0	Employees	17	17.0
31-40	48	48.0	Government	13	13.0
41-50	19	19.0	officers		
> 50	9	9.0	Office Staff	7	7.0
<b>Gender</b>			Merchants	17	17.0
Male	19	19.0	Agriculturist	3	3.0
Female	81	81.0	Others	1	1.0
<b>Marital status</b>			<b>Income</b>		
Single	4	4.0	< 3,000	3	3.0
Married	76	76.0	3,001-5,000	12	12.0
Widowed/ Divorced/ Separated	20	20.0	5,001-7,000	7	7.0
			7,001-9,000	11	11.0
			9,001-11,000	14	14.0
<b>Education</b>			> 11,000	53	53.0
Uneducated	2	2.0			
Primary school	20	20.0			
High school	30	30.0			
Vocational/ Diploma	14	14.0			
University	34	34.0			

**Table 1** presented frequency and percentage of the demographic data of 100 caregivers on gender, age, marital status, education, occupation, and income. It showed that nearly half of the caregivers (48.0%) were adult with ages ranging between 31-40 years old. The caregivers consisted of 81 females (81.0%) and 19 males (19.0%). The majority of caregivers (76.0%) were married. Thirty-four percent of caregivers had graduated from university, and 30.0 percent finished high school. Nearly half of caregivers (42.0%) were housekeepers. And fifty-three percent received more than 11,000 baht/ monthly/ family income.



**Table 2** Frequency and Percentage of Caregivers' Characteristics According to Type of Family, Relationship between Caregivers and Children, Period of Caring, and Knowledge of Autism and Caring.

<b>Characteristics</b>	<b>Frequency (N=100)</b>	<b>Percentage (%)</b>
<b>Type of family</b>		
Nuclear family	63	63.0
Extended family	37	37.0
<b>Relationship between caregivers and children</b>		
Fathers	20	20.0
Mothers	65	65.0
Relatives (Grandmothers, Grandfathers, and aunts)	15	15.0
<b>Period of caring (years)</b>		
< 2	9	9.0
2 - 3	26	26.0
> 3	65	65.0
<b>Knowledge of autism and caring</b>		
Knowledge acquired	86	86.0
Knowledge not acquired	14	14.0

Table 2 presented the frequency and percentage of caregivers' demographic characteristics on type of family, relationship between caregivers and children, period of caring, and knowledge of autism and caring. It showed that more than half of the caregivers (63.0%) lived in a nuclear family and 65.0 percent of the caregivers are the mothers of children with autism. More than half of the caregivers (65.0%) had experience of caring for more than 3 years. Eighty-six percent of the caregivers had acquired the knowledge of autism and caring.

**Table 3** Frequency and Percentage of Children with Autism Characteristics According to Age, Gender, Order of birth, and Duration of illness.

<b>Characteristics</b>	<b>Frequency (N=100)</b>	<b>Percentage (%)</b>
<b>Age (years old)</b>		
2 - 3	29	29.0
3 - 4	26	26.0
4 - 5	45	45.0
<b>Gender</b>		
Boys	70	70.0
Girls	30	30.0
<b>Order of birth</b>		
The eldest child	62	62.0
The middle child	7	7.0
The youngest child	31	31.0
<b>Duration of illness (years)</b>		
< 2	33	33.0
2 - 3	47	47.0
> 3	20	20.0

**Table 3** presented the frequency and percentage of children with autism demographic characteristics on age, gender, order of birth, and duration of illness. It showed that nearly half of the children with autism (45.0%) had an age range of between 4-5 years old. The children with autism consisted of 70 boys (70.0%) and 30 girls (30.0%). The majority of children (62.0%) are the oldest child. And nearly half of the children with autism (47.0%) had a duration of illness of between 2-3 years.

**Part 2. Mental Health of Caregivers of Children with Autism data.**

To describe the mental health of caregivers of children with autism, the results were presented in table 4:

**Table 4** Frequency and Percentage of Caregivers According to Mental Health of Caregivers of Children with Autism.

<b>Mental health</b>	<b>Frequency (N = 100)</b>	<b>Percentage (%)</b>
Persons who had a normal healthy function	73	73.0
Persons who had potential psychiatric disorders	27	27.0

**Table 4** presented the frequency and percentage of caregivers' mental health. The result showed that 73.0 percent of caregivers were persons who had a normal healthy function, while 27.0 percent of them were persons who had potential psychiatric disorders.

**Part 3. Caring behaviors of Caregivers of Children with Autism data.**

To describe caring behaviors of caregivers of children with autism, the results were presented in table 5:

**Table 5** Total score, Range, Mean, Percentage of Mean and Level of Caring Behaviors According to Caring Behaviors of Caregivers of Children with Autism, in each Dimension and Total.

<b>Caring Behaviors</b>	<b>Number of Items</b>	<b>Total score</b>	<b>Range of score</b>	<b>Mean</b>	<b>Percentage of mean</b>	<b>Level of Caring Behaviors</b>
1. Giving oneself helping the children with autism compassion	3	12	5-12	10.23	85.25	high
2. Encouraging the appropriate behavior of the children	3	12	3-12	10.01	83.41	high
3. Sensitivity to the children's needs	4	16	4-16	13.42	83.87	high
4. Being genuine and willing to respond regularly	3	12	4-12	10.55	87.91	high
5. Accepting both positive and negative behavior of the children	3	12	4-12	9.72	81.00	high
6. Utilizing a problem-solving method	3	12	3-12	9.76	81.33	high
7. Training and educating	4	16	3-12	10.05	83.75	high
8. Establishing a safe environment	3	12	6-12	10.44	87.00	high
9. Assisting children to meet their needs	6	24	6-24	19.75	82.29	high
10. Enhancing the children's moral development.	3	12	3-12	8.35	69.58	moderate
<b>Total</b>	<b>34</b>	<b>140</b>	<b>62-</b>	<b>112.28</b>	<b>82.56</b>	<b>high</b>

**Table 5** displayed the score in each dimension and the total of caring behaviors of caregivers of children with autism. The result showed that the caregivers had caring behaviors at a high level; a percentage of mean was 82.56 percent, the total score was 140 and the scores ranged between 62-136 with a mean of 112.28.

In each dimension, the caregivers had caring behaviors in the being genuine and willing to respond regularly aspect, at a high level with a percentage of mean score of 87.91 percent. Next, in the being genuine and willing to respond regularly aspect, the caregivers had caring behaviors in establishing a safe environment aspect, giving oneself helping the children with autism with compassion aspect, sensitivity to the children's needs, and training and educating aspect at a high level with a percentage of mean score of 87.00, 85.25, 87.87, and 83.75 percent, respectively. The caregivers had caring behaviors in the enhancing the children's moral development aspect at a moderate level with a percentage of mean score of 69.58 percent.

**Part 4. The relationship between mental health and caring behaviors of caregivers of children with autism data.**

The relationship between mental health and caring behaviors of caregivers of children with autism are report in table 6.

**Table 6 The Relationship between Mental Health and Caring Behaviors of caregivers of Children with Autism.**

	Mental Health				$\chi^2$	df	P-value
	Person who had a normal healthy function		Person who had potential psychiatric disorders				
	Frequency	Percentage	Frequency	Percentage			
	<b>Caring behaviors</b>						
high level	57	78.08	10	37.04			
moderate level	13	17.81	13	48.15			
low level	3	4.11	4	14.81			
<b>Total</b>	73	100.00	27	100.00			

Table 6 presented the chi-square test of the relationship between mental health and caring behaviors of caregivers of children with autism. The result showed that mental health was significantly related to the caring behaviors of caregivers of children with autism ( $\chi^2 = 15.16$ ,  $P < 0.001$ ).

## **CHAPTER V**

### **DISCUSSION**

In this chapter, the findings were discussed in the following parts:

**Part 1 Mental health of caregivers of children with autism**

**Part 2 Caring behaviors of caregivers of children with autism**

**Part 3 The relationship between mental health and caring behaviors of caregivers of children with autism**

#### **Part 1 Mental Health of Caregivers of Children with Autism**

The result showed that the majority of the subjects (73.0%) were persons with a normal healthy function, which indicated that they were the persons who did not have somatic symptom, anxiety and insomnia, social dysfunction, and severe depression, resulting from caring for the children with autism.

Many studies as mentioned in the previous chapter suggested that caregivers of children with autism experienced a high level of stress, anxiety, and depression as they provided care for their ill children. However in this study, the majority of the subjects (73.0%) were persons with a normal healthy function. These subjects may experienced stress, anxiety, and depression but they could find strategies to effectively cope with these negative emotions, and retain their normal function in daily living. From the interviews, most of the subjects agreed that caring for the child with autism is a severe burden that created stress, discouragement, and hopelessness. One of them

said “When I got support and understanding from others, I realized my role, and tried to cope with my emotions in order to maintain my mental health status.”

This result may be because of the following factors: First, nearly half of the subjects (48.0%) were adult with ages ranging between 31 - 40 years old, that meant they were mature persons who had ability in adaptation, determination, and management that was based on their previous experience and potential (Anderson, 1980: 1519).

