

CANCER SURVIVAL EXPERIENCES RETOLD THROUGH WEB PORTAL

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ABSTRACT

The purpose of this paper is to examine the experience of cancer survivors while they are still a patient of cancer. Their reflections were documented in video form and published via a web portal entitled 'Share'. Besides that, this paper also seeks to understand the impact of experience retold via the portal to media users who are generally the support group members. This research uses a qualitative approach which involved five cancer survivors for the actual interviews while two cancer survivors for pilot interviews. The researcher conducted in-depth interviews with empathetic listening approach in order to collect the cancer survivor's experience. Maslow's Theory of Motivation is adopted as a conceptual framework for guiding the research particularly in framing the interview questions that focuses on exploring the physiological, safety, love and belonging needs of cancer survivors which is the first three levels discussed in Maslow's theory. A survey is disseminated to the support group to understand their perception towards the Share's portal. The results informed that the cancer survivors needs have been identified accordingly to the first three levels of Maslow's theory. The cancer survivors' needs were similar to each other when they were still patients. Their sharing intention was high, because they had reached a certain level of attitude compared to the time when they are healthy after experiencing a bigger challenge in their lives. As for the feedbacks from the support group majority of the feedbacks support the role of this portal to keep them connected and agreed on the importance to have such a portal to cater to their support group. This study enables the researcher to understand the experience sharing process and learning from the cancer survivors. Besides that, this study offers a better understanding of the needs of cancer patients. This study benefits the cancer support group in Malaysia because of the fundamental needs for the cancer support group to enable them to have a better knowledge, experiences, and advice sharing to new cancer patients. Such information offers the community a better understanding of the needs of cancer patients based on Maslow's Theory of Needs. Maslow's Theory is widely used in the healthcare and hospice study in the recent years

Key Words

Cancer Survivor, "Share" Portal, Cancer's Patient, Needs and Experience

INTRODUCTION

A total of 21,773 cancer cases among Malaysians registered in the National Cancer Registry in Peninsular Malaysia in 2006. The sample comprised of 9,974 males and 11,799 females (Ministry Of Health Malaysia, 2006). Since then, there has been no official report on the number of current cancer patients in Malaysia (National Cancer Society Malaysia (NCSM), 2014), despite cancer being the biggest cause of global mortality with an estimated 8.2 million deaths reported in 2012(NCSM, 2014). The number of new cancer patients in Malaysia is increasing each day and the numbers is a worry to our society.

According to a research by Yip (2008), the number of cancer cases differs between ethnic groups, as one in 16 Chinese and Indian women, and one in 28 Malay women are likely to develop breast cancer. The highest incidence of colon cancer is found in the Chinese population, followed by the Malay and Indian population (Sung, Lau, Goh & Leung, 2005). The experiences of cancer survivors could serve as a positive and informative guide for members of the National Cancer Society Malaysia and associated support groups. The study extrapolated experiences and needs from the cancer survivors where they begin to perceive things differently after having gone through such a challenging and life threatening experience. This change in perception can be a source of confusion to many, and as such, gleaning insights from the experiences of survivors can go a long way in preparing current cancer patients and their support groups for this potential major change in life and being. Emerging health care models increasingly focus on patients across the continuum of care, encouraging them to be more proactive in managing their care system (Thorne, Oliffe, Stajduhar, Oglov, et al., 2014). The survivorship of those cancer survivors can serve as a valuable knowledge for the current cancer patients and to the Malaysian public. Most newly diagnosed cancer patients suffer from a terrified state of shock, and it may take some time before patients learn to come to grips with their diagnosis. Picard and Strochecker (2011, p. 254) explain this change in a cognitive sense and assert, "When we change our emotional states, we are switching between different ways to think". With this in mind, having access to the experiences of cancer survivors may assist in achieving a measure of stability in one's life during and after cancer. Cancer survivors shared that attitude plays an important role in the healing process. Remaining positive is central to achieving mental and physical stability. Hence, experience sharing is important to the wellbeing of cancer patients and serves as an important guide to support groups and caregivers (Asbury, Lalayiannis, & Walshe, 2014). By articulating a spiritual outlook on life, Kenneth (2013) shared that people often turn to their faith as a source of solace and support when faced with stressful and hard times. For Kenneth, religion can be a vital source for promoting health and wellbeing while also having the potential to be a source of distress. With this in mind, one must not give up or lose faith when encountering life problems.

