Explanatory Models of Cancer among Sri Lankans: An Interim Analysis

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Abstract - Current research shows that health-related beliefs are important in predicting adherence to treatment, the psychological impact of the condition, and the subsequent quality of life. The personal etiological framework of an individual regarding his/ her health condition is referred to as an explanatory model. Explanatory models have been researched in relation to many diseases. The current research literature shows that in Asian countries, individuals have two parallel sets of explanatory models. One is based on the western medical models, while the other is based on cultural and religious beliefs. Thus, it is very important to understand both belief-systems in providing health care. This appears to be even more important in chronic conditions such as cancer, where treatment toxicity and treatment tolerance may have a continued impact on quality of life. The current study explores the explanatory models related to cancer in a convenient sample of 140 adults in Sri Lanka. The study was conducted as an online survey. The study indicates that the biological explanatory models for cancer are strongly believed. The most strongly believed religious-cultural reason for cancer is "Karma". Most participants believed they would choose both Western medical treatments and religious and culture-specific treatments if they or their family members received a cancer diagnosis. The majority believed Western medical treatment to be the most important treatment modality. Thus, it will be important for clinicians to acknowledge the patient's desire to incorporate alternative treatment methods and non-medical explanatory models in providing cancer treatment.

Keywords: Explanatory models, Cancer, Karma

I. INTRODUCTION

Cancer is a leading cause of death worldwide. According to the cancer fact sheet issued by the WHO (World Health Organization) in January 2014, the incidence of cancer in 2012 was 14.1 million. According to Globocan 2020, the number of new cases of cancer in the world is 19, 292,789. Cancer incidence has been rising in significant numbers. The stated prevalence estimate is 50.5 million. Further, the WHO states "approximately 44% of cancer cases and 53% of cancer deaths occur in countries at a low or medium level of the Human Development Index" (World Health Organization, 2014). This has important implications for Sri Lanka as, Sri Lanka is categorized as a country in the middle-income category, and the incidence of cancer has been in the increase in the country.

Researches further point out that with increased "Westernization" of low and middle-income countries due to globalization, cancer rates and patterns in low and middle-income countries are expected to follow those that are observed in the countries with high HDI (Human Development Index) values. Therefore, it is expected that there will be a decline in infection-related cancers, while there would be an increase in cancers related to reproductive, dietary, and hormonal risk factors.

According to currently available data on Sri Lanka, the crude incidence rate of cancer is 82.5 per 100,000. One out of every ten people has a lifetime risk of developing cancer. (National Cancer Control Program, 2015). Further, the statistics show an increase in incidence rates. This increase has been observed in the overall Asian rates of cancer as well (Pfizer Medical Division, 2008).

At present, there is increased attention to holistic care for many physical illnesses in general and cancer in particular. In providing holistic care paying attention to the patient's psychological aspects is of paramount importance. Especially, the patient's personal belief system has a strong impact on the psychological response to a disease. Recent research indicates that psychological aspects such as personality type are highly influential as etiological factors as well. (Kupper & Denollet, 2018)

A well-established tenet in Health Psychology is that health beliefs play a major role in all stages of any disease or illness. They are important in preventive measures, the course of illness, prognosis, and the outcome and subsequent quality of life in any health condition (Hoffman, et al., 2013)(Daher, 2012). The health belief model is frequently used to indicate the relationship between health beliefs and health behaviours. The importance of health beliefs in the etiology, course, prognosis, and outcome in cancer patients has also been well established in the research literature.

One important type of health belief which is believed to have an impact in the course of illness and outcome is the explanatory models of illnesses. Explanatory models (EM) refer to the personal etiological framework of the individual in explaining diseases and illnesses. This set of beliefs has a strong impact on treatment-seeking, the type of treatment sought, adherence to treatment, prognosis, and other illness-related outcomes. (Mamara, et al., 2017). Explanatory models are believed to be important in both mental and physical illnesses. (Jacob & Kuruvilla, 2018)(Gunn, et al., 2019). These beliefs can be highly influential for cancer patients, given the chronic nature of the disease and the common adverse reactions experienced by patients during treatment. Thus, gaining an understanding of the nature of the explanatory models of cancer can be important in providing cancer care.

