

Social Organization Network Concern of Community and Community Surrounding of Breast Cancer Patients

Agustrisno and Nurman Achmad

Faculty of Social and Political Sciences, Universitas Sumatera Utara, Jl. Prof. A. Sofyan, Medan, Indonesia

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Abstract: Breast cancer sufferers in reality are often overlooked by those around them, whether relatives or the surrounding community. The problem faced is from the point of view of the people closest to the sufferer. How do they care about the sufferer? In addition, breast cancer sufferers are only seen in terms of medical treatment alone, when in fact social and emotional handling of the people closest to the patient is actually needed to be a major factor in the treatment of breast cancer patients. There is an institution formed to tackle the problem of breast cancer, YKI (Indonesian Cancer Foundation), but its activities are more focused on prevention efforts, rather than treatment of those who have already suffered. The organizational network for rehabilitating patients who have already suffered is very minimal. As a result, very few sufferers experience healing again. Therefore, efforts are needed to build solidarity in the form of an effective social organization network as a companion to YKI activities.

1 INTRODUCTION

Patients with breast cancer are not merely physical sufferers, ie there is a threat to the internal organs. But the greatest pain is sustaining a psychological attack due to the disease he suffered. Fear of death actually sometimes accelerates his death as well. But with the help and support of people around, patients can fill their lives better. It is not uncommon to find them filling up more of their lives by doing good for others for the rest of their lives.

Support can be trusted to strengthen each individual sufferer, increasing appreciation for himself, in facing the challenges of everyday life. The most fundamental threat for a patient with breast cancer is how he must survive with the condition of the disease. Social support is a strength needed by breast cancer sufferers. In this case the support of the family and surrounding community seems to have not touched as expected, even though there are formal institutions that handle it.

To realize this expectation, by conducting in-depth interviews in addition to interviewing relatives and family members of patients, as well as neighboring patients with patients who are in their environment. Hopefully, they interact more often with sufferers on a daily basis. Then also strengthened by the FGD (Focus Group Discussion) method so as to

obtain accurate information to be used as a policy analysis in drafting strategies for handling patients with breast cancer. However, how that support is interpreted in the form of care, is a problem to be seen. As it is known that the handling of breast cancer sufferers requires their own way so that the family and those around them do not come exposed or cause feelings of disgust towards the patient.

2 PATIENT FAMILY CONCERN

Concern comes from the word care which means it will be by "paying attention, ignoring" (Purwodarminto, 2006). So caring means the high-low attitude of attention, ignoring something. Concern of relatives will be seen as a form of formal family functions, namely the nuclear family and extended family. While the concern of local residents, seen as a form of participation in breast cancer sufferers who are around they live.

As social beings, sufferers are not alone. Breast cancer sufferers have a dependency on family and others who can help and provide support. When sufferers undergo therapy, a significant impact not only on individual sufferers themselves, but families can also feel it. Prognosis of disease sufferers, can not

be predicted about its development, is it possible to be improved or not, it is also very influential on other family members. Therefore, other family members have an important role as providers of support to sufferers.

Family care is considered an important coping strategy, the family also experiences and directly affects the mental health of sufferers (Friedman, 1998). Kane quoted from Friedman (1998) defines family support for sufferers very closely. Because support from the family is a process that occurs throughout the lifetime of the sufferer. This family support will be lighter if the personal support becomes wider in the arena.

Family care according to Francis and Satiadarma (2004) is a support assistance received by one family member from another family member in order to carry out the functions contained in a family. Treatment efforts at the hospital, namely the administration of drugs will be in vain if it is not supported by the role of the family. Research conducted by Jenkins, et al (2006) shows that family care givers are a very potential source for supporting drug delivery in patients.

