

---

## **THE EFFECT OF TRADITIONAL GAME STIMULATIONS AND DEPRESSION ON MEMORY LOSS AND COGNITIVE PROCESSES IN ELDERLY DEMENTIA**

Joni Haryanto<sup>1\*</sup>, Elida Ulfiana<sup>2</sup>, Rista Fauziningtyas<sup>3</sup>

Faculty of Nursing, Universitas Airlangga, Surabaya

### **Article History**

Received: October 2024

Revised:

Published: April 2025

### **Keywords**

Stimulation, Traditional Game, Dementia, Elderly

### **Contact**

joni-h@fkip.unair.ac.id

### **ABSTRACT**

#### **Introduction**

Elderly often experience dementia, and dementia is a serious problem. World Alzheimer's Reports (2015) noted with dementia will be the biggest health crisis in this century, the number of patients continues to grow. Indonesia have 1 million more people with dementia in 2015. Traditional of game east java is solution for prevention memory loss and cognitive lost

#### **Method**

This research used quasy experiment design with pre-posttest design control method. The population of this research was seven member of a district who plays role as the stimulation of traditional game for dementia elderly. This study employs the purposive sampling method. The data is gathered through interviews and field notes that is then analyzed with the Collaizi technique. This research generated three themes

#### **Result**

The results illustrate families display the grieving process as a cycle. They feel a deep, permanent and long period of grief through in to five stages of grief: denial, anger, depression, bargaining and acceptance. The Grieving is come from the caregiver and the autism child. Large amounts of grief cause families in grief for a long period and this causes family burden. There are six family burden, psychological burden, physical burden, financial burden, social burden, time burden and thought burden

#### **Conclusion**

Finding of the research would hopefully be beneficial to professional health staff, especially psychiatric nurses to complete their ability in minimizing various negative impacts that the family may suffer from while taking care their autism children with autism through nursing care plans designs development, researches about family empowerment in burden managements and also a research to improve the Family Psycho-education Therapy and a specific Supportive Group Therapy modules for family with autism children.

## INTRODUCTION

As found in several autism therapy services and special needs schools, the role of nurses in empowering families still needs improvement, as nurses focus more on implementing therapy for children with autism (Bappenkar RSU Dr. Soetomo, 2009). This study aims to identify the grief process and burden experienced by families caring for a child with autism. This description of the grief process and burden experienced by families can provide fundamental knowledge that will be useful in developing a more appropriate mental health and nursing approach to improve families' ability to adapt to the stressors of caring for a child with autism. The researcher sought to understand the grief process and burden experienced by families while accompanying and caring for a child with autism attending SKK Bangun Bangsa Surabaya.

In 2015, the elderly population in Asia reached 485 million, with 22 million experiencing dementia. This number is expected to increase to 38 million by 2030 and to 67 million by 2050. Indonesia is among the top five countries with the highest number of elderly people in the world. The 2010 population census reported that the number of elderly people in Indonesia reached 18.1 million (7.6%). In 2014, the number of elderly continued to increase to 18.78 million (Ministry of Health of the Republic of Indonesia, 2015; WHO, 2015; WAR, 2015).

Indonesia is among the top ten countries in the world with the highest rate of dementia sufferers, at 1.2 million people. The provinces with the largest number of elderly people in Indonesia in 2015 were Yogyakarta Special Region (13.4%), Central Java (11.8%), East Java (11.5%), and Bali (10.3%). The number of elderly people in East Java reached approximately 4.2 million (BPS, 2015). Several regions with elderly people

suffering from dementia in East Java, selected as the areas, are Surabaya, Sidoarjo, Mojokerto, Lamongan, Kediri, Blitar, and Madiun (BPS, 2015; East Java Marine and Fisheries Department, 2009).

Depression is a problem closely related to the accelerated decline in memory and cognitive abilities in elderly clients with dementia (Drag, 2010; Turana, 2013; Mahzan, 2012). Dementia is a syndrome that occurs in the elderly due to physiological changes characterized by a decline in cognitive function, memory, language, and visuospatial abilities (Hussein et al., 2012; Erol et al., 2015). One type of dementia is frontotemporal dementia (FTD) with a percentage of cases of 10% of dementia cases (Ray and Davidson, 2014). Frontotemporal Dementia (FTD) is a progressive degenerative disease that can slowly affect aspects of cognition, memory, behavior, emotions, communication and meeting daily needs (Miller, 2016).

