



Effectiveness of Resilience Training to Reduce Caregiver Burden in Family Caregivers of Children with Cancer

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ABSTRAK

Cancer patients generally have families who provide some level of care. The family or family caregiver has a big task and role in serving the needs of the patient, both physically and psychologically. The role and level of these responsibilities can lead to a high burden or pressure felt by the family caregiver, which is called the caregiver burden. This training targets resilience as a variable that can reduce the caregiver burden of family caregivers. The research design is a one group pretest and posttest experimental design. The number of participants who took part in the entire training process was four people. The results of the different test showed a significance of 0.144 ($p > 0.05$), which means that there was no significant difference in the caregiver burden level after the training. Several factors that influence the failure of resilience training to reduce the level of caregiver burden from family caregivers are the existence of a social desirability bias towards measuring instruments, differences in the educational background of participants, and the short training implementation.

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BACKGROUND

Cancer in Indonesia is a disease with patients who are at the highest rank. The number of cancer patients continues to increase every year. In 2013, the Basic Health Research (Risikesdas) showed that the prevalence of children affected by cancer in the age range 0-14 years was around 16,291 cases each year (Kemenkes, 2016). The increasing prevalence of cancer in children is in line with the increasing number of children who need cancer treatment. Cancer patients generally have families who provide some level of care and support.

Family care sometimes raises safety concerns in two ways that should be a concern for giving a care in all settings (Reinhard et al., 2008). First, the formal caregiver is sometimes referred to as the "second patient", who needs and is entitled to protection and guidance. Second, family caregivers are unpaid service providers who often need assistance in learning how to become competent and safe workers to protect their family members, patients who receive care (Reinhard et.al., 2008).

The National Hospice and Palliative Care Organization (2021) states that caregivers have a duty and role in meeting the needs of patients, physically and psychologically. Caregivers play a role in providing financial support, assisting with medication administration, helping to meet basic daily needs, such as providing emotional and spiritual support, as well as being an active listener and social support provider. Many caregivers experience times when they feel lonely, anxious, guilty, angry, afraid, frustrated, confused, lost and tired. The role and duties of the caregiver eventually trigger high pressure, which will create a caregiver burden.

YKAKI Makassar branch is a branch owned by Yayasan Kasih Anak Kanker Indonesia (YKAKI). YKAKI is a foundation that provides houses as a place to live for

cancer patients, especially children and families (caregivers) undergoing treatment. YKAKI Makassar branch has been active since May 2014 carrying out main programs, namely managing "Rumah Kita", "Sekolah-Ku", and educational outreach.

The house provided by the foundation is called "Rumah Kita". Rumah Kita provides services for cancer patients and caregivers from different regions in Eastern Indonesia. At Rumah Kita, apart from receiving housing and food assistance, children with cancer also receive educational services facilitated by the foundation in the "Sekolah-Ku" program.

Based on the results of interviews with the Branch Head, it is known that the child caregiver who lives in Rumah Kita sometimes has disagreements with one another. Disputes between caregivers are caused by several things, which are usually triggered by the child's condition and the behavior of one child towards another. The caregiver's inability to control the response to negative things causes them to easily get angry with other caregiver. Caregivers who experience stress due to health conditions and the treatment process that must be carried out by children ultimately affect relationships with other people around them.

The results of interviews conducted with the administrators and family caregivers, it is known that there are several problems experienced by parents as caregivers of children with cancer. These problems include being difficult to accept the fact that their child has cancer, blaming themselves for the condition experienced by the child, neglecting their own health, fatigue in providing care, difficulty controlling emotions both towards children, partners, and others, and disagreements with other caregivers. The following are some of the results of interviews conducted with the management and several caregivers at YKAKI.

Based on the results of interviews with the coordinator of Rumah Kita, it is known that parents as caregivers of children with cancer complain that mentoring and caring for children during treatment is a difficult thing to do. Prior to providing care, caregivers also reported feelings of guilt and difficulty accepting the fact that their child had cancer. This difficulty is exacerbated by the unpredictable changes in the child's condition after receiving chemotherapy drugs, which is one of the factors that causes caregivers to often feel sad.

