Cancer Is a Fatal Disease; Perspectives among Muslim Married Men in Indonesia

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***Abstract*- The aim of this study was to explore married Muslim man's perceptions related to breast and cervical cancer in order to gather information of about their roles in women's cancer. A descriptive exploratory approach was used involving focus group with 11 groups (n=77) of men from rural and urban areas of West Java province, Indonesia. Data were analyzed using The Inductive Comparative Qualitative Analysis Approach in Focus Group (ICQAAF). Men perceived that cancer is a fatal disease for women because they regard it as deadly, dangerous, scary, and costly. Participants also cited that this disease is given from God, and He will help to cure it. The study highlights that men views of women's cancer are various and influenced by experience of cancer in their family or communities, and beliefs. Men's perceptions of women's cancer could be influence to their roles in women's health.**

***Key words:* Perceptions, Breast and Cervical Cancer, Married Muslim Men.**

I. INTRODUCTION

Breast and cervical cancer are the most common cancers among women in western and non-western countries. These cancers are preventable and curable; however, women have different responses and behaviour regarding prevention and treatment of cancer including in Indonesia. According to the MOH of Indonesia data in 2012, cancer cases were dominated by women's cancer such as breast (30% of all cancer cases) and cervical (24%). The MOH report described that the prevalence of cancer in women was higher than the prevalence in men with 5.7 per 1000 people for women, and 2.9 per 1000 people for men [1]. In 2013, the MOH target for women's participation in prevention programmes was that 80% of women aged 30-50 would participate in screening programmes for cervical and breast cancer every five years. In 2008, a national programme for breast and cervical cancer screening was declared by the first lady of Indonesia. Alongside the national declaration of breast and cervical cancer screening, other programmes were established, such as training health workers involved in cervical screening and health education in breast self-examination (BSE), and a pilot project of breast and cervical screening was developed. BSE and Visual inspection with acetic acid (VIA) methods were chosen by the MOH as recommended interventions for screening for breast and cervical cancer, because both techniques require few tools, are low cost, and can be delivered easily by health providers [2]. However, by late 2012, four years after both screenings techniques had been introduced nationally; only 500 of 9500 Primary Health Centres (PHCs) had introduced the screening. As a consequence only 550,000 of the eligible 35,000,000 women were reported as being involved in the cervical screening programmes. Other studies have also found that women's participation in cancer screenings and treatment in Indonesia is low [2-5]. Unfortunately, searching the real incident of women's cancer patients are difficult in Indonesia since no national cancer registry.

Some factors known to influence women in Indonesia participating in screening and treatment of breast and cervical cancer are women's knowledge, limited availability of information, family supports including the husbands' support, the woman feeling healthy, shame or worried about cancer, economic factors, accessibility, the roles of health providers, social culture, and women's lack of motivation [6-16]. Studies suggest that husbands' support (for or against) is one factor that influences women's engagement in screening, prevention and treatment. Studies have found that the husbands' role can have a positive or negative influence on participation in disease management [17] and health promotional behaviour of their spouses [18]. It is possible that the husband factor in Indonesian studies is related to women's beliefs related to being Muslim. According to O'Mahony and Hegarty [19], beliefs are one factor that influences health seeking behaviour.

From an Islamic perspective, a man (the husband) has full responsibility to take care and protect his family members, and has an important role in decision making as it relates to giving consent for health treatment [20]. The health behaviour including protecting family's health is depend on individual beliefs of illness severity and its impact [21]. It is beneficial to understand men's perceptions related to women's cancer because their perception could be influence to their actions in supporting women's health. However, little is known in Indonesia about men's views of breast and cervical cancer. This article aim to determine married men's perceptions about women's cancer in the Indonesia Muslim community.

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II. METHODOLOGY

A. Research Design

This qualitative research uses the descriptive exploratory approach, and adapt the analysis to specifically search for group comparisons. The goal of qualitative description is to generate a summarisation of everyday events experienced by individuals or groups of individuals [22]. An exploratory study begins with a phenomenon about which little is known; and the methods are designed to explore the nature of the phenomenon, manifestations, factors that are related, and factors that led or contribute to it [23]. Generally, comparative analysis is commonly used in quantitative studies designed to pursue understandings of differences and similarities between two or more subjects or groups [24]. In qualitative research, a comparative approach is used in grounded theory research: constant comparative analysis [25], and also in case study: cross case analysis [26]. Little is written about using comparison in descriptive research.

B. Participants

Participants were recruited using the purposive sampling method. The inclusion criteria were married Muslim men aged between 20 and 60, living in urban or rural areas, and voluntary participated. The total number of participants were 73 men.

The participants were divided into 11 focus groups; five groups in urban areas, and six groups in rural areas. The urban groups comprised three groups of men 40 years or more, and two groups of 40 years and under. In the urban areas I divided the groups into two areas: those with low incomes living in down town areas and middle income group. In the rural areas the groups consisted of three groups of men 40 years or more, and three groups of men 40 years or less. Further, participants came from different tribes; Javanese, Sundanese, and Sumatran. Each group had five-seven participants, and included those with no personal history of cancer, and 13 who had a member of their family with a history of cancer. The education and occupation background varied amongst the participants.

