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Life after Cancer Treatment: Fear of Recurrence among Thai Colorectal Cancer Survivors

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Abstract

Background: **After cancer treatment, cancer survivors have been living with fear of recurrence more than people with other kinds of illness. Because cancer is such a difficult illness to treat, there is a chance that it might come back again. Psychological consequence of fear that cancer recurrence could occur following transition from patient to survivor status may interfere and diminish their quality of life.**

Objectives: **The study was aimed at exploring and describing life after cancer treatment among Thai colorectal cancer survivors focusing on experiences surrounding fear of cancer recurrence.**

Materials and Methods: **The qualitative research method was employed to gain, in depth, qualitative data. By interviews and participant observation data, an understanding and explanation of this social phenomenon are hoped to be achieved. The participants of this study composed of 22 Thai colorectal cancer survivors who had completed over one year of cancer treatment. In-depth interviews, close observation and field notes were used to collect data. The constant comparative method was used to analyze the data collected as well as inductive and deductive approach. Through the use of this method in the analysis of data, patterns in the data/behavior can be ascertained and a general concept developed.**

Results: **Analysis of the data provided evidence supporting a distinct pattern in which the fear of cancer recurrence among Thai colorectal cancer survivors was coupled by the fear of death, the fear of re-treatment and the fear of suffering. Fear of recurrence always occurs when facing medical appointments, health deviation and arousing media. The intensity of fear of cancer recurrence varies and was dependent on time elapsed, but for some survivors the fear was constant throughout. The fear may effect daily life and induce hypersurveillance. As a result, coping strategies were identified. These strategies included deflecting bad thought through activities, self-control, self-entertaining, suppression, denying, positive thought, relying on treating physician, utilizing alternative prophylaxis, religious activity and increasing self-strength. Belief, faith and hope are crucial mechanisms in driving coping behaviors.**

Conclusions: **Fear of cancer recurrence may interfere with a cancer survivor's daily rituals and routines. Yet, a normal level of fear of recurrence may assist colorectal cancer survivors in controlling and adjusting to the situation and build a stronger sense of security. Focus on one's belief, faith and hope play an integral role in determining coping strategies and attaining life balance.**

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Introduction

The experiences associated with the diagnosis of cancer and life, after complete treatment, may be perceived as destructive and traumatic to survivors. Fear of cancer recurrence after treatment was commonly found accompanied by a level of uncertainty and anxiety[1]. Affected patients may be kept on constant watch for signs and symptoms of recurrence.[2] Fear of disease recurrence has been found to intensify as survivors are treated for more advanced diseases such as a complexity of adjuvant therapy.[3] It was found that the fear of cancer recurrence was a precursor to psychological[4] and spiritual distress[5] which may diminish the quality of life. An in depth analysis surrounding this fear may help health professionals understand and assist colorectal cancer survivors in coping with this life threatening situation.

Literature review

Cancer survivors are always concerned with the issue of "recurrence", more than people inflicted with other kinds of disease. Since cancer is perceived as a complex disease to treat, an increased possibility of recurrence is at the forefront of every cancer survivor's concerns. A study by Schover[6] and Vickberg[7] found that breast cancer survivors reported the possibility of cancer recurrence as their prevailing concern above all others. Similar findings were discovered by Ness, Holmes, Klein, Greene, and Dittus[8] where an analysis of interview transcripts by focus groups of colorectal cancer patients (after 1-3 years of treatment) yielded that the fear of cancer reappearance was also a "primary" concern. Similarly, Northhouse et al.[9] revealed that the greatest concern of colorectal cancer patients and their spouses was the fear of reoccurrence and lifestyle changes as a result of the illness. The uncertainty of illnesses developing after treatment and concerns about treatment outcomes and survivability were most frequently reported by cancer population.[10] All of these uncertainties were associated with the fear of cancer recurrence[7,11].

The majority of researches on cancer in Thailand were conducted during hospitalization and during treatment by chemotherapy and radiotherapy. These studies were conducted on patients during treatment and found that the primary fear in regards to cancer was the fear of unpredictability: fear concerning cancer reoccurrence, treatment outcome and survival[12]. Some studies focused on the uncertainty after treatment, by operation, among Thai colorectal cancer patients[13]. An investigation in the psychological distress among cancer patients during chemotherapy found that patients felt heightened anxiety concerning treatment outcomes and survival. A coping mechanism to release this anxiety during chemotherapy was the practice of meditation[14]. Religious beliefs and activities play a vital role to help patients attain a peaceful mind set during treatment. High levels of fear of recurrence can diminish the quality of life; but little attention is given to this fear after treatment has ended.