According to WHO (2015), FTD has a negative impact on the lives of older adults. One of these negative impacts is changes in family relationships with older adults. Increased family burdens due to sudden anger, crying, or sadness for no apparent reason, and talking to themselves in public can embarrass the family (Dua and Clark, 2011). This can trigger elder abuse, where an older adult may receive poor treatment from their family, such as isolating them from the community and neglecting their nutritional needs. This condition can worsen the health of older adults, leading to the worst possible outcome, suicide (Prince and Acosta, 2009).

These negative impacts have led nurses, as care providers, to adopt preventative measures using the reminescence theory approach. Reminiscence, a structured and dynamic way of recalling past events, can improve

memory and cognitive decline. Traditional East Javanese games include Halma, Chess, Tiga Jadi, Dam Daman, Dakon, Ceki, and Teka Teki Silang, all games commonly played by the elderly in their youth.

The impact felt by families with autistic children includes the emergence of psychological, social, financial, work-related, and time-consuming burdens that will affect the family's behavior in accompanying and caring for the child with autism, even to be able to maintain and continue family life. Families need strengthened family support, the ability to manage stress related to the presence of autistic children and their care needs. Families need the help of professional health workers, one of which is nurses, especially psychiatric nurses. Family members with autism will be a stressor for every family member because the family is a system. Families feel embarrassed to have a child who is different from children the same age when gathering with extended family or work friends. Even families must face situations where the family is not included in community activities that involve all family members because they have a child with autism.

The role of psychiatric nurses is to empower families who have children with

disabilities or children with chronic conditions by helping parents to choose appropriate coping strategies, teaching effective communication within the family, training families in using conflict management strategies and skills (Serr, Mandleco, Olsen & Dyches, 2005). The reality found in several places of therapy services for autism and schools with special needs, the role of nurses in empowering family capabilities still needs to be improved because nurses are more focused on implementing therapy for children with autism (Bappenkar RSU Dr. Soetomo, 2009).

This study aims to identify the grieving process and burden experienced by families while caring for a child with autism. This description of the grieving process and burden experienced by families can provide basic knowledge that will be useful in developing a more appropriate mental health and nursing approach to improve families' ability to adapt during the stressors of caring for a child with autism. The researcher aims to understand the grieving process and burden experienced by families while accompanying and caring for a child with autism who attends SKK Bangun Bangsa Surabaya through this research.

## MATERIAL AND METHOD

This study used a qualitative design with a descriptive phenomenological approach to describe the experiences of families caring for children with autism at the Bangun Bangsa Special Needs School in Surabaya. The sample in this study consisted of six participants obtained using a purposive sampling technique, a sample selection method that is in accordance with the research objectives. All research participants experienced the phenomenon being studied and met the characteristics desired by the researcher, namely: 1) families caring for children with Autistic Disorder/Classic Autism; 2) families

responsible for caring for and fulfilling the daily needs of children with autism or who play a role in decision-making regarding children with autism; 3) at least 20 years old; 4) able to communicate well using Indonesian or regional languages (Javanese) that are understood by the participants and researchers and 5) physically and mentally healthy during the interview. Saturation was achieved with the sixth participant after it was felt that the information conveyed by the participant no longer provided additional new information. The methods used in this study were in-depth interviews and field

notes. Data collection tools in this study were Media Player (MP4), interview

guides, field notes and the researcher herself.

## RESULT

Researchers identified three themes as a result of the research. The process of

emerging these themes is described based on the research objectives.

### 1. The grieving process experienced by families while caring for a child with autism.

#### Theme 1: The grieving process

The stages of grief experienced by families caring for a child with autism consist of five stages: denial, anger, bargaining, depression, and acceptance.