C. Methods

The data was gathered using focus groups with married Muslim men. Focus groups are useful in studies when little is known of a phenomenon. This method is appropriate to gather data related to married Muslim men's roles because focus group tasks in exploratory studies include gathering different opinions, finding people needs, expectations, and issues [27]. In addition, it can result new ideas and creative concepts, and participants can learn from the discussion and talk about the phenomenon of interest [28].

The data collection process for focus groups included: explaining the study to the participants, asking for their agreement and understanding about the study's processes, obtaining their informed consent. In addition, I became the moderator, and a member of my team was the note taker and recorded all the focus groups' processes. Each focus group was tape recorded and transcribed. The duration of the focus groups was approximately 60-90 minutes. A semi-structured focus group and interview guides were developed by me, as the researcher, and my primary supervisor. This instrument was used to uncover men's perceptions of breast and cervical cancer from different perspectives with regard to the research question. The interview items were guided by theories such as the Family System Theory, the Health Belief Model, and the Help Seeking Behaviour and Influencing Factors Framework. Open- ended questions were developed to explore the perspectives of married Muslim men's perceptions.

The instrument was approved by the human ethics committee of Victoria University, Wellington and piloted in two groups each of Indonesian Muslim men in Wellington.

The analysis data for focus groups are based on integration between the F Rabiee recommendation [29]and the QUAGOL framework[30]. Some modifications of these frameworks apply in this study. The integrated framework here is named the Inductive Comparative Qualitative Analysis Approach for Focus Group (ICQAAF). It is divided into four main steps including, pre-coding, coding process using software, formulating themes, and descriptions of the results.

III. RESULT

Themes

The data present that men from different groups offered diverse opinions with regard to the nature of breast and cervical cancer and these were influenced by their experiences and beliefs. The men believed that suffering an illness is not coincidental for women. The men's religious beliefs in God underpinned their opinions related to women's cancer and other diseases. They perceived that cancer is a test from God, and God gives this disease to women because breast cancer patients are mostly women. They also believed that God would cure the disease.

Some focus group participants, from different groups, commented that a disease in their family was because of a test from God or they were sinful. *"I often think about the causes, are they because of my sins, or a test from God?"* (A3). Another commented that cancer causes are difficult to detect because this is given from God.

I read about cancer, sorry I forgot the source. It explained that the cause of cancer is unknown, and 80% of it is given, not because of lifestyle or other causes…it occurs because the cells in our body split imperfectly or quickly. It is just unlucky (E5).

Even though men had pessimistic feelings related to what caused cancer, they strongly believe that God would help them because this disease comes from him so it can be given back to him.

I believed that my God is the only one who can cure this disease, and the doctor is only a facilitator to help us recover from a disease (J2).

However, some participants did not consider that Allah alone could cure cancer, but people could also help Allah with their maximum efforts. *"I believe as humans we have*

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to strive but the final result depends on our God" (J3). Another participant had a similar opinion:

I believed, if we have a disease that God provides medicines, so he is the one who will take the disease from our body...You should believe it, insyaallah [a hope from Arabic term] *God will help us* (B4).

The data indicates that men have opinions of how God applies his roles including curing this disease. On the other hand they believe that as human beings they need to take actions and give maximum efforts to solve this health problem.

In addition, men perceived that cancer is fatal disease for women because deadly, dangerous, scary, and costly disease.

1.1. A Deadly Disease.

The participants from both urban and rural areas described cancer as a deadly disease because many women they had known had died …"*In this village around 10 women suffered with breast cancer, and only one recovered*" (J4).

Another participant from the same group who had experience with cancer in his family followed the doctor's suggestions for different types of cancer therapies, however it was not cure the patient.

In my opinion, whether it is breast or cervical cancer, most of women who had these cancers passed away, especially after surgery. They had had chemotherapy but it did not help them. (J).

In addition, a participant from urban groups have the same perception about cancer that it is a deadly disease. He said, it was difficult to treat even though the patients had gone to an International hospital, as noted:

In my perception, it is clear that medical treatments only help cancer a bit. They did not show good results for my relative with cancer, even though we sent her to hospital in another country, but the result was minimal. ...As there was no improvement in her health we finally we preferred Palliative care (C).

1.2 *A Dangerous Disease.*

Participants highlighted that women's behaviour, a family history of cancer, and some perceptions of it such as a low expectation of recovery or that it is difficult to prevent were reasons that they thought it was dangerous.

Participants observed that the health condition of patient with cancer decreased quickly "*Sometimes this disease came suddenly, then in only a few days it changed and become severe. The change was so fast"* (E).

It could be happen because of women's behaviour including delaying screening and visiting health services after severe conditions.

My perception, it's because of the lack of screening, so most cancers are found in the late stages, then they are difficult to treat, and, the patient could die. Some patients may survive but only in a few years (C).

1.3 A Scary Disease.

Men talked about their fear when they compared cancer with another disease.