Case 1: Ms. Yusnani with her siblings

Ms. Yusnani who is a breast cancer sufferer. Her neighbor's view of her, after knowing that Yusnani's mother had breast cancer. According to her neighbor, Mrs. Halimatusadiah or her nickname, Ibu Lima, whose house is next to Ibu Yusnani's house, is only a few meters away. Ms. Yusnani has been suffering from breast cancer five years ago. Initially the disease was covered by Mrs. Yusnani. However, because his illness was felt to be getting worse, in 2017 Bu Yusnani underwent an operation to remove her left breast on the advice and recommendations of her friend who said, the chance to recover was greater in this way. It was at this time that Mrs. Lima only learned that Ms. Yusnani was affected by breast cancer, a month before Mrs. Yusnani would undergo breast lift surgery to the left.

According to Mrs. Lima, initially Ms. Yusnani's husband actually did not approve of the operation on the grounds that she was afraid of having a dangerous effect on Ms. Yusnani. However, because it is indeed the stubborn nature of Mrs. Yusnani and the pain she suffered, despite the encouragement from Mrs. Lima, her husband finally agreed to the breast removal operation. All of Ms. Yusnani's family, neighbors including Mrs. Lima were more surprised to learn

from Mrs. Yusnani's explanation that she had been suffering from breast cancer four years earlier.

Mrs. Lima regrets the action of Mrs. Yusnani who never told her that she had the disease. After the surgery, Bu Yusnani's condition had not yet healed, and even made her left arm become swollen and painful when moved. As a result, Mrs. Yusnani struggled to stand up and had to be carried wherever she went. Therefore, her husband proposed to bring Mrs. Yusnani to undergo chemotherapy at Adam Malik Hospital in Medan on the grounds that in the Hospital the chemotherapy program had healed her friend's relatives, and offset the costs of receiving BPJS.

The chemotherapy was carried out after Mrs. Yusnani had her left breast removed. Mrs. Yusnani's chemotherapy schedule is biweekly and is usually accompanied by her husband and children. The distance of the house and the husband and children who are busy working make Bu Yusnani sometimes decide to stay for a month at her house. Sometimes Mrs. Lima also accompanies Mrs. Yusnani for chemotherapy if her husband and child cannot because of business. As long as Mrs. Lima knows that Ms. Yusnani has breast cancer, she always gives support to Mrs. Yusnani to stay motivated to undergo treatment.

Case 2: Ms. Yasin in the eyes of her siblings and neighbors

In June, when visiting the home of another breast cancer sufferer, in the city of Medan, Mrs. Yasin. Precisely on Jl. Pringgan, Pond Village, Alam Lestari Tembung housing complex. Information from several of Ms. Yasin's neighbors about their view of Ms. Yasin's condition. One neighbor who was successfully interviewed was Mrs. Halimah, who is *Bou*¹ from Ms. Yasin.

Explanation from Mrs. Halimah, the sufferer (Ms. Yasin) whose real name is Hilda has two children. At first Ms. Yasin once complained of feeling pain in her breast, then she took herbal medicine (who did not know where she got it). Over time, the pain was felt to be getting worse, and finally it was recommended by his cousin who works as a midwife to see a doctor to make it clearer. Then, after checking in Malahayati Hospital, located on Jl. Pangeran Diponegoro, Medan, is known to have stage 3 breast cancer.

During his illness he was recommended by doctors to undergo chemotherapy and other intensive

¹ *Bou* is the name of the Mandailing regional language to mention aunt.

treatment at Malahayati Hospital which happened to be close to where his aunt lived. The actual residence of Ms. Yasin is very far to the hospital, so to undergo treatment she must stay at her aunt's house. Ms. Yasin had undergone Chemotherapy eight times, but it made her physically weakened so she decided not to continue the medical treatment, but instead switched to Islamic spiritual treatment, namely by Rukiyah. During her chemotherapy, Ibu Yasin was not overly burdened because all of her medical expenses were fully borne by the BPJS.

