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The emerging cancer support system in traditional and religious values: a qualitative study of the cancer community in west Sumatera, Indonesia

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Abstract

Introduction: Comprehensive cancer care was recently developing in west Sumatra province. Accordingly, there was a need to establish a support system for cancer patients while considering traditional and religious values rooted in the community. **Objective:** To explore the cancer support system and its values in west Sumatra. **Methods:** In-depth interview with peer group (N=16), Focus group discussion with patients, caregiver, survivor group, Indonesian cancer organization and professional (N = 18) and observations patients interaction in Andalas University Hospital. **Results:** West Sumatera cancer support consist of several components, which is: health worker for guiding patient during treatment, patient's extended family as decision-maker, financial support, and escort during treatment, friend and colleague for emotional dan spiritual support, survivor groups as emotional support and counter hoax, Indonesian cancer organization to increase awareness dan advocate policy. Each component with different role in order to support cancer patients. Communication and coordination of the support system component were just started and becoming more intense. Traditional and Islamic religious values deeply influence the support system. **Conclusion:** A cancer support system was emerging in West Sumatera province. The support system involving components around patients, and begin to synergize and accommodate traditional and religious value.

Keywords: "Cancer support system", "West Sumatera", "Traditional value", "Religious value"

1. INTRODUCTION

Cancer is one of the top non-communicable diseases worldwide, causing significant mortality, morbidity, and disability. Cancer prevalence increased from 1.4 per 1000 in 2013 to 1.79 per 1000 in 2018. Indonesian health ministry report estimates an 8% increase in cancer incidents annually [1]–[3].

As a middle SDI country, cancer treatment facilities in Indonesia were limited and spread unevenly. Moreover, cancer treatment facilities are primarily found on java island. There is an effort to increase access to cancer treatment facilities in other island provinces, including West Sumatera. Accordingly, the cancer community was recently growing in West Sumatra province, which involves patients, families, survivors, cancer organizations, and medical workers.

Cancer patients from receiving diagnosis will have a long stressful and traumatic journey [4]. Most of them will be struggling physically because of cancer disability, adverse effects of treatment, and disruption of quality of life [5]. Most patients feel uncertain because of lack of information, anxiety, and depression [6]. Cancer can also impact patients' financial stability, which will add a burden to the patients and families [7]. Cancer communities in West Sumatera recognized these problems and the need to support cancer patients.

West Sumatera's population was heavily influenced by Islamic religion and traditional Minang ethnic values. These values also influence patients' perceptions and social interactions during cancer treatment. Each community component has tried a different approach to support cancer patients while accomodating religion and traditional values.

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The main objective of our study was to explore cancer patients' perceptions of what kind of support they need, the potential support from the cancer community, and how traditional and religious values influence cancer support.

2. METHODS

The research was conducted using qualitative methods combining observations, in-depth interviews, and focus group discussions.

2.1. Observation setting

The observation was conducted at the radiotherapy department of Andalas university hospital. The hospital was opened in 2016 with a comprehensive cancer treatment focus and one of Sumatera island's primary cancer referral hospitals. Radiotherapy treatment is given five days per week for 2-3 months, enabling intense and frequent interactions between patients, families, medical staff, survivors, and cancer organization volunteers. We observe the interactions between cancer community components, giving rich and valuable background and behavioral information.

2.2. In-depth Interview

Sixteen peer supporters from survivor organizations were selected using purposive sampling. We interview the peer supporter separately. The interview was conducted according to the peer's request, whether face-to-face interview in preferable location or the interview were done online via video call or phone. The interview started with the need for support for cancer patients, we encouraged the peers to be active in telling their stories, and we explored according to their topic of interest. Topic in the interview include :

- 1) The experience of struggling to understand the cancer diagnosis and treatment.
- 2) Family, tribes, and community support.
- 3) Type of Support needed by the patient.
- 4) Cancer support affecting the quality of life.
- 5) Religion role in cancer support

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2.3. Focus Group Discussion

Focus group discussion participants were chosen using judgmental sampling. We consider community components such as patients, families, close friends, survivor organizations administrators, Indonesian cancer organization administrators, medical staff, and psychiatry experts. Focus Group Discussion was held online via video conference application according to COVID-19 pandemic protocol at the time. Eighteen persons attended the FGD. We encourage each

community to speak their mind, listen to other participants' commentary, and give feedback accordingly. The discussion was explored until the topics were saturated. The topics during FGD were perception of cancer support, the experience of cancer support in the community, traditional and religious value influencing community, suggestions, and recommendations to improve cancer support in West Sumatera province.