In addition to feeling sad when they see changes in the condition of children who drop after receiving chemotherapy drugs, caregivers also often find it difficult to control the emotions they feel during the child's treatment process. The results of interviews with family caregivers indicate that caregivers tend to be provoked to anger when children are difficult to manage and are told to take medication according to their schedule. The caregiver even vented his anger by pinching or hitting the child.

The many responsibilities in the care undertaken by the caregiver can cause them to see the activity of caring for the patient as a caregiver burden. The caregiver burden felt by the caregiver itself is divided into personal strain, role strain, and feelings of guilt in providing care. The caregiver's subjective burden is caused by the individual's perception of the experience in caregiving. Meanwhile, role strain is felt due to the roles and responsibilities of the caregiver (Siegert et. al., 2010). The results of research by Gupta, et.al. (2015) showed that 80% of caregivers experienced a moderate level of caregiver burden. The highest level of care burden is experienced by the patient's spouse, followed by the patient's parents.

One way that can be used to overcome the caregiver burden is by increasing the resilience of the caregiver. Previous research

by Ong, et. al. (2018) shows a negative relationship between resilience and caregiver burden. This means that increasing individual resilience can reduce the level of caregiver burden. Palacio, et al. (2019) states that a resilient coping style can significantly reduce the emotional stress associated with illness, the changes experienced (biologically, emotionally, socio-family, spiritual), and the emotional and physical demands of caring for a sick family. The role of a resilient coping style and positive thinking skills can be protective factors to prevent the perceived high caregiver burden (Simpson & Jones, 2013).

Resilience is defined as positive adaptation to face adversity, flexibility, psychological well-being, strength, healthy living, burdens, social networks, and satisfaction with social support (Dias et.al. in Ong et.al., 2018). Resilience involves the individual's personal competence and tenacity to achieve goals, trust in instinct and tolerance for stressors, the ability to adapt to change and establish good relationships with individuals. In addition, individuals also show adequate self-control and spiritual intelligence (Connor & Davidson, 2003).

This study has two hypotheses, namely: 1) There is a significant difference in participants' knowledge between before and after the training; 2) There is a significant difference in the level of participant caregiver burden between before and after being given the training.

RESEARCH METHODS

Research Design

The design of this research is a quasi-experimental design. Quasi-experimental design is an experimental method in which the formation of groups is not done randomly (Hastjarjo, 2019). The research design is a one group pretest-posttest design. This means that there is one group

of subjects, namely the family caregiver who will be given two measurements, namely before being given training (pretest) and after training (posttest).

This research consists of the preparation process to the implementation of the training. The research preparation process begins with a search for literature related to research variables, namely resilience and caregiver burden. After that, the researchers compiled a training module based on the theory of resilience by Connor and Davidson (Connor & Davidson, 2003).

The training is divided into six sessions where each session has a duration of 90 minutes. The first session discussed the concept of caregiver burden, resilience, and the benefits of resilience to caregiver burden. The second session discussed the personal competencies needed to increase resilience. The third session discussed how individuals deal with stress. The fourth session discussed the importance of positive adaptation to changes in life and the ability to build good relationships. The fifth session discussed self-control and its implementation in the treatment process. The sixth session discussed spiritual intelligence and its benefits in carrying out responsibilities as a caregiver

Research Subject

The criteria for the subject of this study are the family as a caregiver for children with cancer. The age of the research subjects ranged from 25-40 years and the educational background was Junior High School, Senior High School, and Bachelor's Degree. The research subjects who participated in the entire training process, from the first to the last session, were four people. Participants who take part in the training will be given a pretest at the beginning of the training meeting, then a posttest will be given at the end of the training session.