Ibu Yasin, who no longer wanted to take chemotherapy treatment, felt that her condition was gradually getting better than before, and could do her usual daily work such as taking children to school, cooking, cleaning the house and others. According to Halima's explanation materially she never helped Mrs. Yasin, but Mrs. Halimah and other neighbors gave motivation and prayers especially when they were staying at her house, said Halimah.

Mama Pahri is Yasin's neighbor. According to Mama Pahri, Ms. Yasin was a very good person. Mama Pahri claimed to have also been to Mrs. Yasin's house to give encouragement and motivation. He could not provide material assistance. Yasin is a typical person who does not want to spit his life, and his circumstances. He doesn't bother anyone, so he will do it alone as much as possible. Mama Pahri learned that Yasin's mother was sick with Stage 3 breast cancer after several months of suffering. Because Ms. Yasin did not want to tell him. Mama Pahri learned that Yasin's mother was suffering from such illness because after being told by Bu Yasin's own husband.

Meanwhile, according to another neighbor Mr. Regar (62 years). Mr. Regar knows that there is information that in their environment there are people who are suffering from breast cancer, he obtained this information from his neighbors. But because their environment is very closed, and fairly apathetic makes it unable to blend and interact well with the environment. According to him, the people in the housing estate are more old people than new people. He also said that the people in the housing estate were still primitive and did not want to progress. The proof is that the STM (Union of Helping) Association of citizens is no longer working. He has lived in the housing estate for three years while it has been established for 6 years. But he felt concerned and sorry for people who suffer from breast cancer, that's all he said. On the matter that Pak Regar is the Head of the Environment in that place.

Another story from Ms. Jovie (35 years) who is usually called Mak Jovie, who said that Ms. Yasin is a person who is very closed with other neighbors. He rarely communicates with the environment in which he lives. Even so far, Jovie's mother has never been to Yasin's mother's house, because she doesn't like the nature of Yasin's family. But her husband, Jovie, once took Ms. Yasin to the hospital in the Medan City area when Yasin's mother's illness recurred. According to Mak Jovie he wants to help sufferers of breast cancer but not for Mrs. Yasin. Because according to him, Mrs. Yasin was a very talkative person who didn't even allow his neighbors to enter his house.

While the other informant, Opung² Rian (58 years) did not even know that in her neighborhood there were people who had breast cancer. According to Opung Rian.

Case 3: Mrs. Serawati and her friends' support

Ms. Cut is a little friend of Mrs. Serawati who is a patient with end-stage breast cancer. Ms. Cut told that Wati's mother had 2 sons and a daughter. His first child is married, and lives in Pekanbaru City, while his daughter is married and has a 1-year-old child and lives with Mrs. Wati. Mrs. Wati has been suffering from breast cancer for one year. According to the story of Cut's mother, Wati's mother was unwilling to be operated on, so her breast cancer had spread to the liver and waist.

According to further explanation from Cut's mother, that the last 2 months Wati's mother had recovered, and even they had gone on a trip to the Sidebu-Dust area together with the medical group. While in Berastagi they were always together, still joking and laughing together and looking for shoes for their grandchildren's souvenirs at home. But now somehow his condition suddenly dropped. He could not move, just lying in bed and his body condition was very thin.

Ms. Cut often visits her fortnightly home to comb her hair, and gives encouragement to her distinctive fussy style, even though her house can be said to be somewhat far from Mrs. Wati. Besides Mrs. Cut, she also has sales activities in her own house, because Mrs. Wati only just falls asleep, apparently the hair behind her has dreadlocks. His son only feeds him, but does not pay attention to how his physical condition. Finally Mrs. Wati was carried by Mrs. Cut to the bathroom to be washed. Cut's mother often even told her son to buy a razor. Then he slowly shaved Mrs. Wati's dreadlocks until bald. Even though Wati's mother was afraid of water, she still

²grandfather in Batak language

insisted on being bathed. finally she was not afraid of water anymore.