Denial is divided into two categories: disbelief and shock. The following transcript excerpt illustrates disbelief:

"...I kept reading, why is my child like this? This bad? I can't believe it." (P1)

Meanwhile, the participants experienced shock as a feeling of unawareness, as illustrated below: "Oh my child, why are you doing ablution (wudhō) (naked) here (in class)... Where should I put this face?" (P3)

The second stage of grief, anger, consists of two categories: sadness and disappointment. The participants expressed feelings of sadness as described below:

"When I got home, I was sobbing..." (P1)

"I couldn't do anything, I was crying... I was so overwhelmed at that time..." (P5)

The disappointment experienced upon realizing her child had autism, disappointment with the attitude of the healthcare provider, and disappointment with her family is reflected in the following participant's account:

"Well... it felt like... (pauses for a moment, her face darkens) what... what did the doctor say, what did he say, what did I dream of... my dreams, my future child, parents want their children to be like this... the stages, right, Miss, but it turns out that's how it is... I think it's all gone (that's what she thought)" (P1)

"Well... I'm looking for another doctor, because that person is unpleasant... he speaks rudely... I don't want to go back there (to (the doctor) again)." (P2)

The third stage, bargaining, encompasses two categories: worry and hope. Two participants expressed concern about their family's ability to care for an autistic child, stating:

"...is that possible (caring for a child with autism)?" (P1)

"Yes, I have time. Will I be able to raise my autistic child?" (P4)

Meanwhile, some participants still held feelings of hope in their child's abilities, as illustrated by the following statements:

"Oh my God, if my child can call me mom, I want to slaughter my goat..." (P1)

"... sometimes (I think)... surely A will be normal..." (P5)

The fourth stage of grief is depression, which is categorized into two categories: physical and psychological. Physical depression was expressed by participants in the following statements:

"... my body is getting thinner... what should I do? I feel like eating doesn't make any sense... I think, what did I do wrong?" (P5)

Most participants complained of psychological depression, as follows:

"I'm just... I'm suffering, right? It's just that... no one understands when I'm told (that K is autistic)... no one understands, instead they blame me, saying

that my upbringing is wrong, just shout at me, don't forbid me, if I play, let me play, like that..." (P2)

Acceptance is described in four categories, namely gratitude, understanding, happiness and adaptation. Gratitude for the child's progress, as expressed by the following participant:

"But, thank God, O. I don't go to the doctor regularly, you know. The medicine, uh... supplements that cost several million rupiah, I can't afford, but how come O can speak? Most autistic children don't have clear verbal language like this, they have a lisp, ma'am... but O's sentences are clear, even the letters are clear." (P1)

Some participants ultimately developed a sense of understanding regarding the presence and circumstances of children with autism in their families, as illustrated by the following illustration:

"Maybe... every autistic child is different, right? 100 autistic children are 100 different. Even O and his younger sibling are different, right? The younger sibling has difficulty, while O is like this (not difficult)" (P1)

"But what can I do? Is this my child... he has to be cared for? Just give up, okay? So,

he'll be cared for. "I'm being treated.... I'm accepted, yes (smiling and eyes starting to well up)..." (P6)

Participant two experienced a feeling of joy due to the autistic child's behavior, which allowed the participant to momentarily escape from the routine of caring for him, as illustrated in the following statement:

"Bathing takes a long time, I'll just soak in the bath, then I'll stop on my own, sometimes I don't let it happen. If I bathe, it's better, I can cook, and I can do other things (laughs)" (P2)

The category of adaptation to the environment and life lived with an autistic child is illustrated in the following excerpt from a participant's transcript:

"I'm used to it, miss.... maybe if other people see me, (for example) my family (who) are far away, come here and see me, it's like... (then they say) be patient, okay? My patience is already building up (laughs). If I finish buying more, and I haven't finished my shopping (while laughing lightly), then I think this is normal, right? (smiles)" (P1)

"In the past... sometimes people said things like that, it hurt me... now it doesn't... (I'm ignorant hehhe (laughs a little))" (P6)

## Theme 2: Cause of Grief

Participants who have gone through the acceptance stage of the grieving process can re-experience feelings of grief when they encounter a cause for grief. The causes of grief stem from two sources: the caregiver and the child with autism. The cause of grief stemming from the caregiver, which is the accumulation of the caregiver's feelings, is illustrated in the following transcript:

"...our patience with a normal child is different from that of a child like this. A normal child is like, 'Hey, you can't do this and that, and they'll understand right away.' If a child like this says it ten times, sis, wooo, they still don't care." (P1)

"Well... how should I do it... (pause for a moment)... I have a variety of feelings,

mostly irritation, and it's unpredictable, basically..." (P2)

Other causes of grief stemming from children with autism include resistance, slow responses, excessive behavior, difficulty concentrating, and incomprehensible behavior. Children's resistance was found in the following statements by participants:

"Well, sometimes these kids get into trouble...you can't tell them." (P1)

Participants also mentioned their children's slow responses, as follows:

"Sometimes in the morning (the autistic child) likes to cause trouble, he can't be quick." (P2)

Two participants described their children's excessive behavior in the following transcript:

"He's so naughty, rolling around on the floor... and he likes to pick up the clothesline... there's a pink shirt, I don't know whose it is, he doesn't care, he changes it on the clothesline, and then he comes home and changes, and then..." (P2)

"... when he goes to that person's house... he's like that, he can't sit still, he keeps going inside the house." (P5)

Participants also described their children's difficulty concentrating as follows:

"... it's hard to write, he's told what to do, he's distracted by homework, he's watching TV, looking at... (demonstrates looking

right and left)... it's hard (shakes head twice)" (P2)

Children's incomprehensible behavior is illustrated by several participants, as described by participants four and six below. :

"He himself... sometimes children like this don't know what they want, if they're given this... it's wrong, if they're given this... they don't want it, but they throw a tantrum, and then they just want what they want, we don't understand" (P4)

" .....sometimes it's like they don't want to be quiet... sometimes they're looking for something... they go around like they're going around, and even now they're still going around like that at home" (P6)

### **The burden felt by families when caring for a child with autism**

#### **Theme 3: Burden as a result of the grieving process**

Participants experienced various burdens, which are the aftereffects of going through the stages of grief. The burdens identified included psychological, emotional, physical, financial, social, and time burdens. The psychological burdens experienced by participants were categorized as feelings of annoyance, anger, shame, suffering, fear, worry, and heaviness/difficulty. The following participant expressed feelings of annoyance at the things they encountered while caring for a child with autism:

"Well... how should I... (pause for a moment)... yeah, I have a variety of feelings, a lot of them, I'm annoyed, it's unpredictable, it's hard anyway." (P2)

Feelings of anger toward the behavior of a child with autism were expressed by the following statement:

"I can't tell him, so I just snap (hit him on the thigh with an open palm), but if he makes a mistake, I get angry, just like other mothers, we can't... be these children's wonder women (chuckles), yeah, and if he keeps getting annoyed (can't control himself), I pinch him" (P1)

"I gave him this, but he didn't want it. I got emotional, wow, I went berserk...

really angry... if I was impatient, I'd be blue-blue (pinched marks)" (P4)

Participants described feelings of shame toward others, as illustrated in the situations described by participants two and five:

"Well, if people knew what autistic children are like, if they didn't understand, it would feel like my child was never taught manners, right? It's embarrassing to be a parent, right? Sometimes I do... there's food at the dinner table, and I just take it... that's how it makes me feel awkward... yeah, I'm embarrassed..." (P5)

Feelings of suffering due to others' unwillingness to understand the condition of autistic children were expressed by two research participants in the following transcripts from participants two and three:

"I'm just suffering, ma'am... yeah... basically, nothing, nothing. Those who understand, instead, they blame me, saying that my upbringing is wrong." (P2)

Participants expressed fear of becoming pregnant and giving birth to a second child, as well as fear of a decline in the abilities of autistic children, as explained in the following statement:

"I'm so scared that if I get pregnant again (holding stomach)... my child might have a cleft palate again... (sighing and shaking head)" (P2)

Feelings of worry about the future of autistic children were expressed as follows:

"W needs a companion, who knows who that companion will be tomorrow. As long as Dad is still alive, even if it's far away, I hope that even after I die, I hope everyone will still (the older sibling) help the autistic younger sibling." (P3)