Second, the majority of subjects (76.0%) were married. This indicated that they might receive support from their spouse. Gallagher (1983: 12-15) and Siegel (1996: 138) stated that marital support is an important factor in how well caregivers can work together in raising an autistic child. The caregivers acquire best support from their spouse, that makes them have self-satisfaction, gratification, safety, relaxation, and stable emotions as they have good mental health status. (Brown, 1986 quoted in Butsakon Intaravichai, 1996: 4). From the interviews, one mother said “Primarily, I obtained an empathic understanding from my husband which helped increasing my willpower, positive attitude toward my ill child, as well as enhancing my ability in facing the problems related to the care for my ill child.” Whereas, caregivers who had single status experienced difficulties in caring for their child with autism because they were faced with the complicated problems and the emotional cast of having an autistic child (Siegel, 1996: 139).

Third, the majority of subjects had a rather high education level. A person with high education has an ability to understand a difficult situation realistically, and find a better way to solve the problems (Jolowice & Power quoted in Phoenphit Laohaviriyakul, 1988: 31). From the interviews, it was found that most of the subjects were persons who had knowledge of autism reported caring at a high level. One of them said that “I tried to seek more information to better understand what is autism, and how to care for my ill child by reading books, asking health professionals, or watching television and listening to radio about autism.” This probably allowed the subjects to effectively adjust themselves in problem solving in caring for children with autism, and maintain normal healthy functions.

Fourth, more than half of the subjects (53.0%) had a comparatively high income. Generally, having inadequate income may cause stress for any family. Children with autism have severe impairments and need a special training program in order to develop the appropriate skills. Caring for children with autism will create financial problems for the caregivers, since they have to pay for any special treatment, medication, and transportation. Some families may employ a care providers to help care for their ill child, since they could not handle their child alone at home. Therefore, most subjects had an opportunity to manage their child and follow the treatment plan that helped to reduce their tension. These probably allowed the subjects to effectively solve the problem resulting from caring for children with autism, and maintain normal healthy functions.

Fifth, more than half of the subjects (65.0%) had experience of caring for more than 3 years. That meant they had experience in caring for their ill child that helped them have the ability to solve the problems appropriately. Some subjects said that they had to spend more time in caring, they observed the child's needs and abnormal behaviors and attempted to solve the problems.

Sixth, the majority of subjects (86.0%) had acquired the knowledge of autism and caring from the parents training groups provided by staffs at Yuwaprasart Withayapathum Child Psychiatric Hospital. The parents training groups provided the knowledge of autism and caring for them to increase the parents' ability and supported their emotions. In this group, the caregivers were enabled to share their feelings and experiences. Harris (1994: 168-169) reasoned that participating in the group would allow the families more time to relax and engage in the complicated activities of caring for their child with autism.

Seventh, the children with autism in this study were out patients and had been in the special training program provided by health professionals at Yuwaprasart Withayapathum Child Psychiatric Hospital. They were trained to behave appropriately through behavior modification. They were taught about self-care and communicating with others. This training consequently allowed the caregivers to better manage their autistic child, resulting in reducing their tension. Most of the subjects agreed that the progress of their child could support them in continuing their care.

Eighth, Although caring for child with autism was a stressful situation that affected the caregivers' mental health status, they might appraise the situation in a positive and challenging way. This made them find an effective coping method to solve that problem. These caregivers would have competence to function and maintain health status, particularly mental health status. From the interviews, one subject said that "Although I was faced with severe problems in caring for my autistic child, I knew it was necessary to realize my role, particularly my mother's role. This helped me solve that problem." One added that "I tried to think caring for autistic child was not much more difficult than I could do."

Though the result showed that the majority of subjects had normal healthy functions, 27 % of them were identified as persons with potential psychiatric disorders resulting from caring for their children with autism. This indicated that they experienced somatic symptom, anxiety and insomnia, social dysfunction, and severe depression. Their problems may be due to their inability to cope with the complicated problems of their autistic child who had severe impairments in development and they had difficulty in managing their care. Though these children received ongoing treatment, their condition might progress slowly and in some cases did not progress at all. From the interviews, one of the subjects said that "If I had high expectations of my child's condition, and could not cope with his problems, I felt hopeless, tense, discouraged, and exhausted." Furthermore, some of the subjects had to resign from their job in order to spend more time with their children. These subjects reported low self-esteem, and loss of social networks. Therefore there were some of the caregivers who still experienced mental health problems though they received social support from their spouse and had high education and income.

## **Part 2 Caring Behaviors of Caregivers of Children with Autism**

Caring behaviors of caregivers of children with autism was measured by the Caring Behaviors of Caregivers of Children with Autism Questionnaire, developed by the researcher which was based on Watson's caring concept (Watson, 1985) and concepts from the related literature review. The questionnaire consisted of caring behaviors in 10 aspects as follows: altruism, encouraging the appropriate behavior of

the children, sensitivity to the children's needs, spontaneity, accepting both positive and negative behavior of the children, utilizing a problem-solving method, training and educating, establishing a safe environment, assisting the children to meet their needs and enhancing the children's moral development.

The result showed that the majority of the subjects had caring behaviors at a high level; the percentage of mean score was 82.56 percent. This indicated that the subjects had caring behaviors for their child at a high level. This result corresponded to the study of Kanlaya Wiriya (1996), who studied perception and caring behaviors in 100 mothers of children with autism, and found that there was a relationship between perception of autism and caring behaviors of mothers of children with autism. Most of mothers reported a high level of accurate perception and caring behaviors. These caring behaviors consisted of having their children vaccinated, following up the treatment, showing affection to their child by hugging, and calling their name gently, talking and playing with them. This study suggested that the mothers who were mentally healthy, particularly with accurate perception of their child's illness would provide better care for their child and develop his/her potential and self-reliability.

Caring behaviors are actions and activities directed toward assisting, supporting, or enabling another individual or group with evident or anticipated needs to ameliorate or improve a human condition or life-way (Leininger, 1991: 46). This study, showed the majority of the subjects had caring behaviors at a high level. This finding may come from several reasons. First, the most important factor was Thai culture. From the past up to the present, the importance of caring for children has been emphasized and there is a belief that life's foundation is based on appropriate caring. Mothers have the most important role in caring for a child. The children acquired love, nurture, closeness, enhancement in self-care skills and physical, emotional, social, intellectual, and moral developments from their caregivers (Thitsana Khammani, et al., 1993: 1-21). Second, when the children have autism, the caregivers have willingness and wish to care for their child. They are interested in bringing their child to follow up and interested to participate in the parent training groups, continuously. Second, the majority of the subjects were adult, married, had a comparatively high education level and they received a comparatively high income.

These factors probably allowed the subjects to effectively adjust their caring behaviors for their children with autism.

Another factor was that the subjects acquired the knowledge of autism and caring that enhanced the effectiveness of their caring behaviors. Yuwaprasart Withayopathum Child Psychiatric Hospital provided useful services such as the parent training groups. This group aimed to provide knowledge about autism and caring for autism through family psycho-education. In the group process, the caregivers felt they had friends who were faced with similar problems. And some problems could be solved in the process of the group. The result of the parent training groups was that not only did the subjects acquire the knowledge but also they understood more and accepted their child and cooperated in treatment planning (Chom Chumchuai, 1996: 7-11). In addition, other services for children with autism were provided such as self-help skills training, recovering efficiency in learning, understanding language, concentrated and interesting training. These services helped the children with autism progress, and the subjects could more easily care for their child, thus their caring behaviors probably were at a high level.

In this study, caring behaviors of caregivers of children with autism consisted of giving oneself helping the children with compassion, encouraging the appropriate behavior of the children, sensitivity to the children's needs, being genuine and willing to respond regularly, accepting both positive and negative behavior of the children, utilizing a problem-solving method, training and educating, establishing a safe environment, assisting the children to meet their needs and enhancing the children's moral development. The result of each aspect, is as follows:

*Giving oneself helping the children with compassion:* The subjects reported caring behaviors at a high level with a percentage of mean score of 85.25 percent, which meant the subjects demonstrated their care for children with autism with love, mercy, and great attention. They took care of the child wholeheartedly. The result could be explained by several reasons. First, in Thai culture, where the caregivers, particularly mothers gave love, warmth, and attention for their child (Thitsana Khammani, et al., 1993: 1-5). They called the child's name with a gentle voice,

hugged or touched the child, while they were talking or playing with their child. They provided time to talk, play with their child. From the interviews, most of the subjects reported that they gave love, warmth, attention. One of them said "I gave attention in caring for my ill child more than I care for myself, and I played, talked, did activities together with my child more than with other children." However, some of the subjects reported that they had other responsibilities such as their occupation, housework, and caring for other children in their families, so they could not provide enough time to talk, play with their ill child. One mother said "I could not call my ill child's name with a gentle voice, several times I called his name loudly in order to call for his interest."

*Encouraging the appropriate behavior of the children:* The subjects reported caring behaviors at a high level with a percentage of mean score of 83.41 percent, which meant the subjects encouraged their children to behave appropriately by praising with verbal and nonverbal communication. They praised, nodded heads, clapped, smiled, hugged, kissed cheeks of their child when their child tried to improve behaviors. They encouraged and helped their ill child to do activities. From the interviews, a few subjects said that several times they could not encourage and help the child to do activities because their child refused, and this made them feel hopeless.