2.4. Analisis

We analyzed the data using systematic text condensation methods.

- 1) Raw verbal data from the in-depth interview, focus group discussion were analyzed to get an overview and general understanding of the complete statement from the respondents. Furthermore, we try to identify the themes from the impression.
- 2) We analyzed the transcript line by line to identify the meaning units and organized them into code groups.
- 3) From all of the code groups, we establish condensed code groups that will reduce the number of transcripts while still revealing all of the themes that appear from respondents.
- 4) Concept and descriptions were synthesized from condensed code groups, revealing trustworthy stories to answer the study's objectives.

3. RESULT

Based on analyzed data, we establish our founding into several themes :

3.1. Support needs for cancer patients

Receiving a cancer diagnosis and the long and complex fight to treat cancer seem overwhelming to most patients. They need all the helps they can get. The type of support stated by the informants can be information, physical, emotional, financial, and spiritual.

3.1.1. Escorting support

Most patients will need to travel into several cities, sometimes in different provinces or islands, to treat cancer. Most of the time, as an outpatient, they will have to come to the hospital daily, and it feels very lonely and hard if no one is escorting them. Patients feel supported when being accompanied :

"Sometimes, if I go to the hospital alone to get treatment and I see other patients accompanied by their families, I feel lonely and overwhelmed."

"I feel grateful for my son, who was escorting me through all my treatment schedule. I do not think I can finish the treatment if I were by myself..."

3.1.2. Emotional Support

Cancer is emotionally stressful for patients and their families. The patients stated that emotional support is one of the essential supports that they need :

"In a couple of months after my diagnosis, if no one stays beside me, I will cry and drown in my sorrow..."

"Emotional support is more important because I think I can bear some degree of pain alone. Nevertheless, I need someone who listens when I feel helpless or sad."

3.1.3. Information Support

Most cancer patients were not well informed about cancer diagnosis and its treatment. From receiving a cancer diagnosis, most patients were confused by overwhelming information from the doctor, medical staff, friends, families, the internet, and even social media. The patients need reassurance which information was authentic and which are a hoax :

"I feel reluctant discussing my illness to friends and colleagues. Some of them will tell contradicting information from what I got from the medical doctor. Quite often, I found, later on, the information that they share was a hoax."

It is easier for the patients to trust cancer-related information if other patients who have been experiencing it before confirmed the information :

"Sometimes, when I feel in doubt about some information, I will ask other patients who have an experience about it."

Some of the patients still seek confirmation of the information they got from medical staff and family :

"While waiting for treatment, we usually having conversations with another patient around us. They will give us information or some tips about taking care of adverse effects at home. It is reassuring when they confirm the information from the medical doctor was true and helping..."

The patients' families also confirm this behavior:

"I have a medical doctor degree, but my father as a cancer patient will more incline to believe the information he got from other patients."

Cancer treatments have much information that the patients need to know. The information can be about the treatment procedures, how to deal with adverse effects at home, what to bring in the next appointment, the administration process, and other detailed information. Even though the medical staff has explained to them, the

patient cannot remember all of them. They need to ask again, or someone else repeat or simplify the information. Some of the patients do not even want to be bothered listening to the information, and they let some else do it for them :

"There are too many things they tell us about my treatment, and often I need to ask my family to repeated to me."

"I do not understand my treatment. It is too complicated for me. I trust my son to ask all the questions he needs from the doctor."

3.1.4. Spiritual Support

In fear of sickness and death because of cancer, patients tend to use religion to cope. Family, friends, and colleagues also often using the spiritual and religious approach to soothe patients' emotional state. This approach is more manageable because Islamic teaching is part of the community's beliefs and culture, and it prepares its believer to face death and the afterlife :

"...My friends tell me that death is part of takdir (fate). I must learn to accept this illness..."

"When we know that my mother will die soon, we try to support her spiritually by inviting ustadz to our house..."

3.2. Role of cancer community in cancer support

Cancer patients will be involved in the cancer community from getting a diagnosis to the end of their life. They will spend more time in the cancer community. According to our informants, the patients' social interaction in the cancer community was described as below :

3.2.1. core family

The core family is the direct financial support, such as the spouse or parents. Even when the patients were still working and earning money, the core family would help the financial burden. Most of the time, during a hospital visit, patients were escorted and accompanied by the core family member.

"My expense during treatment mostly from my spouse, my spouse or my child will take turn to accompanied me during treatment..."

3.2.2. Extended family and tribes

Extended family and minang tribe bonds were still strong today, especially in rural areas. On the other hand, the circle was smaller in urban areas focusing on the core family. Nevertheless, when someone in the family was

diagnosed with cancer, it is considered a significant moment that caused the extended family and even tribe to strengthen the bond during the hard times.