Method of Collecting Data

The caregiver burden level was measured using the Indonesian version of the Zarit Burden Interview (ZBI) of 22 items with a reliability value of 0.907 (>0.90) which means perfect reliability (Afriyeni & Sartana, 2016). There are three aspects that are measured, namely personal stress, role strain, and feelings of guilt. The ZBI measuring instrument is a Likert scale which is rated in the range of 0-4. The number 0 indicates the subject has never felt it, and the number 4 indicates the subject almost always feels it.

The measurement of the level of resilience uses the Connor-Davidson Resilience Scale (CD-RISC) measuring instrument in Indonesian, which consists of 25 items with a reliability of 0.92 (Wahyudi, et al., 2020). There are five dimensions in this measuring instrument, namely personal competence, high standard, and tenacity; trust in instinct, tolerance to negative affect, and overcome the effects of stress; adapt to change positively and maintain good relationships; control; and spiritual influence. This scale is a Likert scale that is rated from 0 to 4. The number 0 means the statement is not true at all, and the number 4 means the statement is true almost all the time.

Intervention Procedure

The intervention is a resilience training consisting of six sessions where each session has a duration of 90 minutes. The research subjects received the training module prepared by the researcher under the guidance of a psychologist, but the module has not yet been tested. To optimize the delivery of material in the training, several methods were used such as lectures, games, roleplay, question and answer and audio visual.

Table 1. Training Session Material

Session	Material
1	<ul style="list-style-type: none"> • The concept of <i>caregiver burden</i> • The concept of resilience • Benefits of resilience to <i>caregiver burden</i>
2	Personal competence for increase resilience
3	Trust your instincts and how to deal with stress
4	Positive adaptation to changes in life and building a good relationship with others
5	Self-control and implementation in providing care
6	Spiritual intelligence and its benefits in carrying out care responsibilities

Data Analysis Technique

The data analysis technique was carried out using the SPSS version 23 program. Data analysis was carried out using the Wilcoxon test. The Wilcoxon test was used to measure differences in the condition of the same research subject before and after the subject received an intervention in the form of resilience training.

Research result

This study was followed by eight participants, but four others did not attend the training until the final session. This resulted in only four participants being given measurements until the end. The characteristics of the participants can be seen in the table below.

Table 2. Subject Characteristics

Subject	Gender	Age	Education	Occupation
WA	Female	34	Junior High School	Housewife
LA	Male	35	Junior High School	Construction Worker
SS	Female	28	Senior High School	Housewife
SL	Male	32	Bachelor's degree	Self-employed

The results showed two results, namely the results of the measurement of the knowledge aspect and the measurement of the level of resilience and the level of the caregiver burden of the

participants. The first measurement is the measurement made on the knowledge of the research subjects regarding the resilience variables before and after being given training.

Table 3. Knowledge Difference Test Results

Score category	df	p
Pre-test score		
Post-test score	4	0.045

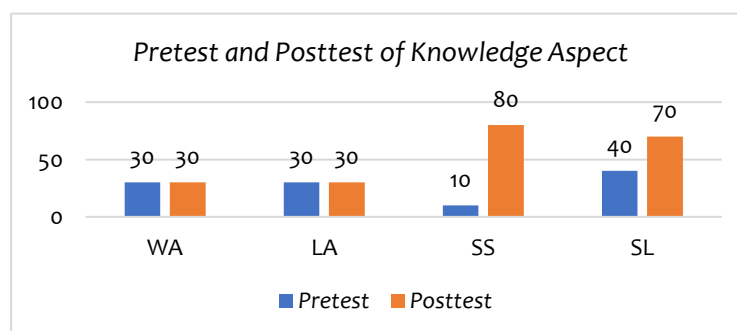


Figure 1. Graph of the results of the pretest and posttest of knowledge aspect

The first hypothesis was tested using the Wilcoxon test to see changes in the knowledge aspect of research subjects between before and after training. Table 3 shows that there are significant differences

in aspects of subject knowledge before and after attending the training. A significance value of 0.045 ($p < 0.05$) proves that there is a difference in knowledge.