Mrs. Cut bathed and shaved Mrs. Wati's dreads while singing dangdut. The two of them often joked, sometimes mocking each other then laughing together. Mrs. Wati often even called Cut's mother to visit her home. Because Mrs. Cut has a tavern (stall) sometimes she takes it too even though only briefly, but sometimes she is also forced to refuse because they have to look after her shop

According to confession from Ms. Cut, the thing that underlies Cut's mother to do good to Wati's mother aside from being a childhood friend / school friend, and close friends as well, so care for Mrs. Wati, because it is a calling, because Mrs. Cut also works as a bath corpse, and already accustomed to dealing with physical persons, besides that also Mrs. Cut, accustomed to taking care of orphans. According to Cut's mother, Wati's mother is the type of person who is less willing to socialize, is a bit of a prestige, and is picky about friends, even closed.

Based on the three cases above, people who actively care for breast cancer sufferers are: family, neighbors and close friends. In case 1: close neighbors, husband and child sufferers. While the hospital and BPJS, are passive care. For case 2: husband, close neighbor is still a relative of the sufferer, cousin of the sufferer. While the hospital and the doctor are passive, so are the local government officials. In case 3: the family, the patient's child and his neighbor. While others are passive.

Relationships with active sufferers are generally horizontal relationships, that is emotional sentiment relations, so they are still based on the values of kinship, friendship, and friendship. This is still natural. While the vertical relationship is less active, because the bond is having an interest (*instrumental*) or interest, it wants to have a purpose as long as there is an interest; and also relationships that are limited to the task of *power* (Agusyanto, 2014). Visually like the Chart 1. white circles show emotional sentiment relations and colored circles show relationships that are instrumental and power.

3 PEOPLE WHO CARE ABOUT SUFFERERS

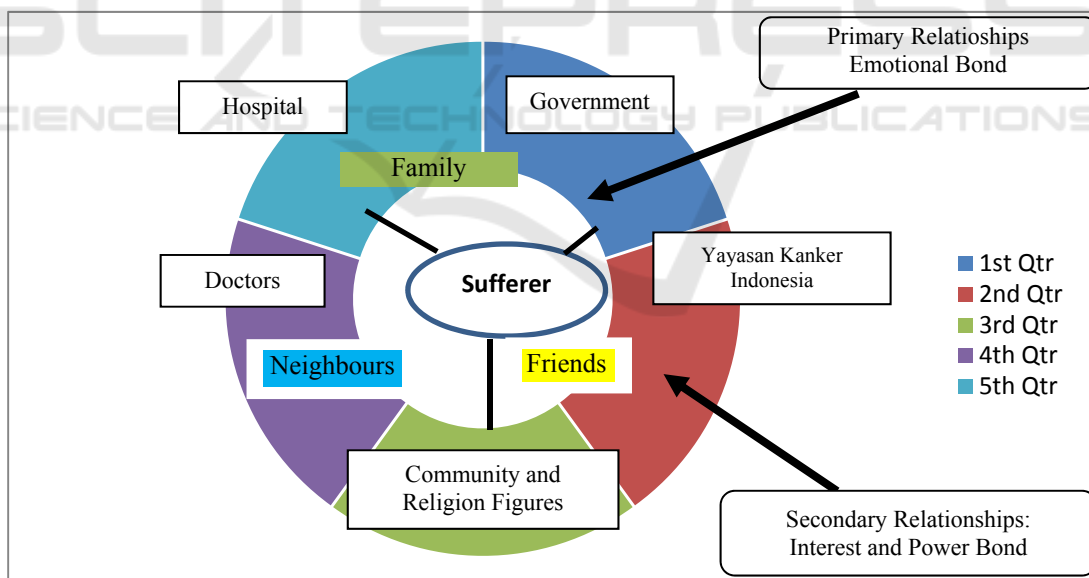


Chart1: Visualization of concern for patients with breast cancer.