*Sensitivity to the children's need:* The subjects reported caring behaviors at a high level with a percentage of mean score of 83.87 percent, which meant the subjects observed any change that occurred in their children whether physical, emotional, social or spiritual, and responded to that change immediately. From the interviews, the subjects said that they observed physical, emotional and mental changes in the child. They observed what things their child preferred or was interested in and they used it as an instrument for teaching. They encouraged their child to express needs by using postures or words such as; begging by opening the hand, going to the toilet by grasping their trousers, etc. They pacified their child when he/she was crying, afraid or alarmed. They persuaded their child to play with them or carried their child to play with other children, when their child was isolated. However, most

of the subjects success fully served the children needs, one of them said that “Sometimes I left my ill child alone after the failure in persuading him to play with me.”

*Being genuine and willing to respond regularly:* The subjects reported caring behaviors at a high level with a percentage of mean score of 87.91 percent, which meant the subjects showed spontaneity in their relationship with their child. The subjects used clear and understandable language when they were talking with their ill child. From the interviews, the subjects said that they tried to talk with their child everyday, even though their child could not speak. They used short and distinct words so their child could understand. They cared with love, mercy, and understanding in their child’s behaviors.

*Accepting both positive and negative behavior of the children:* The subjects reported caring behaviors at a high level with a percentage of mean score of 81.00 percent, which meant the subjects showed an understanding of the meaning of behaviors of children with autism. They tried not to judge whether the child’s behaviors is right or wrong. They used counter talking with their afflicted children so their children could know that they understood in speech and postures. They tried to repress the expression of annoyance with their children, and warned them with short speech and taught them appropriate behaviors. In the past, Thai society used authority in child rearing such as admonition, castigation, warning and unreasonableness, but at the present, severe punishment is not accepted (Thitsana Khammani, et al., 1993: 8-11). In caring for children with autism, severe punishment did not have a good effect on children’s progress and it should not be used in behavior modification. From the interviews, one of the subjects said that “I attempted to repress my bad emotions, clam down my anger and accepted my ill child’s behaviors.” However, some of the subjects said that they could not understand the behaviors of their child. One of them said that “It seemed to be a barrier between me and my child.” Another one of them said “Several times I could not repress bad emotions toward my ill child, and I shouted, flogged, or browbeat by a coat hanger or a rod.” During observation of a girl child

with autism who slapped her mother's face when she could not get what she wanted, and her mother gave her severe punishment.

*Utilizing a problem-solving method:* The subjects reported caring behaviors at a high level with a percentage of mean score of 81.33 percent, which meant the subjects sought more information to understand the cause of the problem that occurred with their child by observing, asking people or health professionals, or making assumptions. The hospital provided books about illness and caring for children with autism for them. They tried to find ways that helped them to solve the problems, and they observed and followed the change of their child's problem behaviors. From the interviews, most of the subjects said that they needed knowledge about caring for their child to solve problems.

*Training and Educating:* The subjects reported caring behaviors at a high level with a percentage of mean score of 83.75 percent, which meant the subjects taught their child to be able to self-care. They trained their child about speaking, social manners (greetings, farewells, etc.), and all-round environments (animals, plants, and fruits). From the interviews, some of the subjects said that they taught their child with considerable endurance, it made them feel discouraged. Some of them thought that social manners and all-round environments were more difficult for their child to learn.

*Establishing a safe environment:* The subjects reported caring behaviors at a high level with a percentage of mean score of 87.00 percent, which meant the subjects had established a home environment to make their children with autism feel safe and secure. The caregivers arranged the home to be clean, and cozy with good ventilation. They kept dangerous things away from their child, protected him/ her from infection, and encouraged their child to participate in the daily life of the family. Chom Chumchuai viewed that caregivers of an autistic child wanted to protect their child, and particularly when the child had autism, the caregivers wanted to protect their ill child more than usual (Chom Chumchuai, 1996: 8).

*Assisting the children to meet his / her needs:* The subjects reported caring behaviors at a high level with a percentage of mean score of 82.29 percent, which meant the subjects helped their children to meet their needs including physiological needs (food, water, personal hygiene, elimination, rest and exercise), psycho-social needs (security, safety and sense of belonging). They selected beneficial food, and drink, provided rest that was sufficient for the child's physical needs. They taught their child in self-care skills by grasping the child's hand and told them to understand and remember. They took their child to a playground, department store, zoological garden or public park. However, some of the subjects said that they tried to completely help their children with autism to meet their needs. One mother said that "I did not completely help my ill child to meet his needs because he could not eat any food at all, only drank milk." Some of the subjects reported that they did not teach their ill child about self-hygiene skills because they thought their ill child could not do it. One of them said "I thought that it wasted time without being productive, and it was the reason that I did everything for my ill child." Some of them did not take the child to wander the home because their child always started an incident.

*Enhancing the children's moral development:* The subjects reported caring behaviors at a moderate level with a percentage of mean score of 69.58 percent, which meant the subjects enhanced the children with autism to learn how to give and care for others, what is right and wrong doing by telling stories, guiding their children or being a model for their child to imitate. They taught their child to pay respect to Buddhist monks, pray or took their child to a temple. Thai culture has emphasized moral development, and teaching children to learn about kindness, love, help, respectfulness and Thai children are taught about the way of life in society by following their caregivers to several places such as a temple, relative's house and story telling (Thitsana Khammani, et al., 1993: 2-19). However, some of the subjects said that they emphasized other caring more than moral development. One of them said that

“Enhancing moral development was very difficult for my ill child.” This might explain why caring behaviors in this aspect is at a moderate level.

### **Part 3 The Relationship between Mental Health and Caring Behaviors of Caregivers of Children with Autism**

The Chi-square test was used to examine the relationship between mental health and caring behaviors of caregivers of children with autism. From table 6, it was shown that mental health was significantly related to the caring behaviors of caregivers of children with autism at the level of 0.001. The subjects who had a normal healthy function reported caring behaviors at a high level (78.0%), while those who had potential psychiatric disorders had caring behaviors at a moderate level (48.15%). The result was similar to the finding of Cavanagh and Ashman’s study (1985: 152) which found that mental health was related to the caring behaviors of caregivers of handicapped children. Rosenberg (1977 quoted in Gallagher, et al., 1983: 12) also added that mental health problems negatively influenced the parent’s abilities to care for a handicapped child.

The result of this study may be due to several reasons. A person with positive mental health is an individual who has the ability to love, give, care about others, face reality, cope with stress, find meaning and work productively (Beckingham, & Baumann, 1990:2; Johnson, 1993:5; Pasquali, et al.,1985: 9). These characteristics may enhance these caregivers to care for their autistic child, by showing their love, mercy, and great attention. As suggested by Kanlaya Wiriya’s study (1996), the caregivers who perceived situation realistically, could perform caring behaviors that promoted their child’s growth and development. These caregivers could assess and understand the child’s needs and respond to that need immediately. They had flexible resolution of conflicts, that made them able to accept the abnormal behaviors of their child. They were able to teach their child about self-care skills, as well as encourage their social, emotional, communicative, and moral development.

In this study, the normal healthy caregivers were identified as persons who did not show somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression as they managed care for their ill child. It was found that the stress of

caregivers may contribute to a variety of health problems that affected their ability to care for others (The Family Caregiver Alliance and The State of California's Caregivers Resource Center, 1998b: 1). Persons who could manage their anxiety would perceive situations realistically, solve problems effectively. A person who did not experience social dysfunction were doing things well, capable of making decisions and able to enjoy normal activities. These competence would help the caregivers to manage their time to care for their ill child and for social contact appropriately. Though they had to care for their ill child, they could find their time to enjoy their day-to-day living. The caregivers who did not had depression would provide care for their child with hope. The caregivers who had hope could encourage their ill child to learn new things and skills to care for him/herself. From the interviews, most of the caregivers reported that they had acquired willpower, help, hope, and understanding from their spouse, family members, health professionals, and other caregivers of children with autism. These increased their self-esteem, and acceptance to the ill child's conditions. Conversely, the caregivers who had severe stress and anxiety ineffectively managed their emotion and thoughts , thus could not provide consistent care for their ill child. From the interviews, a few subjects of this study said that they had high anxiety about their child's problem behaviors. With this concern, they would rather do everything for their ill child than attempt to train their self-care skills. This caring behaviors would not promote the child with autism to grow and develop appropriately. These reasons as above mentioned, support the result that mental health is related to the caring behaviors of caregivers of children with autism.

## **CHAPTER VI**

### **CONCLUSION AND SUGGESTION**

#### **Summary of the study**

The purposes of this descriptive study were to examine the mental health, and caring behaviors of caregivers of children with autism. The subjects consisted of 100 caregivers of children with autism who brought the children to the outpatient clinic at Yuwaprasart Withayopathum Child Psychiatric Hospital. The inclusion criteria in the sample were a father, a mother, or a significant family member who have lived with a child with autism ranging in age between 2 to 5 years. The subjects also had the responsibility to give direct care for children with autism who have been diagnosed as having autism for at least 3 months, and these caregivers care for the children without payment.