The feeling of being burdened/difficult in caring for an autistic child is described in the following transcript excerpt: "Caring for him (an autistic child) is very... very sensitive... yes, a child like this (autistic) isn't just W, it's extra... what you do (food choices) really has to be (looked after)" (P3)

Another type of burden is the mental burden experienced by research participants, originating from two categories: caregivers and autistic children. The source of caregivers' thoughts due to boredom during caregiving is illustrated in the following statements from participants one and two:

"So, the mind feels bored, and that's also true..." (P1)

The mental burden originating from children with autism is described as follows:

"...how come I can't let go of A? When I put A at school, I go home, and actually, I'm not with A, right? It feels free, right? But I can't, hehe (laughs) That's what a child is like... carried in my belly for 9 months... I wonder what will happen at school..." (P5)

Physical burden was also identified as a type of burden in the research, in the form of physical exhaustion during care of autistic children, as described below:

"Yes, sometimes I'm tired... I'm definitely tired, miss. Imagine caring for two autistic children all day long." (P1)

Participants also mentioned financial burdens in the categories of

spending money on medication, nutrition, and school. Using money to meet the needs of autistic children becomes a burden for families due to the uncontrollable urges children have when they have autistic purchases. Therefore, families must allocate a special budget to meet their children's demands, as recounted by the following participant:

"Every day, when Sari Roti passes by, Mama asks for bread, Mama asks for ice cream, they all ask for it, Mom. It's like that... Every time we see ice cream, we ask for it... The money has to be in this pocket. We spend a lot of money on snacks." (P2)

The high cost of medical treatment can be illustrated by the following statement:

"It's like that, Mom. I'm broke, Mom. I have to buy medicine, supplements, go to the doctor, and get therapy... That's it, Mom..." (P2)

The high cost of meeting nutritional needs was conveyed by the following two participants:

"For food, I buy snacks, it's a mess.... Well, milk, ma'am, a can is around 150 rupiah... at least 6-7 cans a month... how much is that for milk, man?" (P2)

Participants also cited the high cost of school as a financial burden in the following excerpt:

"Now tell me how much (it costs), compared to school fees for children (regular elementary school) it's different." (P3)

Another type of burden is the social burden, which can be described in two categories: limiting socialization with caregivers and limiting socialization with children with autism. Participants described how they limit their socialization with their environment, as illustrated below:

"But if I go to a relative's house, I limit it. I can't let my child go to their house. I still visit, but not for long, so just for a short time, just to show up." (P1)

Participants limit their autistic child's socialization with their environment, as described below:

"Since then, I've kept him locked up at home. If the house isn't locked, he can open the door himself, and if he goes out, it makes me uncomfortable, doesn't it?" (P5)  
Time burden is another type of burden experienced by participants and is

described in two categories: sacrificing personal time and personal freedom. Sacrificing personal time to accompany an autistic child is expressed as follows:

"Um... well, now I feel like I don't have a life for myself... nothing. If Papa K comes that night, I'll just be tired, I can't just sleep, Mom..." (P2)

## DISCUSSION

### Theme 1: Stage of Grief

The grief found in this study represents a lifelong experience. This is consistent with research conducted by Blaska (1998) on the "grief cycle model" and similar to the opinion of Mallow and Bechtel (1999, in Collins, 2008), who explained that the grief experienced by families with autistic children is a form of "chronic grief." The results of this study indicate that families will experience grief immediately after learning that their child has autism and will continue as long as the family accompanies the child through every stage of their development. Participants will experience stages of grief and reach a stage of acceptance of the fact that they have a child with autism. Participants have not yet ended their grief. This grief will be felt again when the family faces circumstances that trigger feelings of grief again. As stated by Blaska (1998), grief is a continuous cycle: one moment the family feels grief, a moment later feels acceptance, and then suddenly feels grief again. Mallow and Bechtel (1999, in Collins, 2008) use the term "chronic grief" to describe feelings of deep grief that persist, recur, increase over time and occur throughout the family's life.

The stages of grief identified in this study are similar to the stages of the loss process developed by Kubler-Ross (2005), which consist of five stages: denial, anger, bargaining, depression, and acceptance. No participants experienced all five stages of grief. Participants two and six did not experience the bargaining stage.

