

Feasibility, acceptability and efficacy of bibliotherapy for patients with cancer:

A randomized controlled trial

Nicole Roberts

Department of Educational and Counselling Psychology

McGill University

August 2015

A thesis submitted to McGill University in partial fulfillment of the requirements for the
degree of Doctor of Philosophy

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Abstract

As the number of Canadians diagnosed with cancer continues to grow and treatment effectiveness improves, cancer survival rates increase. An estimated 62% of people are expected to survive for 5 years after their cancer diagnosis (Canadian Cancer Society, 2012). Increasing numbers of Canadians requiring ongoing medical treatment, surveillance and supportive care places a strain on current healthcare resources (Canadian Cancer Society, 2011). Given the limited funds available, and the growing demand for services, there is a strong need for feasible, accessible, cost contained psychosocial interventions for patients with cancer. Bibliotherapy is a psychological self-help intervention that relies primarily on books and has been shown to be efficacious for decreasing distress in many clinical settings. Despite this, very few studies have investigated the efficacy and acceptability of bibliotherapy in patients with cancer.

The aim of this randomized controlled trial was to examine the acceptability and efficacy of a self-help workbook in enhancing the sense of empowerment and quality of life and reducing distress in patients with cancer. The findings for Study 1 suggest that participants found the workbook helpful and 17 out of 18 of the respondents reported that they would recommend *Mastering the Art of Coping in Good Times and Bad* (2010) to other patients with cancer. Respondents noted that the most helpful aspects of the book were (a) the skills that focused on thinking more positively, (b) instructions on how to practice mindfulness, and (c) the emphasis on the importance of relationships. The findings from Study 2 indicate that participants in the bibliotherapy group experienced improvements in empowerment, quality of life and distress when compared to the control group. The limitations and areas for future research, as well as the clinical implications of this dissertation are discussed.

Résumé

À mesure que le nombre de canadiens diagnostiqués avec un cancer s'augmente, le taux de survie subi une croissance favorable en conséquence de traitements plus effectifs. Il est prévue qu'environ 62% des individus diagnostiqués survivront 5 ans après un diagnostic de cancer (Canadian Cancer Society, 2012). L'accroissement du nombre de canadiens qui exigeront un traitement médical, de la surveillance et du soutien de façon régulière pèse lourd sur les ressources du système de santé actuel (Canadian Cancer Society, 2011). Face à des fonds limités et de la croissance des demandes de services, un besoin important s'impose pour une intervention psychosociale disponible aux patients avec un cancer qui est à la fois réalisable, accessible et économique. La bibliothérapie est une intervention psychologique, se fiant principalement sur l'usage de livres de développement personnel, et qui se montre efficace pour améliorer l'état de santé mentale dans plusieurs milieux cliniques. Toutefois, les études qui ont exploré l'efficacité et l'acceptabilité de la bibliothérapie chez les patients avec un cancer sont peu nombreuses.

Le présent essai contrôlé randomisé a pour but d'examiner l'acceptabilité et l'efficacité d'un cahier d'auto-assistance en vue d'enrichir le sens d'habilitation et la qualité de vie, et de réduire la détresse chez les patients avec un cancer. Les constats de l'Étude 1 suggèrent que les participants ont trouvé le livre utile et 17 des 18 répondants ont déclaré qu'ils recommanderaient *Maîtriser l'art de l'adaptation des bons et des mauvais moments* à quelqu'un d'autre. Selon les répondants, les aspects du livre les plus utiles étaient (a) l'apprentissage de nouvelles compétences liées à un état positif, (b) les instructions sur la pratique de la plénitude (c) la mise en valeur des relations interpersonnelles. Les constats de

l'Étude 2 indiquent que les participants dans le groupe de bibliothérapie ont connu une amélioration de leur habilitation, de qualité de vie et de détresse. Les limites et les domaines de recherches futurs qui découlent ainsi que les implications cliniques de cette dissertation sont examinées.