The demographic data questionnaire, the General Health Questionnaire-28 (Thai-version), and the Caring Behaviors of Caregivers of Children with Autism Questionnaire were used for data collection. The General Health Questionnaire-28 (GHQ-28) in the Thai-version was translated by Tana Nilchaigovit, Chakkrit Sukying and Chatchawan Silpakit from the General Health Questionnaire of Goldberg (1972). The reliabilities of the GHQ-28 was 0.92 that was examined by Cronbach's alpha. The Caring Behaviors of Caregivers of Children with Autism Questionnaire was developed by the researcher, and was based on Watson's caring concept (1985) and the related literature review. The content validity of the Caring Behaviors of Caregivers of Children with Autism Questionnaire was evaluated by experts, and the reliabilities was 0.93 that was examined by Cronbach's alpha. Analysis of data was completed by a computer using the Statistical Package for Social Science (SPSS/PC). Demographic data of caregivers and children with autism, mental health, and caring behaviors were analyzed by mean and percentage and the relationship between mental health and caring behaviors of caregivers of children with autism were analyzed by the Chi-Square test.

## **Conclusion of the study**

### **1. The demographic data of caregivers and children with autism**

The subjects consisted of mothers (65.0%), fathers (20.0%), and relative (15.0%). Nearly half of the subjects (48.0%) were adult with ages ranging between 31-40 years old. The majority of the subjects (76.0%) were married. Thirty four percent of the subjects finished university. Nearly half of the subjects (42.0%) were housekeepers and 53.0 percent received more than 11,000 baht/monthly/family income. The subjects (63.0%) lived in a nuclear family and 86.0 percent acquired the knowledge of autism and caring.

Nearly half of the children with autism (45.0%) whom the subjects cared for were aged between 4-5 years olds. The majority of the children with autism (70.0%) are boys and 62.0 percent of them are the eldest child. Forty-seven percent of the subjects care for children with autism approximately 2-3 years.

### **2. Mental health and caring behaviors of caregivers of children with autism**

2.1 Regarding the mental health of the subjects, the result showed that the majority of the subjects (73.0%) were persons with a normal healthy function, indication that they were the persons who did not have somatic symptom, anxiety and insomnia, social dysfunction, and severe depression. Meanwhile 27.0 percent of the subjects were persons with potential psychiatric disorders, that mean they were the persons who were abnormal in the four conditions of mental health as above-mentioned.

2.2 Concerning the caring behaviors of the subjects, the result showed that the majority of the subjects had caring behaviors at a high level with percentage of mean score was 82.56 percent. Considering each aspect, it was found that the first five aspects of caring behaviors that the subjects reported at a high level were 1) being genuine and willing to respond regularly aspect at a high level (87.91%), 2) establishing a safe environment (87.00%), 3) giving oneself helping the children with autism with compassion (85.25%), 4) sensitivity to the children's needs (87.87%), and 5) training and educating (83.75%), respectively. While enhancing the children's

moral development, show caring behaviors at a moderate level with the mean of 69.58 percent.

2.3 With regard to the mental health and caring behaviors of caregivers of children with autism, the result showed that mental health significantly and positively relates to the caring behaviors of caregivers of children with autism at  $\chi^2 = 15.16$  and  $p < 0.001$ . This meant that caregivers of children with autism who had normal healthy functions, had caring behaviors at a high level.

## **Implication and Recommendation**

### **Suggestion and Application of Research Findings**

1. The result showed that the majority of the subjects were persons with a normal healthy function, therefore nurses and related health professionals should realize the importance of the mental health status of caregivers of children with autism. Nurses may establish a training group, conduct psychotherapy groups, self-help groups, consulting services both individuals and groups in order to promote their mental health.

2. The result showed that the majority of the subjects had caring behaviors at a high level, therefore nurses and related health professionals should realize the importance of caring behaviors for children with autism. Nurses may help the caregivers to improve their appropriate caring behaviors by providing them the training programs, and establishing consulting services about how to give caring for children with autism.

3. The results showed that the caregivers had caring behaviors in every aspects at a high level except enhancing the children's moral development at a moderate level. Some of caregivers of children with autism reported that they emphasized other caring more than moral development, and they thought enhancing the children's moral development very difficult for their child. Although the children are incapable of understanding about right, wrong, goodness, and badness, but caregivers should explain, guide, teach, train and be hood models for imitation. These positive teaching methods will show results quickly. Therefore nurses should

emphasize the important role of the enhancing the children with autism's moral development for the caregivers.

4. The results showed that the majority of the caregivers were persons with a normally healthy function and they had caring behaviors at a high level. Therefore nurses and related health professionals should be aware of the importance of promoting mental health, and caring behaviors of caregivers of children with autism, simultaneously.

#### **Suggestion for Further Studies**

1. In this study, the subjects were the caregivers of children with autism who brought the children to the outpatient clinic at Yuwaprasart Withayopatum Child Psychiatric Hospital. Most of them attended the parent training groups and they acquired the knowledge about autism and caring for their child with autism at home. This is the limitation of this study. Therefore the further research should study caregivers of children with autism who do not attend the parent training groups.

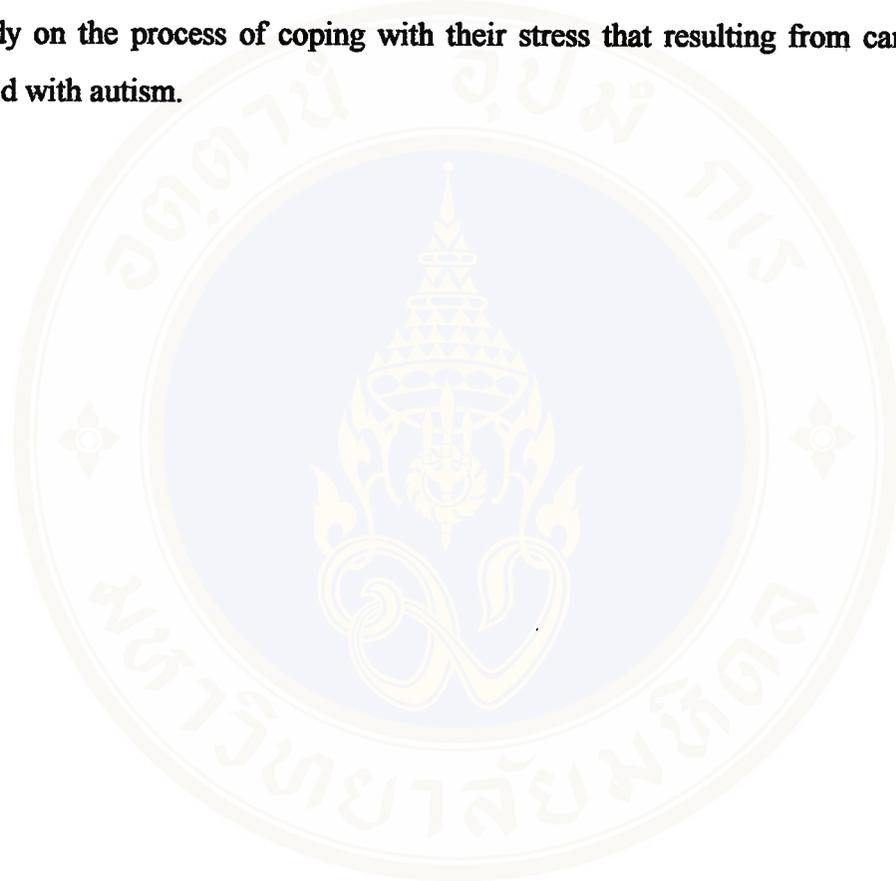
2. The subjects of this study were caregivers of children with autism, with age ranging from 2-5 years. Further study should be done in caregivers of school age children or adolescents. The results will help nurses to understand the mental health and caring behaviors of caregivers of children with autism in each stage of development. Nurses can develop the interventions that are more appropriate for them.

3. The result of this study suggested that positive attitude of the caregivers toward their ill child had an influence on their caring behaviors. Therefore the further research should study influence of the parent training groups on attitude and caring behaviors of caregivers of children with autism and the relationship between attitude and caring behaviors of caregivers of children with autism.

4. In this study, it was found that the demographic data of caregivers and children with autism such as marital status, knowledge of autism and caring, and duration of illness may have influence on mental health and caring behaviors of caregivers of children with autism. Therefore the further research should study the influence of these factors of caregivers and children with autism on mental health and caring behaviors of caregivers of children with autism. The results will help nurses to

more understand the mental health and caring behaviors of caregivers of children with autism.

5. In this study, it was found that most of the caregivers of children with autism had an effective coping that made them stayed in a normally healthy function and had caring behaviors at a high level. Therefore further research should study on the process of coping with their stress that resulting from caring for their child with autism.