More often, cancer's impact on financial and daily life was so significant that the extended family was called to support the patients. In the Minang culture, a crucial decision must consult by the elders.

"I cannot decide on my treatment right now, and I need time to consult my family and elders.."

These elders will coordinate the extended family and tribes in supporting patients. The support can range from decision of treatment, financial, emotional, and additional escort.

3.2.3. Friends and colleague

Friends and colleagues supported the patients emotionally and tried to encourage and sometimes gather charity, primarily when cancer news was known. The emotional support lasts longer with close friends and works colleagues if the patients are still actively working.

"At the beginning, many people supported and encouraging me, and sometimes they gathered money to help me. Nevertheless, my close friends were more frequent supporting me..."

3.2.4. peer patients

During radiotherapy treatment, patients will regularly meet their peers and became closer to one another. They feel better, knowing they were not alone. Patients will discuss their illness, treatment and confirm their doubts and anxiety about the treatment. Patients would also share their experiences and tips.

"I have made friends with other patients in the waiting rooms, and we grew closer each time. We discuss our illness and treatment. It is encouraging talking to them..."

3.2.5. Survivor organization

Some patients became a volunteer in survivor organization. They want to share their experience and knowledge with new patients. They wish another patient to be better at facing their cancer illness.

"I do not want other patients having the fear and anxiety, like what I was experiencing before. That motivated me to volunteer to help other cancer patients."

Survivor organizations launch several programs such as gathering, online group meetings for sharing between the participants as emotional support. Sometimes they held an educational program to inform the community or public about cancer

3.2.6. medical staff

Doctors and paramedics, while giving treatments were also tried to educate the patients and their families. Medical staff is the primary information source for the patients. The medical staff will explain and help the patients understand their illness and guide them when accepting bad news, choices of treatments, administration process, and even miscellaneous information on where to stay and where to find specific drugs or foods.

3.2.7. Indonesian cancer organization

Indonesian cancer organization is a non-profit Non-Government Organization focusing on cancer. This organization branch in West Sumatera has many programs to covers. but Due to limited resources, they have to focus on several aspects such as advocating policy and awareness to health authorities and also advocate awareness for cancer

3.3. Cancer community values

West Sumatera culture and Islamic religion influenced the cancer community values. These values affect patients' perceptions and behaviors.

3.3.1. Traditional values

Family bonds in extended family and tribes are still strong in West Sumatera cultures, especially when one family member faces cancer. The patients often do not directly decide their treatment choice and other important decisions, but to be discussed beforehand with the family and elders. Most of the family will advise using alternative treatment such as herbal medicine or to a shaman.

"Almost everyone in my family will suggest an alternative medicine like boiling some herbs or avoiding eating eggs or meats. A lot of their advice will be contradicted with the doctor's advice.."

The volunteer survivors found that many patients were reluctant to share their stories in front of groups. It is not easy for them to be open to strangers, as mentioned by some of the survivors' volunteers :

"Many of the patients were just silent in the group chats, but many of them send a direct message if they want to ask a question..."

The barrier to be open to strangers also happen between patients. Discussion between peers patients mostly happens during radiotherapy treatment when they meet regularly and have a chance to know each other before telling their stories.

3.3.2. Religious values

Cancer diagnosis stigma was associated with death. Having a cancer diagnosis is a life-changing moment. Islamic religion perceptions teach to accept illness and death as part of fate from god. Illness was also viewed as a way to erase sin. These perceptions help the patient during their step of grieving into acceptance and tranquillity.

"At least my suffering because of cancer will erase my sins and helps me in the afterlife...."

"This illness made me became closer to god, and reminds me to make a better my preparation to afterlife..."

3.4 hopes and dreams of the cancer community

The cancer community was recently aware of their components. Many patients and their families never knew about survivors organizations or cancer support before. They also realized each of their limitation and strength. The cancer community wished to increase the communication between the component.

"I am delighted knowing there is supports system for patients. we should hold a meeting like this more often."

"Our support can be better if we collaborate between family, organizations and doctors..."

4. DISCUSSION

Cancer support has shown a benefit to increase the patients' quality of life. A sound support system helps patients reach the "acceptance phase" more quickly and has a crucial role in supporting the continuity of patient therapy [8], [9].

There are many forms of cancer support and various programs that could be used. Understanding the community's support needs, available resources, and values were necessary to form a suitable cancer support system.