Acknowledgments

Completing this PhD would not have been possible without the dedication, input and support of many!

- Foremost, I would like to express thanks to my research supervisor, Dr. Annett Körner. Thank you for giving me the opportunity to be a part of your team. You have made this PhD a wonderful experience, above and beyond the research, you have taught me invaluable life lessons.
- My gratitude to the members, past and present, of the Health Psychology Research Group. Special thanks to my volunteers – your interest and commitment to my project provided rejuvenating practical and emotional support.
- To my clinical mentor, Dr. Vera Romano, thank you for believing in me so early on in my career. You have shaped me into the clinician I am today – I am forever grateful.
- I am indebted to my awesome friends who have supported me over the years - you know who you are and how much you mean to me. Our coffee dates and happy hours have kept me going.
- A heart-felt thank you to my Mom. I would not be who I am today without your monumental sacrifices, guidance and support.
- To my husband, my rock, I couldn't have done this without your love and unwavering confidence in me over the many years. We did it!
- My son, my world, your beautiful presence gives me perspective and reminds me every day what is truly important in this life. Mama loves you.
- Lastly, thank you to all the participants who enrolled in this study for having the strength and courage to engage in this process with me.

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Preface

Contributions of Manuscript Authors

As the author of this thesis, I was responsible for the design, obtaining ethics approval, data collection, analysis and interpretation of data and writing the manuscripts.

My co-author and research supervisor, Dr. Annett Körner, was actively involved in supervising and had input on all aspects of this thesis.

My co-authors and committee members, Dr. Russell Steele, Dr. Virginia Lee, and Dr. Zeev Rosberger, were involved in providing statistical and conceptual feedback as well as editorial comments for relevant components of this thesis.

Statement of Originality

I hereby certify that I am the sole author of this dissertation. I confirm that this dissertation is an original work and contribution to the advancement of knowledge. Other scholarly works included in this dissertation are fully acknowledged in accordance with the standard referencing practices of the American Psychological Association. I certify that, to the best of my knowledge, this dissertation does not infringe upon anyone's copyright nor violate any proprietary rights.

Chapter One - General Introduction

Cancer Prevalence and Mortality Rates in Canada

Cancer is a leading cause of death worldwide (World Health Organization, 2012). An estimated 62,600 Canadians die every year from cancer, accounting for 29% of all deaths in the country (Mirolla, 2004). Forty percent of women and 45% of men will develop cancer during their lifetimes and 24% of women and 29% of men, or approximately one out of every four Canadians will die from cancer (Canadian Cancer Society, 2012). The number of new cases continues to rise steadily as the Canadian population grows and ages (Public Health Agency of Canada, 2012). Alongside this increase in incidence, earlier diagnosis, new technologies and improved treatments have resulted in more people surviving cancer (Phillips & Currow, 2010).

An estimated 62% of people are expected to survive for at least 5 years after their cancer diagnosis (Canadian Cancer Society, 2012). Cancer survival now means living with a complex and chronic disease. Survivorship care is an essential element of overall cancer care which commences at diagnosis and continues throughout the survivor's life (Phillips & Currow, 2010). The increasing number of Canadians being diagnosed with and surviving cancer results in more persons requiring health care resources for on-going medical treatment, surveillance and supportive care (Canadian Cancer Society, 2012). At the same time, health care costs increase due to more advanced yet more costly treatment options, such as personalized medicine in oncology. This therapeutic approach strives to identify the biomarkers that characterize an individual's cancer in order to provide treatment regimes, which specifically target the genetic foundations of this cancer leading

to better treatment outcomes. Yet, personalized medicine does neither change the psychosocial issues patients are dealing with in response to a cancer diagnosis, its treatment and survivorship nor the psychosocial interventions that have been shown to be effective in addressing psychosocial correlates of cancer.