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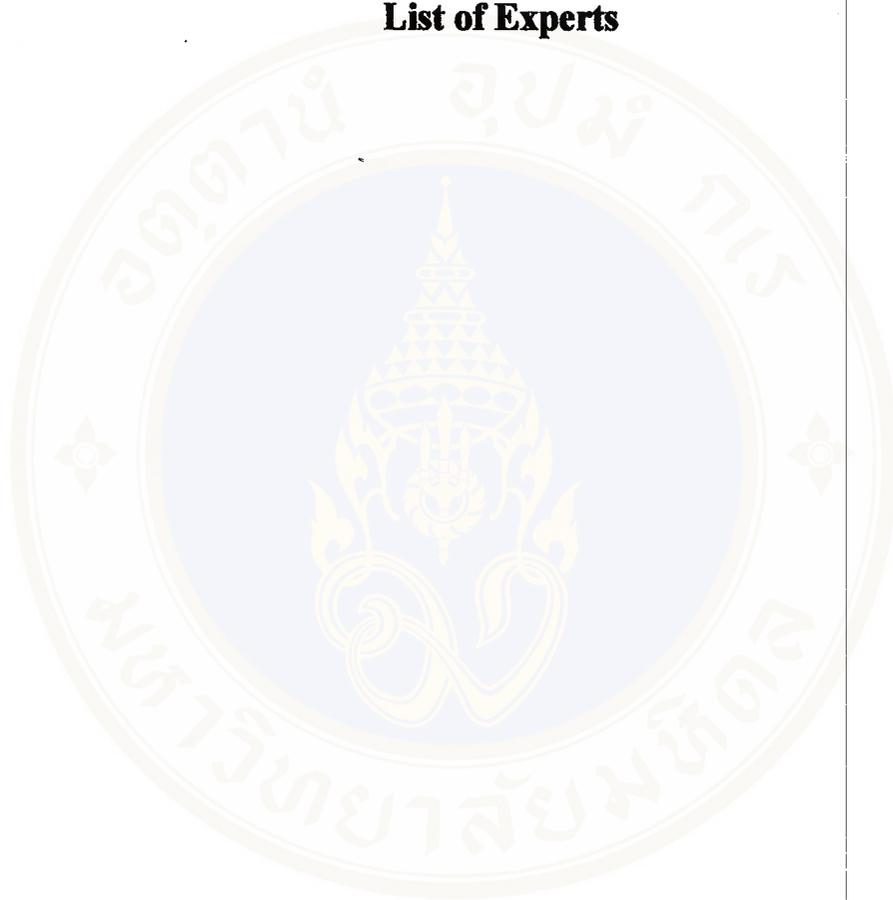
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**APPENDIX**



## **APPENDIX A**

### **List of Experts**



## **List of Experts**

In this study, the content validity of the Caring Behaviors of Caregivers of Children with Autism Questionnaire was evaluated by experts

Following is the list of experts

1. **Dr. Payom Euswas**  
Associate Professor, Associate Dean  
Faculty of Nursing, Thummasart University.
2. **Dr. Saipin Kasemgitvatana**  
Associate Professor, Department of Surgical Nursing  
Faculty of Nursing, Mahidol University.
3. **Dr. Fongcum Tilokskulchai**  
Associate Professor, Department of Pediatric Nursing  
Faculty of Nursing, Mahidol University.
4. **Mr. Chom Chumchuai**  
A child psychiatrist, Yuwaprasart Withayopatum Child Psychiatric  
Hospital, Samutprakan.
5. **Miss Phitsamai Phongsathirut**  
A staff nurse, Child Mental Health Center,  
Department of Mental Health,  
Ministry of Public Health.

## APPENDIX B

### Informed consent



## **Informed consent**

My name is Prapawadee Supuckwanich. I am a psychiatric nurse and I am studying psychiatric nursing at a master's degree at the Faculty of Nursing, Mahidol University. I am conducting a nursing research project entitled "Mental Health and Caring Behaviors of Caregivers of Children with Autism". You are the important person in completion an information. So I would like to ask for your participation in the study.

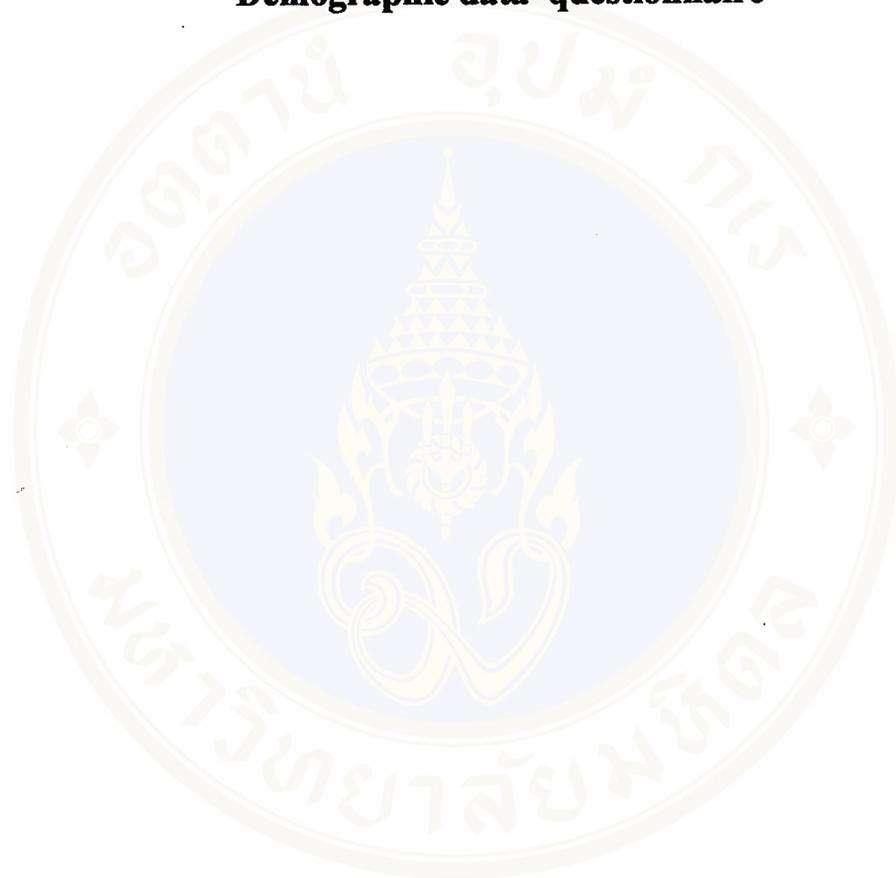
The purposes of this study were to examine mental health, and caring behaviors of caregivers of children with autism. The results of this study will be useful in helping nurses and related health professionals to promote mental health, prevent mental health problems, and help improving appropriate caring behaviors of caregivers of children with autism. If you agree to participate, you will be asked to complete the questionnaires. It will take you about 25-30 minutes to complete the questionnaires. All of your responses and the information from the hospital record will be remained confidential and your identity will not be revealed.

There are no known risks to participate in this study. However, your participation is voluntary, you have the right to participate or not participate. You may withdraw from this study at any time, even after you start to answer the questions, will not affect you and the care for your child in any way.

**Prapawadee Supuckwanich**  
**Investigator**

## APPENDIX C

### Demographic data questionnaire



## Thai version

## แบบสอบถามข้อมูลส่วนบุคคล

คำชี้แจง แบบสอบถามข้อมูลส่วนบุคคลเป็นคำถามที่เกี่ยวกับตัวท่านและเด็ก มีวัตถุประสงค์ที่จะสำรวจข้อมูลทั่วไป โปรดใส่เครื่องหมาย  ลงในช่อง  และเติมข้อความลงในช่องว่างที่ตรงตามลักษณะที่เป็นจริงของท่าน

1. ปัจจุบันท่านอายุ \_\_\_\_\_ ปี
2. เพศ  ชาย  หญิง
3. สถานภาพสมรส
 

<input type="checkbox"/> โสด	<input type="checkbox"/> คู่
<input type="checkbox"/> หม้าย	<input type="checkbox"/> หย่า
<input type="checkbox"/> แยกกันอยู่	<input type="checkbox"/> อื่นๆ ระบุ _____
4. ระดับการศึกษาของท่าน
 

<input type="checkbox"/> ไม่ได้เรียน	<input type="checkbox"/> ประถมศึกษา
<input type="checkbox"/> มัธยมศึกษา	<input type="checkbox"/> อาชีวศึกษา/ อนุปริญญา
<input type="checkbox"/> อุดมศึกษา ระดับ _____ ตริ _____ โทร _____ เอก	
<input type="checkbox"/> อื่นๆ โปรดระบุ _____	
15. ท่านมีโอกาสได้ดูแลเด็กตั้งแต่เริ่มป่วยหรือไม่
 

<input type="checkbox"/> ใช่
<input type="checkbox"/> ไม่ใช่ ได้ดูแลเด็กมาเป็นเวลา _____ ปี _____ เดือน
16. ท่านเคยได้รับความรู้เกี่ยวกับโรคและการดูแลหรือไม่  
(จากการบอกกล่าวจากเจ้าหน้าที่ การอบรมผู้ปกครอง การอ่านหนังสือที่เกี่ยวข้อง ฯลฯ)
 

<input type="checkbox"/> ไม่เคย			
<input type="checkbox"/> เคย และท่านมีความเข้าใจมากน้อยเพียงใด กับความรู้ที่เคยได้รับ <table style="width: 100%; border: none;"> <tr> <td><input type="checkbox"/> มาก</td> <td><input type="checkbox"/> ปานกลาง</td> <td><input type="checkbox"/> น้อย</td> </tr> </table>	<input type="checkbox"/> มาก	<input type="checkbox"/> ปานกลาง	<input type="checkbox"/> น้อย
<input type="checkbox"/> มาก	<input type="checkbox"/> ปานกลาง	<input type="checkbox"/> น้อย	

### Demographic data questionnaire

**Introduction** The following items are demographic data about yourself and your child. The purpose of this questionnaire is to survey general data, please indicate by ✓ in  and fill in gap that as a matter of fact among you and your child's characteristics.