Research on explanatory models in Asian populations has shown that people hold two categories of EMs simultaneously. One which is informed by the Western medical models and another informed by the religious-cultural practice. (Mathews, et al., 2019) This could be, because most Asian countries have adopted the Western medical model, while also retaining their traditional religious-cultural belief systems and treatment modalities.

Thus, obtaining an understanding of both these systems in cancer care may be important as they may impact the treatment outcomes. The current research expects to explore the impact of these EMs on wellbeing. The current paper is based on an online survey of a convenient sample of adults as the first step of the study.

II. METHODOLOGY

An online survey was conducted using the free google forms facility using the author's Gmail contacts and by posting the information on Facebook. A self-developed questionnaire which was developed after 05 mini-interviews and pre-tested was used for data collection. The questionnaire was available in English, Sinhala, and Tamil. The consent form was incorporated into the same google form. The responses received were analysed using IBM SPSS software.

Sample

72 participants responded in English, 29 responded in Tamil, and 39 responded in Sinhala. Only 05% of the sample had a current or a past diagnosis of cancer, while 20.7 % had a first-degree family member with a diagnosis of cancer. The mean age of the sample was 36 years. 35% of the sample was males while 65% were female. 33.6% of the sample had a postgraduate qualification. 29.3% had a degree and 15.7% had G.C.E A/L qualification.

III. RESULTS

A. Outcomes during the Development of the questionnaire

During the development of the questionnaire, when participants were asked regarding their EMs related to cancer, most participants mentioned only the EMs related to the Western medical model. When further probed, participants expressed strongly held religious-cultural EMs. During the mini-interviews, the participants revealed that for research they believed the medically related EMs were expected as responses, and providing cultural explanations would make them appear less knowledgeable. Therefore, unless specifically asked, people may not reveal their religious-cultural beliefs related to health conditions. Therefore, the questionnaire was

developed to acknowledge the presence of both Western medical model-related EMs and religious and cultural EMs.

B.   Outcomes of the Survey

According to the results of the survey the most strongly believed EM of cancer which is related to the Western medical model was the biological reasons (genes, infections, and abnormal metabolic processes), the second most believed the EM was behavioural factors (Unhealthy diet, lack of exercise, etc) while the least believed EM being environmental factors (Toxins, climatic changes, etc)
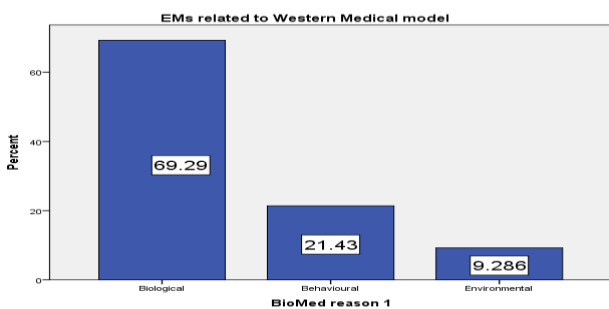
Graph – 01- EMs related to the Western medical model.

Outcomes related to the cultural and religious EMs are shown in the below graphs.
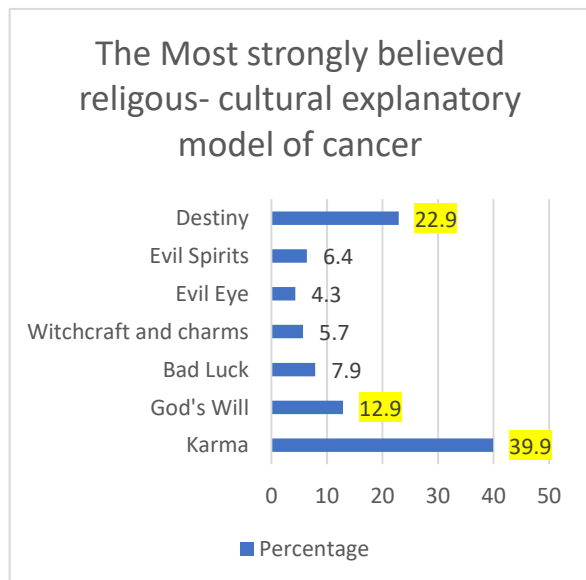
Graph 02- The Most strongly believed religious-cultural explanatory model of cancer

As shown in the above graph, from the seven EMs listed in the questionnaire, the most strongly believed religious-cultural EM is "Karma". The other six EMs that were listed were God's Will,

Destiny, Bad luck, Evil Eye, Evil Spirits, and Witchcraft and charms.