4 MORAL SUPPORT FOR CANCER PATIENTS

Late treatment for breast cancer patients to get treatment, in an advanced stage or already severe, the action can not be done optimally (Tiolena, 2009). Rastad et al. (in Aruan and Isfandiari, 2015) said that delays in treatment caused by weak ties of interest and power. This can happen because the patient does not feel any symptoms of pain, even though there are oddities in her breasts. In this section we can see an example of a case that happened to Wati's mother who initially only considered a lump in her chest, as a result of catching a cold. However, when the omission is done and the disease has reached the final stage of cancer, everything becomes too late. The desire to operate was eventually rejected by the hospital because it was considered a futile effort.

Sometimes all family members suffer, the disease arises because of heredity, because there is no family history of breast cancer so they do not understand what is faced by family members. So they are reluctant to check their complaints with oncology specialists.

Sufferers are frightened when diagnosed with breast cancer, so they feel safer because they do not know that they are diagnosed with cancer. Patients do not see that they are at risk of developing breast cancer. Factors of sufferer's family and commitment to the patient's work, because the patient is afraid of leaving responsibilities in the family and afraid of being interrupted by his work when following breast cancer treatment

Treatment delay can occur due to factors originating from within the individual. At an early stage the patient feels healthy so the disease is left alone for some time, monthly, or yearly until the disease is no longer felt by the patient. Patients pay less attention to themselves, so that new sufferers realize and know of breast cancer in their bodies, after breast cancer is large or after complaints arise.

Patients do not understand or are less aware of the dangers of cancer. There is fear because it is known that the disease is cancer. Patients feel afraid to go to the doctor. Patients have a fear of being operated on. The sufferer and his family feel they have no money. As a result, the patient's family does not allow a doctor. Among those who feel their home is far from doctors or health services.

Behavior changes in health in individuals themselves can be determined by several factors. According to Lawrence Green, it was identified into 3 factors. These factors are, predisposing factors (predisposing factors), enabling factors (enabling factors), and driving factors (reinforcing factors)

(Maghfiroh&Khamida, 2015). Predisposing factors are driving factors in the form of knowledge, attitudes, beliefs / beliefs, and values held by an individual. Supporting factors are factors that are realized through the availability of services or facilities to deal with health problems. The driving factor is a factor that is manifested in the form of encouragement from certain reference groups around individuals which influences the reference of community behavior (Maghfiroh and Khamida, 2015).

Social support in the family according to the House is as emotional support, this support in the form of expressions of empathy, care and concern for family members concerned. Appreciation support, in the form of expressions of positive respect, care and responsibility because of affection for someone. Informative support, this support in the form of advice, guidance and in the form of suggestions to family members. Instrumental support, namely support in the form of direct assistance provided as well as material assistance (costs) or direct assistance (Smet, 1994).

Ms. Yusnani in the discussion of the first case study was a small part of cancer patients who were fortunate, because they had people around who cared about her. The moral support he received made Yusnani's mother able to live her days lightly, even though her illness was very severe. Inversely proportional to the conditions experienced by Wati's mother where her own family seemed indifferent and even no longer wanted to pay for her care during illness. However, fortunately Wati's mother still had several loyal friends who helped her and gave her moral support so that she could fight her illness.

Social support is needed for breast cancer sufferers when sufferers undergo chemotherapy treatment. According to Mutmainah et al. (2013), through good family support can make an individual more independent and confident in his own abilities. Through this support can increase motivation in a person. Family support is a very important aspect and is very much needed in determining the sooner or later the healing process experienced by the patient concerned.

5 CREATING A COMMUNITY FOR BREAST CANCER PATIENTS

After the researchers conducted in-depth interviews with several patients, families and neighbors of breast cancer sufferers, the researchers clearly saw how

important an organization or community was to gather breast cancer sufferers.