LITERATURE REVIEW

According to Abraham Maslow's Theory of needs motivation model, there are five different levels of basic human needs (Gaurav, 2010). Maslow developed a model of his hypothesis in the shape of a pyramid, which is divided into five different levels where the bottom levels need to be achieved before moving to the next level in the pyramid. According to Maslow, a human need is related to behaviour. The nature of needs to be satisfied will be adjusted accordingly. The bottom of the hierarchy forms the basic human needs progressing towards greater self-actualization, which is at the top of the model. As for this study, the researcher is only studying the first three

To support the importance health needs in Maslow's Theory, Judith (2006, p.117) mentioned that:

"According to the theory of the hierarchy of needs by Maslow, once human's immediate requirements for survival are addressed, we as the human will turn our attention to quality of life. Thus, as the numbers of long-term cancer survivors grew, cancer clinicians and investigators increasingly acknowledged a responsibility to minimize the adverse effects of treatment and the disease on quality of life"

This theory is used to guide this study because the researcher seeks to determine the needs of cancer patients from Maslow's Theory based on the experiences shared. However, different potential aspects might affect the needs of particular cancer survivors such as financial and geographical factors. This theory is used in this research as it helps to better understand the differences between a normal healthy person and cancer patients. The model suggests that when the basic human needs are met, the next level of needs will need to be fulfilled. However, this may differ for cancer patients as their needs differ. Advancing from the basic needs, the theory progresses to the need for safety and security, belonging and love, esteem, and at the highest peak is self-

actualization (Kline, 2011). For this study, the researcher limits the study on the experience shared by the cancer survivors by focusing their basic, safety, belonging and love needs which are the first three levels of Maslow Theory's. Cancer stands as one of the top three diseases that patients and their caregivers will frequently seek information on the Internet as shown in the study of Dolinsky, Wei, Hampshire, and Metz (2006). This particular study shows that the patients and their caregivers rely on the Internet for information and support before they proceed to get treatment. This strengthens the reason for cancer support groups in Malaysia to provide sufficient and reliable information to the public. Most of the time, a newly diagnosed cancer patient and their caregivers will be looking for information about cancer. The Malaysian's government has allocated RM19.3 billion for healthcare and development service, which shows the initiative of the government to focus on the country's wellbeing and healthcare of the country (The Star, 2012, p.17). Ernstmann, Neumann, and Ommenet et al. (2009) found that almost a third of the cancer patient population indicated toward an unmet need of psychosocial support. Emotional functioning is a central predictor of the requirement for psychosocial support. This means that patients need motivation to help them overcome long and arduous journey of combatting cancer.

"The internet is seen as having the potential to provide the emotional support needed to make an appointment, informational support to prepare the health professional and patient during their consultation" (Wald, Dube & Anthony,2007). This supports the methodology of this study to convey the content to the viewer via a portal. In this technological era, the number of smartphones and computer users has increased significantly. Valued feeling of the patients by their health professionals is equally important for those patients who wish to take a more active role (Broom, 2007).

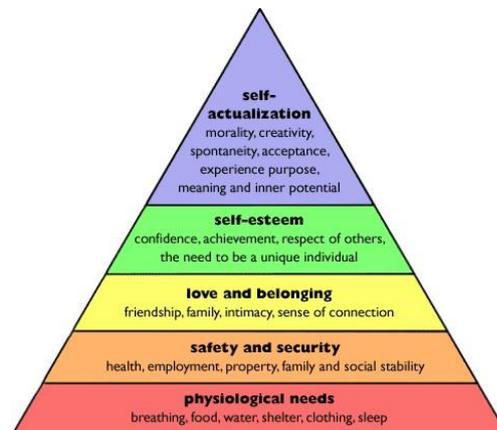


Figure 1: Image of Maslow's Theory of Needs (Image courtesy of <http://quentinhafner.com/wp-content/uploads/2014/06/maslows-hierarchy2.jpg>)

PROBLEM STATEMENT

There are a few media which cancer survivors and patients can share their experiences such as BlogSpot and Facebook. As research findings from Laughlin, Nam, Gould et al., 2012, they found that cancer survivors used the social network as a way to fulfil their needs that were not being met in their real life. It is also important for this research to address the cancer survivors' needs because most of the time the patients and their caregivers will look for advice and also knowledge on the disease itself. Besides that, different patients will have different needs in their lives as they are receiving the treatment. So it is important to understand the needs of cancer patients to make sure that they will at least feel secured and comfortable in their treatment process. Compared to the western countries like the United States of America and United Kingdom where there are varieties of mediums such as radio talk shows, Internet portals and Television shows in support of cancer

patients and survivors such as The Ellen DeGeneres Show, Oprah Winfrey Show and the Fran Drescher Talk Show. Here in Malaysia on the other hand, we are more discreet and sensitive talking about this issue. In general, Asians are more comfortable suffer in silence rather than speaking out. In Asia, cancer is considered as a taboo and sensitive issue for which discussion should be avoided (Pang, Ho & Lee,2013).