Like that Ma'am, I am scared when someone talks about cancer. For example, I asked Pak XXX, What are your health problems? If he answers "I have a problem with my hip", I don't find it unusual, but if he answers "Cancer", I feel different, scary scared Ma'am.... (A).

They also scared because most women with cancer have died.

Honestly, I am scared if somebody talks about cancer, whether it is breast cancer, brain cancer or other cancers, because almost 75% of people afflicted with it have died (J).

However, one participant had different opinion of cancer. He often read about cancer term in the advertisement on the cigarette packages that influenced his thinking about cancer.

I got information about cancer from the cigarette package (laugh), I read that smoking causes cancer. Honestly, I like to read it ma'am (laugh), so the cancer is not a scary disease for me ma'am (D).

1.4 A Costly Disease.

Different views noted by men who have experienced in managing family with cancer, they focused on the expensive fees of cancer treatments.

For me, first "tepok jidat" [a confuse expression put hand on his forehead], because I can imagine how much it costs for the treatment. Cancer treatments, previously, the surgery fee was 3.5 million rupiah [$350 NZD], I don't know the latest prices, a chemotherapy was 2.5 million rupiah [$250NZD] each and the patient needed six times. We can count on it. Then a radiotherapy was 750 thousand rupiah [$75NZD] and the patient needed around 35 times, it depends on the cancer's stage (J).

The data informed that men from different group shared their perceptions of cancer from different views. Men who have cancer experience in their community tend to share about the dangerous of cancer and their fear of this disease. On the other hand men who have experienced managing patient with cancer, they reported related to financial spending. The focus groups also indicated that men shared with regard to men's religious belief of cancer. Themes below describe men's perceptions to roles of God in cancer.

IV. DISCUSSION

The purpose of this study was to explore married Muslim men's perceptions of women's breast and cervical cancers. The study participants were varied in terms of age, where they live, their tribes, and experience of cancer**.** The study showed that men perceived God intervened in women's cancer in various ways. For example, they believe that one of the causes of cancer was sent by God was to test them because they had been sinful.

In addition, participants have the opinion that God will help them to cure the disease, so as a human we need to surrender to God for everything including recovery from diseases. On the other hand they believe that they should

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seek treatment even the disease comes from God. Similar trends are presented by Allen. D. Jennifer (2014) who studied religious beliefs and cancer screening behaviours among Catholic communities in the United States of America [31]. Allen's study showed that participants' believe God showers blessings on these Catholic believers as well as testing them. They also believe that God influences their health as well as making them suffer in sickness, and that he cures them. All of which align with the findings of my study. Allen's participants said that being healthy and actively caring for their health is part of human's responsibilities. Although participants in both studies come from different religious communities: Muslim and Catholic, the results showed the belief in God influences them in perceiving things including cancer disease.

In addition, surrendering health problems to God were mentioned in Kumar's study (2010)[32] which found that the majority of participants applied their religious rituals to ask for God's help and mercy to avoid cancer. This study also identified perceptions with regard to God's roles in Women's cancer.

Many participants who had experience with breast or cervical cancer either in their family with neighbours, or college acquaintances perceived cancer as a fatal disease for women because they reported that most women with cancer passed away. They also have the perception that medical or alternative treatments are of no help to patients, especially if their cancers are in the late stages. Daher's study(2012) interviews with people from Middle Eastern (ME) countries revealed that they believed that cancer is a fatal disease because they view it as being unpreventable [33]. Further, his study found some myths and perceptions of cancer including death, fear, pain and suffering, loss of control, helplessness, and isolation.

My study identified that men perceived that cancer was dangerous because most cancers quickly became severe/terminal. This may be because most women visited health services in the late stages of cancer so they cannot survive. Few participants have the opinion that the low uptake of cancer screening impacted to delay treatment. These findings are in-line with McLaughlin's study (2012) [34] which showed that the greater the interval between diagnosis and treatment was linked to a higher risk of death.

Feeling afraid of cancer was another of the men's perceptions. They compared cancer with others diseases, and reported that cancer scared them because based on their experience most women with cancer died. Only one participant was not scared of cancer. This finding mirrors a pervious study where fear of cancer was discussed in focus groups of men that gathered perceptions about prostate cancer[35]. OR This finding mirrors a pervious study where focus groups of men discussed their fear of cancer and their perceptions of prostate cancer??

Participants who help cancer patients reported their perceptions of the processes and fees of cancer treatments, based on their experiences. These included the expense and accessibility of treatments, screening and drugs. As with other developing countries there is a lack of availability of cheap and accessible health services in low-middle income areas in Indonesia. There is also limited access to cancer diagnosis, few facilities and a dearth of health professionals all of which are burdens for optimal cancer treatments in developing countries [36-38].

V. CONCLUSION AND RECOMMENDATIONS

This descriptive exploratory study explored perceptions of breast and cervical cancer among married Muslim men in Indonesia. The study identified men's perceptions with regard to the roles of God in women's cancer and their views of the nature of cancer. Different perceptions and opinions were evident about beliefs, psychological aspects, and economic aspects. These findings will make a significant contribution to identified data from men as part of developing suitable methods to improve men's roles in women's cancer.

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