Fear is an emotion experienced in anticipation of some specific danger usually accompanied by a desire to flee or fight and associated with an external real threat or danger.[15] Fear of recurrence is comprised of cognitions, beliefs and emotions. Cognitions include worrying thoughts about recurrence of the disease, doubts about the eradication of the cancer and concerns that the doctor is not checking carefully enough.[16] Algase[17] defined fear as a sufficiently potent, biologically driven, motivated state wherein a single, salient threat guides behavior. Goldman[18] addressed the perception of fear and of being threatened, and associated this with a sense of vulnerability and preparations for responding, which characterized an either fearful or anxious state of mind. The amount of stress is a function that effects an individual and that individual's interpretation of the stressful situation or event as personally threatening or dangerous.[19] Cancer survivors who believe themselves to be at risk of the cancer returning will be more likely to be emotionally aroused by their perceptions of neutral health deviation. Similarly, a survivor's past experiences with cancer will have an effect on the degree of concern about a situation and the chances of the cancer returning. It is not surprising that the influence of cognitions and beliefs gives rise to fear responses. Fear of cancer recurrence was found to be a precursor of psychological distress.[20] Some individuals are able to cope with this fear, whereas others develop symptoms of panic whenever exposed to these particular stimuli or situation.[19] Some individuals' failure in coping with fear experienced a false sense of hope regarding cancer outcome, an increase in somatic complaints and an increased perception of physical symptom distress.[5] This heightened the levels of fear of recurrence and

dramatically affected a survivor's quality of life and requires appropriate management[21] to help them cope with fear of recurrence. It is essential to understand the cancer survivors' experiences surrounding the fear of cancer recurrence because individuals perceive their fears based on their beliefs and previous experiences. Understanding the context of life threatening illnesses, like fear of cancer recurrence, requires the investigation of the survivors' expereinces[7]. The exploration of experiences may unveil multiple realities which can be used as a guideline for health professionals to assist cancer survivors through their beliefs and values. The aim of this study was to explore and describe experiences surrounding the fear of cancer recurrence among Thai colorectal cancer survivors.

Materials and Methods

The qualitative research method was employed to uncover colorectal cancer survivors' experiences with the phenomena of fear of cancer recurrence as perceived by Thai colorectal cancer survivor in Thai cultural environments.

Participants

The participants of this study composed of 22 Thai colorectal cancer survivors who were diagnosed with colorectal cancer by their treating physician and had completed more than 1 year of treatment, with no evidence of cancer recurrence.

Data collection

After the participants signed consent forms, data collection began through in-depth interviews and observations of verbal and non-verbal expression during home visits. Field notes were collected during and after data compellation to determine current findings and ascertain future requirements.

Data analysis

During the interview process, participant verbal data was recorded by audiotape in order to obtain a thorough account of each participant's comments. Verbal accounts were also transcribed and coded. Analysis of the data utilized an inductive coding process as well as a constant comparative method. The goal was to understand how existing paradigm regarding the fear of cancer recurrence was affecting the interpretation of data collected. Each interview was read and re-read to gain a holistic sense of fear of recurrence and a stronger focus on specific reaction/s to this fear.

Results

It is evident that the fear of cancer recurrence was accompanied by a fear of death, fear of re-treatment and fear of suffering.

Fear of cancer recurrence is an emotional response through the interpretation of a life-threatening event or the possibility of reappearance of cancer which leads to death, re-treatment and suffering.

Fear of death is defined as a feeling of apprehension to encounter death in the near future when cancer recurs. The participants develop feelings that they are going to die in a short period of time after cancer recurrence. Fear of death has now been cognitively associated with the fear of cancer recurrence.

Fear of re-treatment refers to the fear in the treatment process itself. The most common effects in patients receiving chemotherapy, radiotherapy are stomatitis, fatigue, nausea, vomiting, anorexia, alopecia and neutropenia. For treatment by operation, pain is the most commonly found. Treatment for cancer recurrence always takes time and requires repetition. Unexpected adverse reactions after treatment may increase and create adverse feelings in patients as a result.

Fear of suffering is a perception by cancer survivors associated with the intensity of suffering when the cancer recurs at a later stage. Whether the cancer spreads to adjacent organs or not it could induce pain and suffering. In a case where cancer recurs, cancer cells may metastasize to the bone and in turn induce great pain and suffering.

The occurrence of fear of recurrence

Fear of cancer recurrence occurs when participants are faced with medical appointments, health deviation and arousals caused by viewing adverse media. These situations were all perceived and interpreted as life threatening.

Participants visited their treating physician according to their medical appointment. The physical check up, including blood tests, x-rays and various in-

depth investigations were performed. Simply waiting for the results of the physical exam was enough to increase the fear of recurrence.