4.1 Cancer community dynamic as a support system

Our investigations found that since cancer treatment was established in West Sumatra Province, many people who have been around the patients tried to give support to cancer patients in various ways. These people came from different components such as core families, extended families, tribes, peer patients, medical staff, survivor organizations, and national cancer organizations. As time flows, their interaction was increased and made a cancer community in West Sumatra Province.

West Sumatera province's Cancer community is relatively young. Based on our observations, interviews, and discussions (FGD), it turns out that most patients and their families are not aware of the existence of other cancer community components and their support systems. Those who are got the chance to receive the support feel grateful and hope that the support from the cancer community will grow and can be accessed by all patients.

Every support system component includes nuclear family, relatives, friends, peer groups, survivor organizations, and national cancer organizations that have tried to support cancer patients. However, the support provided has not been structured yet, so the results are not optimal in helping cancer patients. Each component focuses on helping in the way they understand and are capable. Every component in the cancer community has its strengths and weakness. For example, core families primarily help as financial and escort support, but they do not have the skill to support emotionally and have a limited understanding of the cancer illness [10]. On the other hand, survivor organizations have the skill and experience to support emotionally but have limited resources.

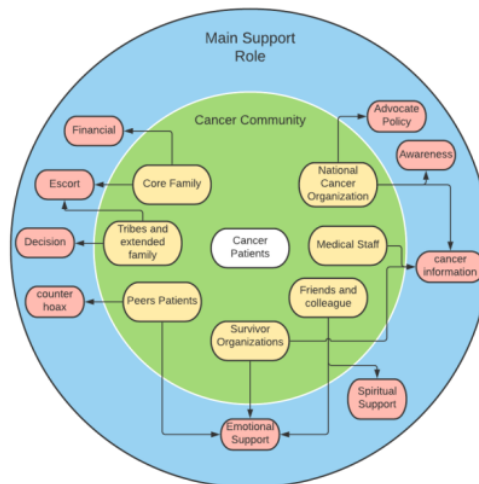


Figure 1. Cancer community components and their main support roles.

The medical staff has struggled to support the patients with cancer-related information and helping patients deciding on the treatment to enroll. Most of the time, patients do not decide for themselves. After receiving information, they will consult with their extended family and elder who did not present when the information was explained. This situation often brought miscommunication and informed consent problems [11].

There was a common misconception within the Indonesian population that alternative treatments were

cheaper than medical treatment, even though cancer treatment was covered by national health insurance [12], [13]. Families and friends usually give the advice to use alternatives treatment. This advice often causes delay or cessation of cancer treatment [14].

Several meeting was initiated between the cancer community components. Every component agrees that they have a better chance to give a broader and better support system if they work in synergies. In one of the meetings, the medical staff mentioned their hope in cooperation with extended family and tribes to helps the patients choose the suitable treatment decision and educate the family to understand cancer better.

The same vibe was also coming from survivor organizations and national cancer organizations. They agree that the cancer support system will be more comprehensive and remarkable if they combine their resources and launch collaboration programs.

Hopefully, in the future, there will be a system that can facilitate the collaboration of these components so that they can synergize with each other in realizing a reliable and comprehensive support system for cancer patients.

4.2 Applying values in cancer support system

Culture and values in the region affect how the community sees things and their behavior. West Sumatera has a unique Minangkabau culture that upholds religious values. The philosophy was "*Adat basandi sarak, sarak basandi kitabullah*" meaning the culture is based on Islamic principles and the Qoran.

Advancement of information and communication technology media causing a rapid social interaction between cultures. Some of the traditional values may reduce in practice, but we observe that in supporting cancer patients, they still uphold the extended family and elder's position for advising essential decisions. Furthermore, despite modernization, the West Sumatera population is generally religious. The culture of traditional healings methods is still prominent, ranging from using local herbal medicine and Islamic healing methods.[15], [16]

The cancer community components during FDG have discussed the importance of integrating these values into cancer support in West Sumatera province. They could apply the traditional and religious values into their programs in several ways:

1. Extended family and elders should be involved in cancer information sharing and the process of making treatment decisions.
2. A balance of traditional and religious healing methods and modern cancer treatment should be established.
3. Emotional support should be combined with Islamic religious support.

The cancer community in West Sumatera province is establishing a unique support system that involves all cancer community components and integrates local values. If managed properly, the support system has a great potency to be accepted in the region and can answer the unique challenges of the local cancer community.

5. CONCLUSION

The cancer support system in West Sumatera was growing and starting to form connections and interactions between its components. Traditional and religious values were considered to be an essential aspect of the cancer support system. The community hopes that in the future, they can establish an integrated support system and be better at helping cancer patients in West Sumatera.

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