Table 4. Caregiver Burden (ZBI) Test Results

Category	Mean	SD	Sig.
Pre-test score	42.25	10.532	0.144
Post-test score	27.25	8.539	

Table 5. Score Category of Caregiver Burden (ZBI)

Subject	PRE-TEST		POST-TEST		Description
	Score Total	Category	Score Total	Category	
WA	50	Moderate	15	Very Low	Down to 1 category
LA	52	Moderate	28	Low	Down to 1 category
SS	37	Low	34	Low	Constant
SL	30	Low	32	Low	Constant

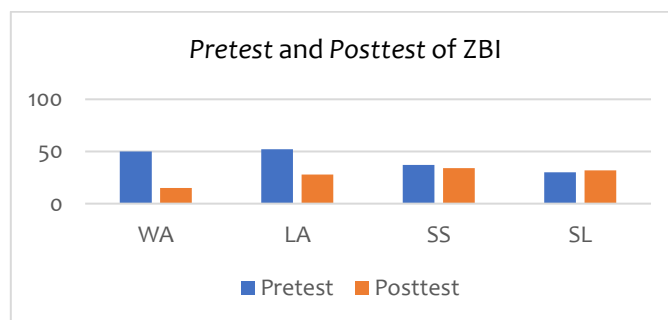


Figure 1. Graph of ZBI's Pretest and Posttest Results

Testing of the second hypothesis was also carried out by using the paired sample t-test. Table 4 shows the results of the different caregiver burden variables for participants before and after being given

training. The significance value of $p = 0.144$ ($p > 0.05$), means that there is no significant difference in the caregiver burden level between the subjects before and after the training.

Table 6. Resilience Variable Test Results (CD-RISC)

Score Category	Mean	SD	Sig.
Pre-test score	58.00	12.884	0.141
Post-test score	66.00	8.446	

Table 7. Score Category of Resilience (CD-RISC)

Subject	PRE-TEST		POST-TEST		Description
	Score Total	Category	Score Total	Category	
WA	48	Low	59	Moderate	Up to 1 category
LA	48	Low	59	Moderate	Up to 1 category
SS	75	High	70	High	Constant
SL	61	Moderate	76	Hight	Up to 1 category

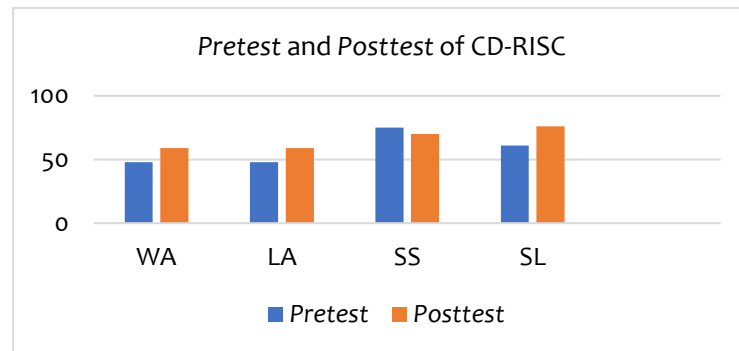


Figure 2. Graphics of CD-RISC Pretest and Posttest Results

Table 6 shows the results of different tests on the level of resilience before and after being given training. The results of the different test show a significance value of 0.141, which means it is greater than 0.05. The significance value indicates that there is no significant difference in the level of resilience.

Based on the results of the difference test above, it is concluded that the hypothesis that is fulfilled is the first hypothesis, namely there is a difference in knowledge before and after being given training. While the second hypothesis is not met, it means that there is no significant difference in the level of caregiver burden before and after being given resilience training.

DISCUSSION

The pressure felt by the caregiver strain is the caregiver's perception or feeling of difficulty regarding the duties and responsibilities associated with her role as a caregiver (Oncology Nursing Society in Afriyeni & Sartana, 2016). While the burden felt by the caregiver (caregiver burden) is a problem, difficulty, or things that are detrimental and affect the caregiver's life of the patient. The way the caregiver views or believes in the duties and responsibilities of care will affect the perceived burden (Thara in Afriyeni & Sartana, 2016).