Facing health deviation is a perceiving minor illness, such as pain, flatulence, or abnormal movement of the bowel which could trigger the fear of recurrence. The perception that cancer has the potential to metastasize reminded them that the cancer could spread to adjacent organs. Any form of illness can occur. The association between illnesses and the fear of recurrence was revealed.

Fear of facing arousing media stems from exposure to informative resources provided in the form of pictures and descriptions of cancer and cancer treatment. Participants revealed that they perceived cancer as a dreadful and grotesque disease when exposed to such media. Exposure to such media had the potential of triggering the fear of cancer recurrence.

Conversations in daily life and meetings with friends can be quite a chore for cancer survivors. Every meeting with loved ones in sighted conversations concerning the illness, inquiries on the current state of wellness become a constant reminder that the disease never takes a back seat to all other concerns. Simply by sharing experiences on the treatment, the progression of the illness resulted in an apprehension of relapse.

Intensity of fear of recurrence

The intensity of fear of recurrence refers to the level of fear of cancer recurrence. The intensity of fear of cancer recurrence varies. For some survivors, at the early stages after complete treatment, feelings that they are at risk of recurrence begin to develop. Fear of recurrence was often discovered at early stages because participants are more insecure about their lives. A perception was developed between the number of medical appointments and the level of danger associated with the disease; the more medical appointments the greater the danger that the illness will reoccur. The transition from weekly appointments to monthly appointment to yearly appointments provided various feelings of fear of recurrence. For some, the fear of recurrence was constant and the intensity did not diminish, even though a considerable amount of time had elapsed.

Effect of fear of recurrence

Fear of cancer recurrence attributed to considerable disruption of participants' daily routines and quality of life. When a participant's thoughts focused on cancer recurrence, the fear effected meal times and the participant developed poor appetite. Sleeplessness was another adverse, and health deteriorating symptom to be reminded of the effects of cancer and the possibility of the disease recurring.

Hypersurveillance is the existence or absence of a sign and symptom of recurrence, cancer survivors tended to seek more physical examinations than recommended due to hypersurveillance. Some survivors asked for special check ups without reason or recommendations. Through self-observation, a patient may be more in tune and anxious to focus on minor illnesses or physical change as an increased threat to their life.

Coping strategies

Coping strategies was the chosen method participants utilized to manage and gain positive control over this fear. Coping strategies employed by the participants included self-control.

Self-control is a participant's control over their behaviors and emotions which are believed to be a cause for cancer cell proliferation. Self-control involves both behavioral control and emotional control.

Behavioral control is an action to avoid and get rid of factors which able to stimulate cancer cell growth. Participants control their behaviors by avoiding food which they believe to be harmful, such as broiled foods, burnt foods, preserves and pickled foods. Taboo diet "Sa-lang" is able to trigger cancer cell growth quickly. Selecting specific foods which are believed to be anti-cancer cell proliferative and avoiding foods which trigger cancer cell metastasizing are behavioral control strategies used to cope with fears of cancer development and recurrence. A chronic constipation is believed to be the cause of colon cancer. Ridding a chronic constipation is done through consumption of more fiber. Cigarette smoking can cause cancer. By giving up cigarette smoking an individual decreases his/her chance of cancer recurrence.

Emotional control Participant's attempt to control their emotions by trying not to worry oneself and be preoccupied with the disease. They attempt to reduce any anxiety they may feel, particularly the fear of recurrence. A "whatever will be will be" attitude is adopted and a more peaceful mindset is attained. A

belief that emotions such as stress, anxiety or fear only stimulate cancer cell proliferation is developed. In contrast creating a peaceful mind is believed to decrease the chances of cancer recurrence.

Deflecting bad thought through activity Survivors attempted to distract their thoughts and fears of cancer recurrence through increase of focused activity, such as fixing things, running computer program, cooking, gardening, raising gold fish and flower arranging. These activities could distract their thought of the returning of cancer.

Denial is defined as not thinking about disease recurrence and not focusing on the effects of the disease at any level. Denial was another method participants employed to cope with this fear. It is believed that concerns and feelings of anxiousness in regards to recurrence promoted cancer cell proliferation.

Suppression is an emotional response to fear of cancer recurrence by trying not to concern one's self about cancer recurrence. By suppressing one's thoughts of the cancer they once had and all memory they suppress the fear of recurrence.

Reliance on treating physician refers to an increased dependency by the participants to their treating physicians with the goal of creating an atmosphere of calm and increased security. In this study, participants increased doctor visits as their apprehensions and fears grew concerning cancer recurrence. By speaking with an accredited and trusted physicians, participants became more confident that their condition was improving with each visit and their fears decreased.