1. Your age \_\_\_\_\_ years old.
2. Gender  Male  Female
3. Marital status  Single  Married  
 Widowed  Divorced  
 Separated  
 Other, please specify \_\_\_\_\_
4. Education  Uneducated  Primary school  
 High school  Vocational/ Diploma  
 Academic, please specify by ✓ in gap  
\_\_\_\_\_ bachelor \_\_\_\_\_ master \_\_\_\_\_ or doctor's degree  
 Other, please specify \_\_\_\_\_
15. Do you care your child from the beginning that the child have illness with autism ?  
 Yes  
 No, period of caring is \_\_\_\_\_ year (s) \_\_\_\_\_ month (s)
16. Have you ever received the knowledge of illness and caring for children with autism yet ?  
(From health professionals, parent- training groups and/or relate books, etc.)  
 No  
 Yes, Which level do you think that you understand your child's illness ?  
 high  moderate  low

## APPENDIX D

### General Health Questionnaire



**Thai version****แบบสอบถามเพื่อคัดกรองปัญหาสุขภาพจิต**

สุขภาพโดยทั่วไปของท่านในระยะ 2 - 3 สัปดาห์ที่ผ่านมาเป็นอย่างไรบ้าง กรุณาตอบคำถามต่อไปนี้โดยขีดเครื่องหมาย ✓ หน้าคำตอบที่ใกล้เคียงกับสภาพของท่านในปัจจุบันหรือในช่วง 2-3 สัปดาห์ที่ผ่านมามากที่สุด โดยไม่รวมถึงปัญหาที่ท่านเคยมีในอดีต และกรุณาตอบคำถามทุกข้อ

ในระยะที่ผ่านมาท่าน

1. รู้สึกสบายและมีสุขภาพดี

ดีกว่าปกติ       เหมือนปกติ       แย่กว่าปกติ       แย่กว่าปกติมาก

2. รู้สึกต้องการยาบำรุงให้มีกำลังวังชา

ไม่เลย       ไม่มากกว่าปกติ       ค่อนข้างมากกว่าปกติ       มากกว่าปกติมาก

3. รู้สึกทรุดโทรมและสุขภาพไม่ดี

ไม่เลย       ไม่มากกว่าปกติ       ค่อนข้างมากกว่าปกติ       มากกว่าปกติมาก

4. รู้สึกไม่สบาย

ไม่เลย       ไม่มากกว่าปกติ       ค่อนข้างมากกว่าปกติ       มากกว่าปกติมาก

26. รู้สึกว่าบางครั้งทำอะไรไม่ได้เลยเพราะประสาทตึงเครียดมาก

ไม่เลย       ไม่มากกว่าปกติ       ค่อนข้างมากกว่าปกติ       มากกว่าปกติมาก

27. พบว่าตนเองรู้สึกอยากตายไปให้พ้นๆ

ไม่เลย       ไม่มากกว่าปกติ       ค่อนข้างมากกว่าปกติ       มากกว่าปกติมาก

28. พบว่ามีความรู้สึกที่อยากจะทำลายชีวิตตนเองเข้ามาอยู่ในความคิดเสมอๆ

ไม่อย่างแน่นอน       ไม่คิดว่าเป็นอย่างนั้น       มีอยู่บ้างเหมือนกัน       มีแน่ๆ

## General Health Questionnaire

**Please read this carefully:** We should like to know if you have had any medical complaints, and how your health has been in general over the past few weeks. Please answer all the questions on the following pages simply by ✓ in  which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past. It is important that you try to answer all the questions. Thank you very much for your cooperation.

**Have you recently...**

1. Been feeling perfectly well and in good health?

- |                                            |                                                |
|--------------------------------------------|------------------------------------------------|
| <input type="checkbox"/> Better than usual | <input type="checkbox"/> Same as usual         |
| <input type="checkbox"/> Worse             | <input type="checkbox"/> Much worse than usual |

2. Been feeling in need a good tonic?

- |                                                 |                                               |
|-------------------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> Not at all             | <input type="checkbox"/> No more than usual   |
| <input type="checkbox"/> Rather more than usual | <input type="checkbox"/> Much more than usual |

3. Been feeling run down and out of sorts?

- |                                                 |                                               |
|-------------------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> Not at all             | <input type="checkbox"/> No more than usual   |
| <input type="checkbox"/> Rather more than usual | <input type="checkbox"/> Much more than usual |

26. Found at times you couldn't do anything because your nerves were too bad ?

- |                                                 |                                               |
|-------------------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> Not at all             | <input type="checkbox"/> No more than usual   |
| <input type="checkbox"/> Rather more than usual | <input type="checkbox"/> Much more than usual |

27. Found yourself wishing you were dead and away from it all ?

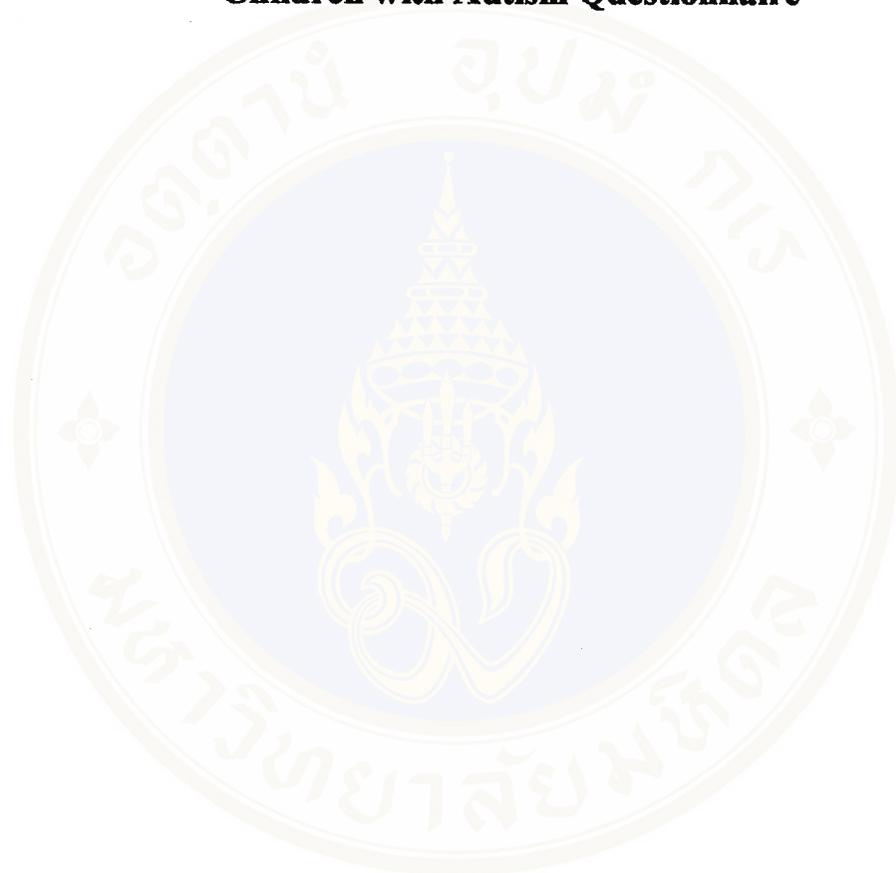
- |                                                 |                                               |
|-------------------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> Not at all             | <input type="checkbox"/> No more than usual   |
| <input type="checkbox"/> Rather more than usual | <input type="checkbox"/> Much more than usual |

28. Found that the idea of taking your own life kept coming into your mind ?

- |                                              |                                           |
|----------------------------------------------|-------------------------------------------|
| <input type="checkbox"/> Definitely not      | <input type="checkbox"/> I don't think so |
| <input type="checkbox"/> Has crossed my mind | <input type="checkbox"/> Definitely have  |

