

Chapter 41

Internet Use and Health Decision Making by Breast Cancer Patients in Malaysia

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ABSTRACT

Being diagnosed with breast cancer is a complicated and disruptive experience for many. Apart from the effects of cancer on their physiological state, patients are required to make important life-changing decisions within a short period of time. To most patients, their physicians act as the main source of medical treatment information. While physicians maintain their trusted role as being the key source of medical treatment information, patients find that their physicians do not provide all the answers to their questions. The Internet is a convenient and inexpensive information resource that assists patients and their care-givers in the decision-making process by providing them with answers to queries that come to mind, detailed explanation of medical jargon and cancer treatment options. Due to the limited time that physicians have with their patients and the power imbalance inherent in their possession of medical knowledge, patients and their care-givers turn to the Internet to seek for more detailed information to supplement the medical advice provided by their physicians. Apart from that, the Internet also provides patients with enhanced capacity to engage in constructive discourse with their healthcare providers thereby bringing new issues and concerns to the patient-physician relationship.

INTRODUCTION

When physicians utter the line ‘you have breast cancer’, patients will almost always experience devastation in their lives as they struggle with feelings of uncertainty about their future and loss of

control over their lives (Arora, 2003; McWilliam, Brown, & Stewart, 2000). From that moment, breast cancer patients face several situations that will further disrupt their lives. These include making sense of complex medical information, making life-changing and difficult cancer treatment decisions, dealing with the side effects of chemotherapy and radiotherapy and living with the fear of recurrence

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(Arora, 2003). The key goal of cancer treatment is to minimize the impact of the cancer and to ensure the patients' well-being (Arora, 2003).

In the past, information regarding cancer treatment and its effects were mainly provided to patients by their physicians. However, with the widespread use of the Internet, patients are now resorting to obtaining information regarding cancer treatment and care online. This brings rise to the notion that patients who have access to complete medical treatment information are in a better position to make more informed decisions and are empowered to take better control of their cancer treatment outcomes. Apart from that, patients need to make crucial medical treatment decisions together with their physicians therefore making the patient-physician relationship and its interactions a central component of the cancer care delivery process. The stigma and fear associated with breast cancer diagnosis and its inherent complexities presents a greater emotional dimension to the patient-physician relationship (Arora, 2003). The objective of this study is to investigate the extent to which the Internet has improved the capacity of breast cancer patients in making informed decisions, their personal accounts of empowerment and how these have affected their interactions with their physicians.

BACKGROUND

The cancer burden afflicting the world today continues to be one of the most difficult and dreaded life-changing events for many people all around the world (O'Hair, Villagran, Wittenberg, Brown, Ferguson, Hall, & Doty, 2003). In the United Kingdom, cancer is a major cause of morbidity and 276,678 new cancer cases were reported in 2003 alone (Cancer Research UK, 2006, p. 1). 1,444,920 new cancer cases were estimated in 2007 with 559,650 estimated deaths attributable to cancer in the USA (National Cancer Institute, 2008b). In Malaysia, there were 21,464 new cancer

cases reported in 2003, comprising 9,400 males and 12,064 females (Lim & Halimah, 2004, p. 34). Cancer remains as one of the main causes of death in these countries with many men and women facing the prospect of a cancer diagnosis in their lifetime (Cancer Research UK, 2006; Lim & Halimah, 2004; National Cancer Institute, 2008b; O'Hair *et al.*, 2003).

There are more than 200 different types of cancer, but breast, lung, colorectal and prostate cancers are the most common and collectively they account for approximately half of all cancer cases in the UK, Malaysia and the US (Cancer Research UK, 2006; Lim & Halimah, 2004; National Cancer Institute, 2008b). The statistics indicate that breast cancer is the most common cancer in the UK despite the fact that it is rare in males (Cancer Research UK, 2006, p. 1) and accounts for 31% of cancer cases among women in Malaysia (Lim & Halimah, 2004, p. 48). According to the Malaysian Oncological Society (2008), 'breast cancer is the most common form of cancer affecting women in Malaysia. About one in 19 women in this country are at risk, compared to one in eight in Europe and the United States'.

Over the years, many initiatives to reduce the cancer burden have resulted in the decrease of mortality rates for cancer and better survival rates (Cancer Research UK, 2006; National Cancer Institute, 2008b; O'Hair *et al.*, 2003). However, having to go through cancer and surviving it is a difficult process for patients, their families and friends. Experiences with cancer for patients are definitely an emotional life-changing experience for patients which includes feelings of anguish, despair, confusion, anxiety among others (Anderson & Martin, 2003; Szumacher, 2006). When confronted with the possibility of having cancer, many view it as being a life-changing moment in their lives. The perception of having limited time left to live is overwhelming, resulting in changes in attitudes, heightened emotions and numerous questions that go through their minds and that of their loved ones (Anderson & Martin, 2003).

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