Chapter 3
Cancer Virtual Communities in the Era of Personalized Medicine:
Perspectives on Scope, Use, and Impact

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ABSTRACT

Cancer is the most common chronic disease worldwide. Cancer patients report significant unmet supportive care needs. Peer support groups show great promise in meeting cancer patients' supportive care needs, and are considered an important complement to the formal health care system. Virtual communities offer a convenient way for cancer patients to collaborative meet many of their supportive care needs in a timely way. This chapter will present current evidence on: the scope and characteristics of virtual communities for cancer patients; prevalence and predictors of use and reasons for non-use; the nature and function of supportive exchanges in cancer virtual communities, including their limitations; and the potential effects, both positive and negative, of participating in cancer virtual communities on health outcomes. Grounded in social support, technology adoption and health behavior theory, this chapter will offer a multi-theory framework for better understanding for how cancer virtual communities work and under what conditions.

INTRODUCTION

Cancer is a leading cause of death, premature death and years of life lost worldwide (World Health Organization [WHO], 2015). In 2012, 14.1 million people were diagnosed with cancer and 8.2 million died from cancer (International Agency for Research on Cancer [IARC], 2014). The number of new cases of cancer is expected to rise by 70% over the next two decades (IARC, 2014). At the same time, cancer survival has improved dramatically as a result of advances in early detection and treatment. It is estimated that there are 32.6 million cancer survivors worldwide (within 5 years of their diagnosis) living with or beyond cancer (IARC, 2014).

Most health systems throughout the world do not yet adequately deal with the confluence of complex, time intensive supportive care issues that people living with cancer and their loved ones have to face daily. These include practical assistance, pain and symptom management support, informational, emotional, psychological, social, spiritual and nutritional support, the need for which can vary over the course of the illness and beyond (Fitch, 2000). Cancer patients are frequently dissatisfied with the quality and amount of information that they receive from health professionals (Jefford & Tattersall, 2002), and rates of psychosocial distress among cancer patients are high, ranging from 30 to 45% across disease subgroups (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Moreover, many cancer patients report significant unmet needs 2 to 10 years post-treatment including physical, financial, informational and psychosocial needs (Burg et al., 2015). Many of these issues are neglected or not adequately addressed because of the fractured nature of care delivery and the lack of mechanisms and incentives to permit their timely management. However, patients whose supportive care needs are met are better able to cope with cancer, have greater quality of life, and rely less on medical services (Kash et al., 2005).

Cancer patients may be able to overcome many of these challenges with support from peers. Support from family, friends and other cancer survivors is recognized as an important complement to the supportive care provided by the formal health care system (Fitch, 2000; Vivar & McQueen, 2005). Family caregivers often serve as the primary source of support (Gass, Weitzen, Clark, & Dizon, 2007). However, support from family caregivers typically drops significantly within the first year of diagnosis (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007). Support from other cancer survivors is highly valued by cancer patients even for those who report high levels of support from family members (Arora et al., 2007). Support form peers can provide a unique sense of community, reassurance and practical information that cannot be gained from other supportive relationships and can improve relations with family and friends by relieving their burden of care (Ussher, Kirsten, Butow, & Sandoval, 2006).

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