## **APPENDIX E**

### **Caring Behaviors of Caregivers of Children with Autism Questionnaire**



**Thai version****แบบสอบถามพฤติกรรมการดูแลเด็กออทิสติกของผู้ดูแล**

**คำชี้แจง** แบบสอบถามนี้มีวัตถุประสงค์เพื่อทราบถึงพฤติกรรมการดูแลเด็กออทิสติกของท่าน เพื่อให้ท่านพิจารณาว่า ข้อความในประโยคนั้นตรงกับกรปฏิบัติจริงหรือการกระทำของท่านมากน้อยเพียงใด ถ้าไม่เข้าใจข้อความใดให้สอบถามได้ โดยให้ตอบให้ตรงกับความเป็นจริงมากที่สุด ท่านเป็นผู้ทำเครื่องหมาย ✓ ลงในช่องคำตอบที่ตรงกับกรปฏิบัติจริงของท่านมากที่สุดเพียงคำตอบเดียว ข้อละ 1 เครื่องหมาย กรุณาตอบทุกข้อคำถาม แต่ละข้อมีคำตอบให้เลือกดังนี้

ปฏิบัติเป็นประจำ	หมายถึง	ข้อความนั้นท่านปฏิบัติเป็นประจำทุกวันหรือทุกครั้งที่มีเหตุการณ์อย่างสม่ำเสมอ
ปฏิบัติบ่อยครั้ง	หมายถึง	ข้อความนั้นท่านปฏิบัติบ่อยครั้งหรือหลายครั้งที่มีเหตุการณ์
ปฏิบัติบางครั้ง	หมายถึง	ข้อความนั้นท่านปฏิบัติเป็นบางครั้งบางคราวแต่ไม่บ่อยครั้งที่มีเหตุการณ์
นานๆครั้ง/ไม่เคยปฏิบัติ	หมายถึง	ข้อความนั้นท่านแทบจะไม่เคยปฏิบัติหรือนานๆครั้งหนึ่งจนถึงไม่เคยปฏิบัติเลยแม้ว่ามีเหตุการณ์

**แบบสอบถามพฤติกรรมการณ์ดูแลเด็กออทิสติกของผู้ดูแล**

ข้อ	พฤติกรรมการณ์ดูแล	ปฏิบัติเป็นประจำ	ปฏิบัติบ่อยครั้ง	ปฏิบัติบางครั้ง	นานๆครั้ง/ไม่เคยปฏิบัติ
1	เรียกชื่อเด็กด้วยน้ำเสียงที่นุ่มนวล อ่อนโยน ในขณะที่พูดคุยหรือเล่นกับเด็ก				
2	กอดรัดหรือสัมผัสตัวเด็กขณะพูดคุยหรือเล่นกับเด็ก				
3	ให้เวลาแก่เด็กในการพูดคุย เล่นหรือฝึกฝนพัฒนาการ				
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32	สอนให้เด็กรู้จักการให้ เช่น แบ่งของเล่นขนม แก่ผู้อื่น				
33	สอนให้เด็กไหว้พระหรือสวดมนต์ หรือพาไปวัด				
34	สอนหรือชี้ให้เด็กรู้ว่าสิ่งใดผิด สิ่งใดถูก ด้วยวิธีการต่างๆเช่น การเล่านิทาน หรือเป็นแบบอย่างให้เด็กเลียนแบบ เป็นต้น				

1. นอกจากข้อความข้างต้น ท่านได้ให้การดูแลเด็กเป็นพิเศษหรือแตกต่างจากเด็กอื่นอย่างไรบ้าง

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2. ท่านคิดว่าอะไรที่ช่วยส่งเสริมท่านในการดูแลเด็กออทิสติก \_\_\_\_\_

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3. ท่านคิดว่าอะไรที่ทำให้ท่านไม่สามารถให้การดูแลเด็กออทิสติกได้ตามเป้าหมาย \_\_\_\_\_

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4. ท่านต้องการให้ทีมผู้รักษาช่วยเหลือท่านในเรื่องใดบ้าง \_\_\_\_\_

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## **Caring Behavior of Caregivers of Children with Autism Questionnaire**

**Introduction** The purpose of this questionnaire is to study your caring behaviors for your child with autism. Please consider the situation of each item and indicate by ✓ below an answer that best represents your caring behaviors of each item in the present.

The answers that presented frequency of your caring behaviors for your child with autism, as follow:

**Usually** means you perform according to the item usually, or when the situation of item occurs, you are performing every time.

**Often** means you perform according to the item often, or when the situation of item occurs, they are performing several time.

**Sometimes** means you perform according to the item sometimes.

**Rarely/Never** means you rarely perform according to the item, or you never perform although the situation of item occurs.

Item	Caring Behaviors	Usually	Often	Sometimes	Rarely/ Never
1	Calling the child's name with a gentle voice, while you are talking or playing with your child.				
2	Hugging or touching the child, while you are talking or playing with your child.				
3	Providing time for your child to talk, play and train developments.				
33	Teaching your child to pay respect to monk, pray or take him/her to a temple.				
34	Teaching your child to learn what is right and wrong doing by telling stories, guiding, or being a model for him/her to imitate.				

1. In addition to above-mentioned items, how do you have especial caring for your child with autism or different caring from other children ? \_\_\_\_\_  
\_\_\_\_\_
2. In your thought and actual situations, what supports you in caring for your child with autism ? \_\_\_\_\_  
\_\_\_\_\_
3. In your thought and actual situations, what obstructs you in caring for your child with autism ? \_\_\_\_\_  
\_\_\_\_\_
4. Please tell what you need more from health professional teams so that you give better care for your child with autism. \_\_\_\_\_

## Appendix F

### Frequency and Percentage of Caregivers According to Scores of Mental Health, for each item



**Table 7 Frequency and Percentage of Caregivers According to Scores of Mental Health, Somatic symptom aspects, for each item.**

Item	Mental Health	Better / Not at all		Same / No more		Worse / Rather more		Much worse / Much more	
		N	%	N	%	N	%	N	%
1	<b>Have you recently... Been feeling perfectly well and in good health?*</b>	2	2.0	65	65.0	31	31.0	2	2.0
2	Been feeling in need a good tonic?	60	60.0	22	22.0	17	17.0	1	1.0
3	Been feeling run down and out of sorts?	32	32.0	38	38.0	26	26.0	4	4.0
4	Felt that you are ill?	28	28.0	48	48.0	20	20.0	4	4.0
5	Been getting any pains in your head?	46	46.0	30	30.0	19	19.0	5	5.0
6	Been getting a feeling of tightness of pressure in your head?	42	42.0	40	40.0	15	15.0	3	3.0
7	Been having hot or cold spells?	62	62.0	28	28.0	9	9.0	1	1.0

\* This item used rating scale Better than usual, Same as usual, Worse, Much worse than usual

**Table 8 Frequency and percentage of Caregivers According to Scores of Mental Health, Anxiety and Insomnia aspects, for each item.**

Item	Mental Health	Not at all		No more		Rather more		Much more	
		N	%	N	%	N	%	N	%
8	<b>Have you recently... Lost much sleep over worry?</b>	43	43.0	32	32.0	25	25.0	0	0.0
9	<b>Had difficulty in staying asleep once you are off?</b>	50	50.0	27	27.0	23	23.0	0	0.0
10	<b>Felt constantly under strain?</b>	38	38.0	39	39.0	21	21.0	2	2.0
11	<b>Been getting edgy and bad-tempered?</b>	30	30.0	36	36.0	31	31.0	3	3.0
12	<b>Been getting scared or panicky for no good reason?</b>	51	51.0	28	28.0	18	18.0	3	3.0
13	<b>Found every thing getting on top of you?</b>	33	33.0	46	46.0	13	13.0	8	8.0
14	<b>Been feeling nervous and strung-up all the time?</b>	36	36.0	46	46.0	20	20.0	0	0.0

**Table 9 Frequency and Percentage of Caregivers According to Scores of Mental Health, Social Dysfunction aspects, for each item.**