Even though YKI (Indonesian Cancer Foundation) actually has its address at Jl. Iskandar Muda No.272, Petisah Tengah, Medan Petisah, Medan City, but its role is still not felt by breast cancer sufferers who are in Medan City, at least it is reflected in a number of case studies that researchers have revealed earlier.

So the research team finally appealed to form a community network of social organizations as a service for breast cancer sufferers. The benefits of this community of breast cancer sufferers are as follows:

a. Get Support and Motivation

Suffering from chronic diseases, such as breast cancer, in fact makes many patients feel inferior. Quite often changes both mentally and physically make their hearts hurt. What's more the series of treatments and treatments that were undertaken felt tiring. So that many patients feel prolonged despair and sadness.

By joining a community member can help patients gradually regain their confidence. Of course the desire to recover and undergo treatment will have the support of other members. Patients will get motivation from friends in the community because they also certainly understand how the patient feels.

b. Sharing Knowledge and Interesting Experiences

The breast cancer community that has formed in various countries, not only consists of people who have the disease. This community is also full of healthy people who care about breast cancer sufferers, people who have had breast problems and even people who are on medication. In some communities there are also members of the experts in cases of this chronic disease.

Every member of the community has the right to share interesting knowledge and experiences. There are many good things to share with other members. By sharing, all members will benefit by joining the community. Members can also learn from the experiences conveyed by other members.

c. Asking Questions

In addition to specialist doctors, breast cancer sufferers can ask the questions you have in mind. So far many sufferers are still lay with these deadly diseases. Moreover, if a patient is suddenly convicted of developing breast cancer, many questions will arise in his mind. Many patients feel embarrassed when asking their specialist doctors in detail.

In the community, breast cancer sufferers need not feel ashamed to ask. This will be easier because some members have experienced the same thing. The same fate, allows sufferers to ask questions

straightforwardly without hurting others. Patients will usually feel more satisfied because it can issue negs that roam in his head.

d. Add friend

In addition to getting interesting experiences, indirectly joining the community will add friends. Patients will meet and talk with many people so they will not feel alone. Friends from various backgrounds will keep patients entertained and enthusiastic about living life.

The presence of new friends will provide positive energy to sufferers. Patients feel more meaningful and ready to undergo treatment because many people accompany him. Recovery from breast cancer is not easy. Not just family, good friends will also help sufferers through difficult times.

e. Practicing Commitment and Responsibility

Members of the social organization network community understand very well how patients feel when they are undergoing treatment in order to recover quickly. That way the responsibility of other members will emerge to provide moral support. Positive commitment in terms of helping others can provide enough motivation for sufferers.

This community will help sufferers undergo a series of treatments to recover from their illness. Commitment and responsibility can also influence attitude. Members will add empathy and sympathy to others. Social souls to help others who are struggling will also form within themselves.

f. Helps Financially

At present the government has indeed launched the Healthy Indonesia Card (KIS) program for poor families and the health BPJS for government subsidy insurance which must pay contributions every month according to the class registered. But, in fact the facilities provided by the government cannot be used fully because there are some drugs or treatments that are not covered. So the patient must pay in a separate bill.

Some communities care about breast cancer, often doing charity actions to help breast cancer sufferers. Donations given to underprivileged patients are expected to help financially. Donations can be in any form, but it would be more helpful if in the form of money considering the costs required are very large. To get help from the community, usually some administrative requirements are needed which show that the patient really comes from a poor family. This is done so that it is right on target.

Many benefits are obtained by joining the breast cancer community. The community will have a positive effect on sufferers so there is no need to feel

strange or depressed because of their illness. Healthy and positive thoughts are needed for patient recovery.

6 CONCLUSION

In this paper, it was concluded that quite a number of family members, relatives, friends and neighbors who do not care about breast cancer sufferers. Usually the people around breast cancer sufferers participate only provide support in the form of morals, and rarely also in the form of energy such as helping to take care of cancer sufferers in caring for themselves. Breast cancer patients generally need more moral assistance than material assistance, this is because the average patient with breast cancer already has a BPJS card, so for treatment is not too concerned about the cost. But often they don't use it.