Utilizing alternative prophylaxis The cancer survivors use alternative methods of treatment exclusively or in conjunction with conventional treatment. Participants seek alternative means such as dietary supplements and herbal remedies or accessories to feel secure or gain control of cancer cells. Belief in the effectiveness of alternative prophylaxis, such as herbal medicines and accessories, increases the perception of prolonging life and gaining positive control. The cancer survivors' decision to utilize alternative prophylaxis becomes a strong tool to combat the fear of recurrence.

Religious activities The belief of having had cancer was caused by bad karma. By engaging in religious activities, such as merit making, merit sharing, meditation, offering some food to the monks, praying and merit chatting, release from the fears associated with the disease reoccurrence can be attained.

Self-entertaining In this method the participant chooses to do something to find enjoyment. Engaging in a favorite activity can promote feelings of happiness and satisfaction in cancer survivors. Most survivors seek favorite activities such as singing, dancing, taking a trip to create peaceful and happy state.

Increasing self-strength Increasing self-strength is defined as the building up of one's physical and psycho-spiritual strength to increase the immune system and combat against cancer cell proliferation.

Increasing one's physical strength involves the development of the body, making it stronger thus further strengthening the immune system. Engaging in healthy exercise like Yoga and Cheevachit pattern of exercise, accompanied by consuming healthy, nourishing foods, vitamins or food supplements are methods of increasing one's physical strength. Increasing physical strength is believed to be one of the best methods to control and overcome cancer cell proliferation.

Increasing psycho-spiritual strength involves enhancing one's faith and hope. In increasing one's faith and hope of living a cancer-free life the participants increase the "will" to fight the disease and changes their cognitions that the disease will prevail over them and shorten their life and increase suffering.

Faith Faith is the belief, trust or conviction that by doing something one can attain a certain desirable outcome. Participants choose to do something rather than stand idly by with the belief that what they do will have a profound effect in prolonging their life and eliminating their fears.

Hope to survive/live longer Participants' expectations and the possibility of a positive outcome give rise to stability, security and resilience. The desire to live longer and the hope of a better tomorrow focus the attention away from destructive cognitions and feelings of fear and despair. Hope is a crucial mechanism of a participant's ability to drive on when faced with the fear of recurrence. Hope is responsible for managing one's coping methods and the means to express one's wishes.

Making a wish Making a wish is a means to express hope. Making a wish is defined as a thought of a wanted event or situation in which the expected outcome is to live a cancer-free life after treatment. It is revolved around the expectation to live longer and

the expectation to be cancer-free and be comfortable. Blessing Blessing is a means to express hope. Blessing refers to praying and asking sacred things, such as Buddha to provide a cancer-free life and bring only good things in the future as well as help build resilience to the disease.

Balancing fear Balancing fear is a method to gain control. Even though the fear of recurrence still remains, it does not disrupt daily life because the participant is in control and uses the appropriate coping strategy to deal with an arising fear.

Belief Belief acts as mediator. It plays a vital role and effects coping behaviors. If the participant believes in whatever causes the cancer, they will try to avoid it. Like the belief in taboo diet or being anxious all of which can make the disease recur, spread and worsen. On the contrary, beliefs in those things which help them feel absolutely free from cancer include such items as seeking herbs to cure cancer and using accessories, making meditation and practicing religious activities, and eating healthy foods with carotinoid. Whatever is precieved to making the disease more resilient or spread out affects coping strategies.

Discussion

Research findings indicated that the fear of cancer recurrence is an important issue among Thai colorectal cancer survivors. It disrupts the quality of life. Facing fear of recurrence requires effective coping strategies. Coping strategies employed by Thai colorectal cancer survivors vary. It is dependent on a set of beliefs. Hope is a crucial mechanism in driving coping behaviors. Self-control and increasing self-strength are main coping strategies used to fight against cancer cell proliferation. Enhancing hope can increase psycho-spiritual strength. Thai colorectal cancer survivors are more confident and gain control over fear of recurrence when utilizing coping strategies coupled with their faith and hope. Hope has been found to create a happier, peaceful life after cancer treatment. The utilization of coping strategies (deflecting bad thoughts, denial, engaging in positive activity coupled with motivators (hope, faith and belief) can only strengthen a cancer survivor's will, mind and body to overcome a traumatic episode in their life. Through the understanding of the patient's experiences, emotions and cognitions, a medical professional will be able to ascertain and identify the driving factors and stimuli that are precursors to the fear of cancer recurrence and guide the patient in properly utilizing the appropriate coping strategies to combat the fear and decrease the chances of cancer recurrence.

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