The burden of care is caused by an imbalance between the demand for care

and the resources available to meet these demands (Kim, et.al. in Nemati, et al., 2017). Knowledge and skills in care are the most important aspects of the treatment process. The lack of knowledge possessed by the family as a caregiver, the ability to adapt to the role of care will increase the burden of care felt by the family caregiver (Nemati, et al., 2017).

Resilience is an individual characteristic that is characterized by positive results in conditions full of threats to the adaptation and development process, where individuals can face even stronger than the existing situation, improve coping strategies, and develop self-adjustment and psychological well-being (Mayordomo in Wijaya, et al., 2020). One of the personal abilities that has a close relationship with the caregiver burden is resilience. Resilience training to reduce caregiver burden on family caregivers of children with cancer at the cancer children's foundation can be said to be quite successful if it is seen from changes in knowledge scores. This can be seen from the increase in the knowledge score with a significance value of 0.045. This means that the training that has been carried out provides new knowledge for participants. The new knowledge is then expected to be used as a provision for participants to learn to improve their resilience.

The results of statistical tests on caregiver burden scores showed that there was no significant difference in scores

before and after being given training with a value of 0.144 ($p > 0.05$). The results of the evaluation of the resilience variable showed insignificant results between the participants' resilience levels before and after the training. This can be seen from the statistical analysis that measures the value before (pre-test) and after (post-test) which is 0.141 ($p > 0.05$). This is in line with the research results of Roij, et.al. (2021) which shows that families as caregiver for advanced cancer patients with high levels of care burden (caregiver burden) often have lower resilience than caregivers with lower levels. The results of measurements of caregiver levels in research subjects who are at moderate and low levels indicate that the provision of resilience training needs to be reconsidered to reduce the level of caregiver burden on family caregivers for cancer children.

Research by Li, et.al. (2018) shows that the heavier the burden on the primary caregiver, the lower the resilience. The complexity of the problem in patient care also affects the resilience or resilience of the family as caregiver (Saputro, et al, 2021). Participants in this study have different complexities. During the training process, two out of four participants had to face a decline in their child's condition, so the number of treatments increased, and this affected the family's resilience as caregivers due to the amount of pressure or burden they felt. This is supported by the results of Hu, et.al. (2016) which states that the longer the duration of care in a day, the higher the burden felt by caregivers.

In addition to quantitative testing, researchers also conducted interviews to find out the changes felt by research participants. The results of interviews with participants showed that there were quite good changes in themselves. These changes are indicated by positive changes from the baseline condition and after receiving resilience training. This can be seen from the

changes in caregiver burden on aspects of personal strain and feeling of guilt. Through resilience training, participants are increasingly aware that their role as parents as well as informal caregivers for children suffering from cancer are valuable.

The results of the follow-up conducted through interviews with the training participants showed that the participants felt helped by the resilience training. Participants said that through the training, they were more aware of their abilities and positive things in themselves and others that could support the child care process. Two participants have even started practicing the relaxation and meditation exercises taught in the training. They admitted that for meditation they still had difficulty being calm and focused, but they began to feel they could be in a calm state longer than during the training day.

Based on the explanation above, resilience training does not significantly help caregivers to overcome the level of caregiver burden felt while accompanying children's treatment. However, some of the exercises taught in resilience training can be considered as a means to overcome aspects of the caregiver burden felt by the family caregiver.

Conclusion

Conclusions based on the results of this study are:

1. The resilience training that has been carried out provides knowledge for the subject, so that there is a significant difference.
2. The resilience training did not provide a significant change to the caregiver burden level of the trainees.
3. Less effective training can be influenced by several factors, namely a) the use of measuring instruments that are susceptible to social desirability bias; b) Most of the educational backgrounds of the participants are Senior High School;

c) The time interval for the training days is quite far due to changes in the chemotherapy schedule from the participant's family; d) The implementation time is long enough for one day of training, so the results are not optimal.

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