Of the many informants from relatives of breast cancer sufferers, almost all of them did not know the initial symptoms of breast cancer. On average only assume these symptoms are solely caused by boils or wind in the body. So many breast cancer sufferers are finally late in getting cancer treatment.

No patient or family knows about the YKI (Indonesian Cancer Foundation) organization. During the patient's treatment, the family never communicated or was visited by YKI so the family did not know anything about the institution. The patient's family also hopes to form a community of breast cancer sufferers whose focus is to gather patients and families of breast cancer sufferers, so that they can encourage one another and also exchange knowledge regarding breast cancer.

7 SUGGESTION

This paper, seeks to provide some advice from various parties related to this breast cancer patient. Are as follows:

1. The patient's family

The patient's family should actively participate in asking the sufferer about what is felt. Then the family also plays an active role in the search for treatment for sufferers, thereby reducing the number of late treatment. The family always accompanies the patient both when the patient goes to the doctor and when the patient checks the symptoms they face. The patient's family also must always provide continuous motivation so that breast cancer sufferers remain enthusiastic in living their days.

2. Government

To the government to immediately carry out proactive and intensive socialization actions to the public at large, about knowledge of breast cancer, especially to those who have suffered including their families. This is considered important so that no more cancer patients who come to the hospital in a state that is no longer helpful, because of reasons of ignorance about the symptoms of breast cancer. Or feel bored to come for treatment as long as it continues.

The government in this case, the Health Service, must be more proactive in efforts to form a Community for Breast Cancer Patients in the City of Medan. The goal is that the sufferers and their families can share information about handling breast cancer in addition to trying to ease their burden. So that the health department will not have to bother registering patients with breast cancer when there is a social network organization that collects those who suffer from breast cancer.

REFERENCES

- Agusyanto, R., 2014. *Jaringan sosial dalam organisasi*, Raja Grafindo. Jakarta.
- Aruan, K.P., & Isfandiari, M.A., 2015. Hubungan dukungan sosial terhadap pengobatan payudara di Yayasan Kanker Wisnuwardhana. *Jurnal Promkes*, 3(2).
- Francis, S., Satiadarma, M.P., 2004. Pengaruh dukungan keluarga terhadap kesembuhan ibu yang mengidap kanker payudara. *Jurnal Ilmiah Psikologi ARKHE*, 9(1).
- Friedman, M.M., 1998. *Family nursing: Theory and practice*, EGC. Jakarta.
- Jenkins, J.H., Garcia, J.I.R., Chang, C.L., Young, J.S., Lopez, S.R., 2006. Family support predicts psychiatric medication usage among mexican individuals with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 41, 624-631.
- Mutmainah, R.S., Priyogo, N.I., Hartanti, R.D., 2013. Hubungan antara dukungan keluarga terhadap motivasi untuk sembuh pada pasien kanker yang menjalani kemoterapi Di RSUD Kraton Kabupaten Pekalongan. *Laporan Penelitian*. STIKES Muhammadiyah Pekajangan: Pekalongan.
- Purwodarminto, W.J.S., 2006. *Kamus Besar Bahasa Indonesia*, Balai Pustaka. Jakarta.
- Maghfiroh, L., Khamida, K., 2015. Peran keluarga dalam peningkatan kemampuan interaksi sosial bermasyarakat klien skizofrenia pascaperawatan di Rumah Sakit. *Journal of Health Science*, 8(1).
- Smet, B. 1994. *Health psychology*, Grasindo. Jakarta.
- Tiolen, H.R., 2009. Faktor-faktor yang mempengaruhi keterlambatan pengobatan pada wanita penderita kanker payudara RSUP H. Adam Malik Medan Tahun 2008. *Skrripsi*. Faculty of Public Health. Universitas Sumatera Utara.