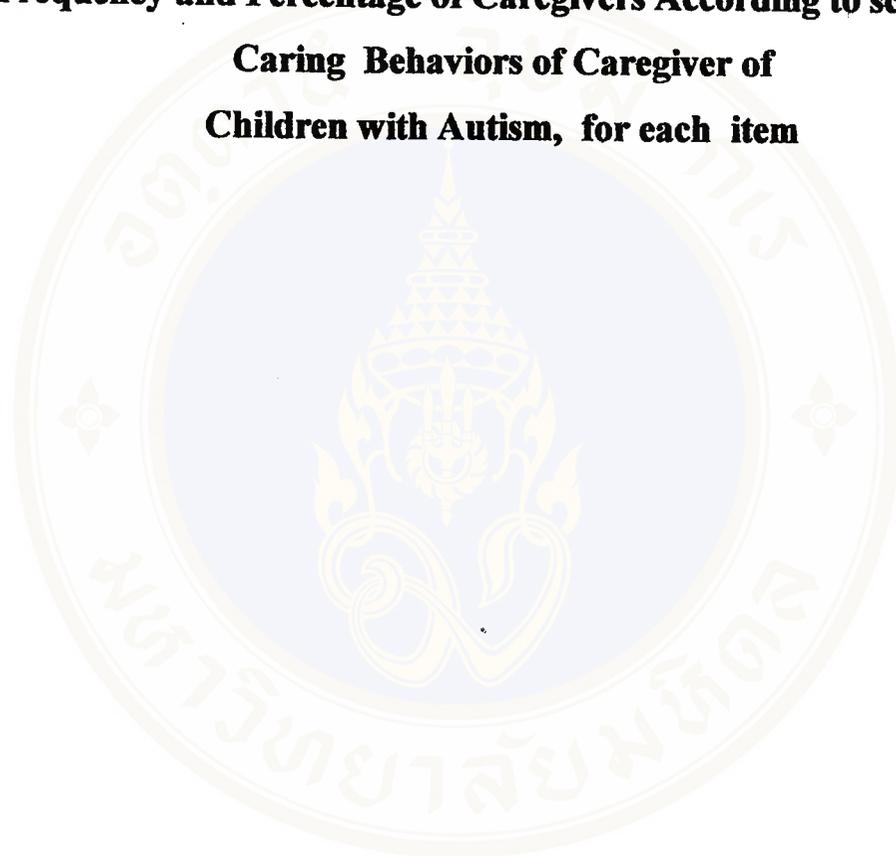
Item	Mental Health	More / Quicker / Better		Same / About the same		Less / Longer		Much less / much longer	
		N	%	N	%	N	%	N	%
15	Have you recently... Been managing to keep yourself busy and occupied?	48	48.0	45	45.0	6	6.0	1	1.0
16	Been taking longer over the things you do?	12	12.0	74	74.0	14	14.0	0	0.0
17	Felt on the whole you were doing things well?	10	10.0	75	75.0	14	14.0	0	0.0
18	Been satisfied with the way you're carried out your task	16	16.0	70	70.0	12	12.0	0	0.0
19	Felt that you are playing a useful part in things?	26	26.0	61	61.0	11	11.0	2	2.0
20	Felt capable of making decisions about things?	9	9.0	78	78.0	13	13.0	0	0.0
21	Been able to enjoy your normal day-to-day activities?	3	3.0	71	71.0	23	23.0	3	3.0

**Table 10 Frequency and Percentage of Caregivers According to Scores of Mental Health, Severe Depression aspects, for each item.**

Item	Mental Health	Not at all/ Definitely not		No more / I don't think so		Rather more / Has crossed my mind		Much more / Definitely have	
		N	%	N	%	N	%	N	%
22	<b>Have you recently... Been thinking of yourself as a worthless person?</b>	78	78.0	12	12.0	10	10.0	0	0.0
23	<b>Felt that life is entirely hopeless?</b>	73	73.0	21	21.0	10	10.0	0	0.0
24	<b>Felt that life isn't worth living?</b>	90	90.0	6	6.0	4	4.0	0	0.0
25	<b>Thought of the possibility that you might make away with yourself?</b>	87	87.0	10	10.0	3	3.0	0	0.0
26	<b>Found at times you couldn't do anything because your nerves were too bad?</b>	52	52.0	37	37.0	11	11.0	0	0.0
27	<b>Found yourself wishing you were dead and away from it all?</b>	90	90.0	5	5.0	5	5.0	0	0.0
28	<b>Found that the idea of taking your own life kept coming into your mind?</b>	88	88.0	7	7.0	5	5.0	0	0.0

## Appendix G

### **Frequency and Percentage of Caregivers According to scores of Caring Behaviors of Caregiver of Children with Autism, for each item**



**Table 11 Frequency and Percentage of Caregivers According to Scores of Caring Behaviors of Caregiver of Children with Autism, for each item.**

Item	Caring Behaviors	Usually		Often		Sometimes		Rarely/ Never	
		N	%	N	%	N	%	N	%
1	Calling the child's name with a gentle voice, while you are talking or playing with your child.	64	64.0	22	22.0	14	14.0	0	0.0
2	Hugging or touching the child, while you are talking or playing with your child.	58	58.0	33	33.0	8	8.0	1	1.0
3	Providing time for your child to talk, play and train developments.	45	45.0	35	35.0	20	20.0	0	0.0
4	Nodding face, clapping, smiling, hugging, or kissing cheeks of your child when he/she tries to improve behaviors.	54	54.0	33	33.0	8	8.0	5	5.0
5	Praising your child when he/she behave appropriately (such as; he/she postures or says words of greetings and farewells).	58	58.0	31	31.0	7	7.0	4	4.0
6	Encouraging and helping your child to do activities.	45	45.0	35	35.0	17	17.0	3	3.0

Item	Caring Behaviors	Usually		Often		Sometimes		Rarely/ Never	
		N	%	N	%	N	%	N	%
7	Observing any change that occur in your child whether physical, emotional and mental change.	53	53.0	30	30.0	15	15.0	2	2.0
8	Encouraging your child to express his/her needs by using postures or words.	60	60.0	28	28.0	10	10.0	2	2.0
9	Pacifying your child when he/she is crying, afraid or alarm.	57	57.0	30	30.0	11	11.0	2	2.0
10	When your child is isolated, you persuade him/her to play with you or carry him to play with other children.	42	42.0	40	40.0	14	14.0	4	4.0
11	Talking with your child everyday, even though he/she can not speak.	65	65.0	26	26.0	9	9.0	0	0.0
12	Slowly talking with your child by short and distinct words for he/she can understand.	64	64.0	26	26.0	9	9.0	1	1.0

Item	Caring Behaviors	Usually		Often		Sometimes		Rarely/ Never	
		N	%	N	%	N	%	N	%
13	Gazing while you are talking with your child. If he/she dose not gaze, you try encourage him/her, for example calling his/her name, catching his/her face, and soft chucking his/her chin or playing game somewhat like hide-and-seek.	56	56.0	35	35.0	8	8.0	1	1.0
14	Trying to repress the expression of annoyance with your child, when he/she has inappropriate behaviors (as; aggressive, throw thing, bully other children or wriggle when he wants toys and sweets, etc.)	34	34.0	42	42.0	18	18.0	6	6.0
15	When your child has inappropriate behaviors, you warn them with short speech and teach them in appropriate behaviors.	47	47.0	38	38.0	13	13.0	2	2.0

Item	Caring Behaviors	Usually		Often		Sometimes		Rarely/ Never	
		N	%	N	%	N	%	N	%
16	Counter talking with a gentle voice, for your child knows that you understand in his/her speech and postures.	53	53.0	36	36.0	7	7.0	4	4.0
17	Seeking information to understand the cause of the problems that occur with your child by observing, asking people/ health professionals, or making assumptions.	38	38.0	42	42.0	16	16.0	4	4.0
18	Trying to solve inappropriate behaviors.	46	46.0	41	41.0	9	9.0	4	4.0
19	Observing and following the changes of problem behaviors.	51	51.0	35	35.0	10	10.0	4	4.0
20	Training your child about speaking, may using picture cards, toys or you point and tell about persons/ things and teach him/her to call follow you.	54	54.0	35	35.0	6	6.0	5	5.0

Item	Caring Behaviors	Usually		Often		Sometimes		Rarely/ Never	
		N	%	N	%	N	%	N	%
21	Teaching social manners (greetings, farewells, thanking, apologizing, requests, denial, etc.), you may show postures and teach him/her imitate.	60	60.0	27	27.0	9	9.0	4	4.0
22	Teaching all-round environments (animals, plants, fruits) by telling and teaching your child to point and call.	47	47.0	34	34.0	15	15.0	4	4.0
23	Keeping dangerous things away from your child (such as; knife, scissors, razor-sharp thing, insect killer drug).	66	66.0	24	24.0	8	8.0	2	2.0
24	Protecting your child from infection by you do not take him/her to congest place or close with patients.	59	59.0	31	31.0	7	7.0	3	3.0
25	Encouraging your child to participate in the daily life of the family, for example eating, reading books, listening to the music.	57	57.0	31	31.0	11	11.0	1	1.0

Item	Caring Behaviors	Usually		Often		Sometimes		Rarely/ Never	
		N	%	N	%	N	%	N	%
26	Selecting beneficial food for your child in everyday.	55	55.0	36	36.0	7	7.0	2	2.0
27	Caring your child to drink ( water, milk, others) that was sufficient his/her physical needs.	53	53.0	37	37.0	8	8.0	2	2.0
28	Caring your child to rest that sufficient his/her physical needs.	60	60.0	32	32.0	7	7.0	1	1.0
29	Teaching your child in self-care skill (such as; bathe, brush the teeth, mouth wash and shampoo the hair).	55	55.0	28	28.0	11	11.0	6	6.0
30	Training your child to sit the spittoon or come to lavatory in the same time including cleaning.	45	45.0	32	32.0	12	12.0	11	11.0
31	Taking your child go to wander such as a playground, department store, zoological garden or public park.	35	35.0	33	33.0	25	25.0	7	7.0

Item	Caring Behaviors	Usually		Often		Sometimes		Rarely/ Never	
		N	%	N	%	N	%	N	%
32	Enhancing your child to learn how to give such as apportion toys or sweets for others.	32	32.0	40	40.0	22	22.0	6	6.0
33	Teaching your child to pay respect to monk, pray or take him/her to a temple.	23	23.0	32	32.0	25	25.0	20	20.0
34	Teaching your child to learn what is right and wrong doing by telling stories, guiding, or being a model for him/her to imitate.	33	33.0	28	28.0	24	24.0	15	15.0

## BIOGRAPHY

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