This is identical to the loss process discovered by Bolwby and Parkes (1970, in Collins, 2008), who described the loss process as having four stages: shock and numbness, desire for resolution, disorientation and disorganization, and reorganization and resolution. The results of this study indicate that the bargaining stage did not occur because, during the desire for resolution stage, the family simultaneously felt anxiety, anger, guilt, and confusion. The family attempted to understand how and why the event that triggered the grief occurred. At the same time, the family attempted to deny the fact that the event did not occur. This was experienced by participants two and six. Participant two attempted to seek information about their child's condition from a health professional, but the family was deeply disappointed with the way the health professional conveyed the information, leading to anger and blame. Participant six repeatedly denied the fact that her child had autism, claiming that her child was actually able to communicate. Participant six's attitude led to a persistent, torturous internal conflict that ultimately led to anger and self-blame. The family tended to blame themselves, anger at others, the environment, and even God. This led to deeper emotional devastation, and the family experienced a phase of disorientation and disorganization, or even entered depression without progressing through the bargaining process.

The final stages of the grieving process, according to Kubbler-Ross (2005), Bowlby and Parkes (1970, in Collins, 2008), and the findings in this study, are similar, namely, the final stage of grief is the acceptance stage. This stage

### **Tema 2: Cause of Grief**

This study found that the grief experienced by families does not end at the acceptance stage, as grief recurs repeatedly when families encounter various causes of grief. The causes of grief originate from the caregiver and the autistic child's condition. This is in line with Blaska's (1998) opinion, which states that there are a number of events that accompany families during the growth and development of children with disabilities, including autistic children, which cause the return of grief. Eakes (1995, in Collins, 2008), in his structure of "chronic grief," strengthens the findings of this study by explaining that the causative events that lead families to experience renewed grief originate from environments, situations, and conditions different from those experienced by the family.

Blaska does not clearly describe the types of events that can trigger the return of grief, while Eakes (1995, in Collins, 2008)

is characterized by the return of energy lost during the grieving process, increased decision-making ability, growing self-confidence, and planning for problem-solving.

more clearly defines the causes of the return of grief. For example, a family will feel sad when they see a child the same age as the family member with autism who is able to speak fluently and express his desires, while their child is still unable to communicate. Eakes's opinion about the causative events was not directly found in this study, but rather a combination of two sources: the child's condition of autism, such as slow response, excessive behavior, and behavior that is not easily understood, which is painful when the family sees a child growing and developing normally. A research participant once said that there was a feeling of annoyance and sadness when seeing a child the same age with autism able to do various things that their child did not yet have. This will gradually affect the family's feelings until it accumulates excessively and causes the family to experience deep grief again.

### **Theme 3: Burden as a result of the grieving process**

The ongoing grieving process will develop into a burden for the family. These research findings are supported by Fontain (2008), who defined family burden as the level of distress experienced by the family as a result of the presence of a family member. In the context of this research, the presence of a child with autism causes the family to experience stages of grief. If the family is unable to balance their ability to cope with these feelings of grief, it will have certain impacts, described in the various burdens that result.

The types of burden identified in this study include psychological burden, mental burden, physical burden, financial burden, social burden, and time burden.

These various burdens have characteristics similar to the types of burden experienced by families with family members experiencing mental disorders according to WHO (2008). WHO divides burden into two types: subjective burden and objective burden. Subjective burden is the burden associated with psychological reactions of family members, such as feelings of loss, sadness, anxiety, shame, stress, and frustration. Meanwhile, objective burden includes disruption of relationships between family members, limitations on social relationships and work activities, financial difficulties, and negative impacts on the physical health of family members.

Psychological burden is expressed in the form of feelings of annoyance, anger, shame, suffering, fear, worry and heaviness/difficulty while caring for a child with autism and this is identical to the subjective burden according to WHO (1998). These various feelings arise alternately and repeatedly based on the causes experienced by the family and are influenced by the characteristics of the participants, such as gender and the severity of the autism experienced by the child. At times the family will be able to overcome it, but at other times the family feels unable to get through it, and this will affect the quality of life of the family as a caregiver. Gray (2003) also strengthens the results of this study and states that 35 families who cared for autistic children for more than ten years experienced continuous emotional stress such as depression, anxiety and anger.