METHODOLOGY

To obtain the experience of cancer survivors, the researcher conducted a qualitative approach of data collection. This method allows for more in depth data gathering, research analysis and interpretation of information. The cancer survivors were provided by the NCSM. Five cancer survivors were interviewed using a structured interview guide to obtain in depth exploratory and descriptive data. The cancer survivor has to be someone aged 30 – 75 years. The justification of the reason on the researcher choosing the age group is because the researcher wanted to study adults. This enables the researcher to understand whether there are differences in experiences and ways of thinking. There were three females and two males involved in this study. However, gender differences were not a focus in this study. Females made up the majority for the interview as they made up the vast majority of membership in the cancer support group. Empathetic listening approach was observed throughout the interview to ensure and encourage the patients to talk and to make them feel comfortable talking. According to Salem (2003), empathetic listening is a way of listening and responding to another person that improves mutual understanding and to gain trust, while according to Floyd (2014), empathetic listening serves a relational function similar to affectionate communications. The researcher believes that this approach is comforting to cancer survivors and their caregivers to better share their thoughts rather than using a formal interview method. An in depth interview with cancer survivors allowed the researcher to gather much information from them to later archive into digital content. Being heard may be very much a part of what the patients and survivors need. Such listening may allow more information to aid in diagnosis and treatment and aid in better patient survivor understanding and compliances. The content used for testing affective approaches causes the learning and sharing to be livelier, trusted, and engaging among the participants of the study. For the feedback of the developed portal, the participants were from the cancer support group, their caregivers, friends, family and volunteers. The questions asked to the cancer survivors are justified as below according to the KayInn, (2011) original interview question. As for the content feedback, the researcher has disseminated a survey form to the cancer support group who attend a public health talk. A total of 30 feedbacks have been collected from the event to understand their perception towards the Share portal.

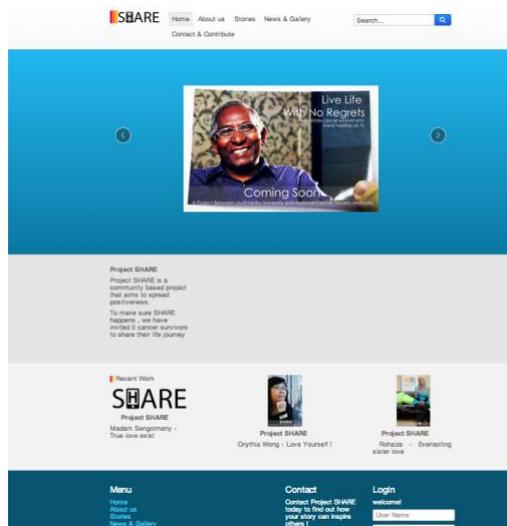


Figure 2: Home Page of SHARE portal

RESULTS & DISCUSSION

There are two phases of reporting the findings of this study. Phase 1 reports mostly the findings of the interviews on cancer survivors' needs. Phase 2 reports mainly on how their stories retold through a Shared portal being used by a support group members. The user group provided their feedback on Shared portal.

Phase 1 – Findings of Cancer Survivor's Needs

The main points from the study are highlighted in the findings. The needs are derived from Maslow's Theory of Needs from level 1 to level 3, which are the physiological needs, safety/security needs and love/belonging needs. The researcher used a thematic approach to introduce data categories. The themes were then checked with an expert from University Malaya to ensure trustworthiness. The themes categorized in this finding are quite common for discussion and it is guided by the Maslow's Theory that has been discussed in literature review of this study.



Figure 3: Keyword Analysis from Wordle.net

The researcher used Wordle.net to analyse the most repeated word from the interviews verbatim. From the image shown as above, the word "cancer" is seen as the most repeated word throughout the interview for the 5 cancer survivors. This shows that the impact caused to their life. The survivor's memory when they are still a cancer patient is still clear in their mind. The survivor has survived through the hard time but they are still very clear of what has happened and how their life was affected due to cancer. Besides that, word such as 'time', 'fighting', 'important', and 'positive' are also being repeated often during the interviews session. This shows the importance for the cancer survivor to have the support and fighting will during their treatment process and not to forget the support that they received from their friends and family to enable them go through the disease. It is important for the cancer survivors to understand the medication that they are undergoing and at the same time have trust in their medical team. On the other hand, word such as 'love', 'knowledge', 'life', 'learn' and 'positive' are shown to have impact on their life as a cancer patient at that time. The cancer survivors have to stay positive and the same time love their life more so that they can go through the disease. As they claimed in the interview, there is no point for them to look back into the past; what is important is to find a cure to the cancer they had. As Maslow's Theory suggested that the first 3 levels of the human needs consist of the physiological, safety, love and belonging needs, the response from the cancer survivors support the first three levels of the theory.