The majority of the sample (73%) had stated that they would choose both Western medical treatments and the religious-cultural treatment methods if they or a first-degree family member of theirs is diagnosed with cancer. 66% had stated that they would choose only Western medical treatments while only 0.7% had stated that they would opt for only religious and cultural treatments.

When asked about their beliefs about the most important treatment modality according to their opinion 52.9% stated that the Western medical treatment to be the most important, while 45.7% stated both treatment modalities are important. Only 1.4 % stated that only religious and cultural treatments are important.

IV.   DISCUSSION

According to the current study, it is clear that there are strongly held parallel Ems regarding cancer among the participants. This confirms previous studies which had pointed out multiple Ems of diseases. "Karma" appears to be the most strongly believed religious-cultural EM among the participants. While it appears that EMs of destiny and God's will are still strong, EMs of evil eye, evil spirits, witchcraft, and charms appear to be very insignificant among the participants. This may be an indication that the beliefs regarding witchcraft and charms and evil eye and evil spirits are reducing in the larger society. With the recent revival of many religious movements in the country, it could be that beliefs regarding Karma and God have been strengthened.

An EM of "Karma" for cancer may produce negative or positive effects. It can lead to acceptance of the situation in some, while some may blame themselves for having been responsible for the karma that brought upon the cancer. On the other hand, this EM can also affect the patient's social support system. If the close family members interpret the caner as a result of the person's karma, it may result in blame and stigma or more acceptance and support to increase one's good karma. The impact this EM would have on the patient and the family will be decided by the individual understanding of the concept of karma itself and other personality variables. Therefore, it

would be of value to conduct further research on the concept of Karma as an EM on cancer.

Further, as evident by the observations made during the development of the questionnaire, unless specifically asked, people, do not disclose their EMs related to their religion or culture. Rather, they choose to discuss the biomedical EMs only, due to social desirability of appearing knowledgeable, or maybe they are unsure of the societal response to these. Therefore, unless a clinician providing western medical treatments demonstrate they are open to discuss such beliefs, a patient would rarely discuss these with them.

The majority of participants appear to opt for both the Western medical treatments and religious-cultural treatments. Still, the majority thinks the most important treatment modality to be the Western medical treatments. It may be an indication that individuals while pursuing Western medical treatments as the most important treatment modality, would also like to supplement this with other more religious-cultural treatment modalities. Therefore, it would be of value to acknowledge the patient's desire to incorporate alternative treatment modalities when it does not affect the medical treatment provided. Accepting and acknowledging this desire of the patient would greatly strengthen his/ her acceptance in medical treatments as the study has already demonstrated that the majority of the individuals already believe the Western medical treatments to be the most important treatment modality for cancer.

V. CONCLUSIONS AND FURTHER RESEARCH

The current study demonstrates that religious and culture-specific EMs such as Karma, God's will, Destiny to be the strongest non-medical EMs, when people try to understand why they developed cancer. These EMs would strongly interact with the individual personality variables of the patient and the societal variables of the micro-social circle of the patient to create positive or negative effects on treatment outcomes and the overall wellbeing of the patient. Therefore, it would be of value for clinicians providing care for cancer patients to explore these beliefs in their encounters with patients and support them in incorporating these beliefs in a way that would be supportive to the treatment outcomes and overall wellbeing of the patient as well as the close family members. While further research on the impact of these EMs is

indicated, obtaining a basic understanding of these belief systems would help clinicians provide more holistic care to cancer patients.

Further, it is clear that according to the current data, the Western medical treatments for cancer are accepted as the main treatment modality for cancer.

The salience of these EMs can be different in individuals who are obtaining treatment for cancer at present, and the subsequent stages of the research expect to explore this aspect. In the subsequent stages, the study expects to explore the impact of these beliefs on psychological well-being among cancer patients and their family members.

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