Physical burden, financial burden, social burden, and time burden have similar characteristics to the types of objective burden according to WHO (2008). The physical burden experienced by families is slightly different from the WHO (2008) opinion, which found a negative impact on the physical health of family members as part of the objective burden. The physical burden of families while caring for autistic children in this study did not cause real physical disorders, but only in the form of physical fatigue, while in families with mental disorders, according to WHO (2008), it had a negative impact on the family's physical health. This study also found that the characteristics of the participants, most of whom were mothers who tended to take over all childcare tasks, often felt excessive psychological burden and were more easily fatigued when caring for autistic children. Gray (2003) supports the results of this analysis by stating that families will experience physical health problems as a result of ongoing stress or a cumulative psychological burden that is always repeated.

The financial burdens found in this study, such as the use of money for the needs of autistic children, financing routine treatment and therapy for autistic children, expenses for fulfilling special nutrition for autistic children and financing special schools for autistic children also illustrate similarities with the financial difficulties felt as an objective burden on families caring for family members with mental disorders according to WHO (2008). Families find it difficult to meet financial needs during treatment because it requires a lot of money and continues throughout the child's life. The difference in terms of financial use for autistic children and family members who have mental disorders, namely in autistic children there is a need to fulfill special nutritional needs and fulfill educational needs in special schools.

The social impacts identified in this study include restrictions on social activities for caregivers and children with autism, similar to the limitations on social relationships experienced by families caring for patients with mental illness. Families limit their interactions with their peers when they are with family members with mental illnesses or children with autism due to fear and worry that the child will display inappropriate behavior and cause embarrassment to the family in public. This social burden is perceived by families as a lack of freedom to socialize with their peers.

This study also identified a time burden, where families must sacrifice personal time and personal freedom while caring for a child with autism. This time burden is identical to the objective burden faced by families caring for a family member with a mental disorder according to WHO (2008), namely the limitation of work activities because the family must make time to care for the family member with a mental disorder. The condition of a family member with a mental disorder or a child with autism requires intensive and continuous attention related to care,

treatment processes, and meeting daily needs. Families as caregivers must make time, even sacrifice time for personal interests, while caring for a child with autism.

This study identified one burden that has not yet been categorized as subjective or objective burden according to WHO (2008): mental burden. The mental

burden experienced by participants originated from caregivers, such as feelings of boredom and fatigue while caring for an autistic child, as well as mental burden originating from the autistic child, where participants could not stop thinking about the autistic child's condition. Mental burden can be categorized as subjective burden.

## CONCLUSION

The experience of families caring for a child with autism is incredibly difficult and challenging. Families experience a deep, persistent, and prolonged grieving process that recurs from the moment they discover that a family member has autism. Families go through five stages of grief: denial, anger, bargaining, depression, and acceptance. This research confirms that families experience the bargaining stage when, after passing through the anger stage, they display feelings and thoughts that balance these feelings of grief. The family expresses both worry and hope regarding their ability to navigate the future of caring

for a child with autism. The grieving stage concludes with the acceptance stage, where the family understands the child's condition and is able to continue living with them. Feelings of grief recur, fluctuating and recurring, even after the family has reached the acceptance stage, when the family encounters a situation that triggers renewed feelings of grief. The causes can originate from the caregiver or the autistic child themselves. The resurgent feelings of grief are expressed in various forms of subjective and objective burdens, experienced by the family psychologically, mentally, physically, financially, socially, and temporally.

## BIBLIOGRAPHY

- Blaska, JK. 1998. *Cyclical grieving: reoccurring emotions experienced by parents who have children with disabilities*, (Online), (<http://proquest.umi.com/pqdweb>., diakses tanggal 10 Juni 2009)
- Dunn, M. E. and Burbine, T. 2001. Moderators of stress in parents of

- children with autism. *Community Mental Health Journal*, 37, 39-51.
- Hulme. 1999. Family empowerment: A nursing intervention with suggested outcomes for family of children with chronic health condition, *Journal of*