Table 1 : Link Between Interview Keywords and Maslow’s Theory

Keywords	Maslow’s Theory of Needs
Life Time Mind	Level 1 Physiological Needs
Medication Positive	Level 2 Safety Needs
Support People Important	Level 3 Love and Belonging Needs

All of the interviews were transcribed verbatim and analysed by means of a standard content analysis framework. The data from this study shows that the cancer patients have common needs. The needs are included:

- to accept the disease- as this can relate to the Maslow Theory’s in the second level which is the safety needs. When the patient body is affected and their health is not in the normal way it should be, the patients would need to accept the fact that they are diagnosed positive with cancer and to look for a solution to it.
- the importance of support group – This fall under the third level of Maslow Theory’s which is the love and belonging level. The survivor felt that it is important to have support from friend and family in the healing process.
- trust the doctor and medical team – This also fall under the third level of Maslow Theory’s as they need to build their trust to their medical team as they will be with the patient for a period of time
- the need to have spiritual belief – the need of spiritual belief fall under then third level of Maslow’s Theory where the patient find their belonging in the spiritual practice.
- gather extra information from books and internet – this need fall under the first level of Maslow’s Theory where it is the basic need for the cancer survivor to have the basic knowledge about the disease
- the fighting will to get through the disease; the fighting spirit for the cancer patient fall under the third level of Maslow’s Theory where they have to keep themselves secured with their body.
- adaptation to the new and lifestyle after treatment. –this need falls under the third level of Maslow’s theory. After becoming a cancer survivor, they need to adapt to their new lifestyle and not repeating their old bad habit such as smoking.

Phase 2 – Feedbacks on Share’s Portal

The survivor’s stories are edited and then uploaded to YouTube. The researcher then develops a portal with a content management system that enabled the portal to capture the databases from the users. The survivor’s stories are available through the portal and the users are able to access the portal using any device or smartphone to view the content. The portal is accessible through this link <http://probmobile.com/share/>. Below is some screen capture images from the portal. The users are guided through the process of accessing the portal by the researcher. The researcher at the same time collected their feedback from accessing the portal. This portal has been named “Project Share” to promote the sharing of experiences among the cancer support group.

Table 2:
Mean and Standard Deviation of survey feedback on SHARE Portal

Questions	Mean	Standard Deviation
Is the content helpful for you?	4.467	0.571
SHARE has a user friendly interface	4.467	0.571
SHARE pages generally have good images	4.467	0.571
After reading SHARE's content, I feel motivated	4.633	0.556
SHARE is easy for me to navigate	4.663	0.556
SHARE can play an important role for the cancer support group	4.663	0.556

Note: Feedback rating is ranging from 1 to denote strongly disagree and 5 to denote strongly agree; n = 30

From the data collected, the audiences strongly agreed that after navigating SHARE portal they feel motivated. On the average, the means of the questions shows that it is skewed towards the "agree" about the portal. The feedbacks also showed that the participants felt that the content is helpful and motivating after they have navigated through Share portal and shows a mean of 4.663. Overall the data collected for this result is showing that the SHARE portal is helpful and benefits to the patients and support group (n=30).

CONCLUSION

This study has identified the needs of the cancer survivors from their experiences. Even though, the experience sharing approach in healthcare is not a new field and study, it is still, however, fresh in Malaysia. More study on our cancer support groups is needed so that we can create a better community for the existing cancer support groups. Positive content and good support groups play an important role for the cancer community so that their needs are not neglected. From this study, it is found that the patients are more likely to be more engaging to their other patient friends and also their own family members. The cancer survivors and patients want their voices to be heard and someone to understand what they feel. From this study, the results show that there is a need for positive content to educate the support group and at the same time to educate the public that cancer is not an incurable disease. Besides that, different needs of cancer patients from various backgrounds are identified from this study. Grounded with Maslow's Theory of Needs, the researcher is able to relate the needs to of the cancer survivors accordingly to the first to third level of the theory, which are the physiological, safety, love and belonging needs. Early detection will save lives and cancer survivors can live as normal healthy persons. The myths about cancer should be erased from our society and at the same time, we should contribute more to help cancer patients and survivors. Their lives maybe in danger but if they survive, the survivors cherish and value their lives more after their experiences. The cancer survivors' stories can make an impact to themselves and others. As technology and lifestyles changes rapidly, everyone should take care of their health, share about their experiences about health, and encourage others to lead healthy lifestyles. It was a second life given them as according to cancer survivors.

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