Psychosocial Impact of a Cancer Diagnosis

Distress

Even though there has been an increase in survival rates, receiving a cancer diagnosis and undergoing cancer treatment continue to be a significant source of distress for many individuals. Common reactions to being diagnosed with cancer involve fear, confusion, denial, anxiety and anger (Labelle, Campbell, & Carlson, 2010). Throughout the illness trajectory, patients may experience concerns related to fatigue, pain, managing emotions/stress, depression, anxiety, parking issues, appearance, coping, sexuality, interpersonal problems and finances (Baum & Andersen, 2001; Carlson et al., 2004). Moreover, there are concerns related to diagnosis, side effects of treatment, fear of recurrence and functionality difficulties that persist throughout survivorship. Few patients are adequately prepared to address all of these problems, consequently 35-55% of patients with cancer experience clinically significant levels of emotional distress (Carlson, Waller, Groff, Giese-Davis, & Bultz, 2011; Labelle et al., 2010; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Distressed patients are more likely to be women, who report practical, emotional and physical problems (Jacobsen et al., 2005). Distress may diminish over time, however, research has shown that 29% of patients continue to experience distress one year after diagnosis (Carlson et al., 2011).

Emotional distress refers to problems such as anxiety, depression and fears related to the cancer experience (Carlson & Bultz, 2004). The Distress Management Panel of the National Comprehensive Cancer Network (NCCN) defines distress as

a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and spiritual crisis (Holland & Bultz, 2007; National Comprehensive Cancer Network, 2012).

Elevated levels of distress have been linked to reduced health-related quality of life, poor satisfaction with medical care and decreased adherence to medical treatment and recommendations (Carlson, Waller, & Mitchell, 2012; National Comprehensive Cancer Network, 2012).

Empowerment

Life-threatening illnesses and the ensuing treatment can induce feelings of powerlessness (Bulsara, Ward, & Joske, 2004; Stang & Mittelmark, 2009). For instance, when receiving a diagnosis and undergoing treatment for breast cancer, many women experience vulnerability, including feelings of uncertainty, anxiety, depression, anger, fear of treatment, impaired sense of femininity, apprehension about survival and health, and loss of control (Stang & Mittelmark, 2009). Treatment decisions are often made by

the health care team, which can intensify ones' experience of loss of control over themselves and their bodies (Bulsara et al., 2004). This feeling of powerlessness is the opposite of feeling empowered, which aims to increase individuals' sense of control, as well as promote positive coping and well-being (Gibson, 1991; Stang & Mittelmark, 2009).

Empowerment is multifaceted, multileveled and influenced by context (Stang & Mittelmark, 2010). As such, empowerment will vary between individuals, organizations and settings. According to Zimmerman and Rappaport (1988), empowerment refers to "the ability of individuals to gain control socially, politically, economically and psychologically through access to information, knowledge and skills, decision-making, individual self-efficacy, community participation and perceived control." More specifically, psychological empowerment represents a proactive approach to life, while critically understanding the socio-political environment (Zimmerman, 1995).

In the medical field, empowerment is defined as a process of helping people to assert control over the factors which affect their lives (Gibson, 1991). More specifically in the context of cancer, empowerment refers to feelings of gaining some control and being better able to manage problems that arise during the cancer experience (Maunsell, Lauzier, Campbell & Livingston, 2011). Empowerment is described as a learning process involving critical awareness and reflection in order to improve one's coping abilities, regain energy and reduce stress (Gibson, 1995). Empowering an individual involves increasing their competence for handling the health problem and the environment and enhancing their capacity to relate to themselves and others

(Zimmerman, 1995). The individual plays a significant role in being empowered, as they themselves have to engage and implement numerous coping strategies to develop a sense of mastery and control over their situation (Bulsara et al., 2004). Obtaining support from family members and close friends and receiving health information relevant to the illness and treatment options can also aid the empowerment process. Achieving a sense of empowerment over one's illness is undoubtedly a very individual and unique experience for patients with cancer.

As a concept, empowerment is related to and encompasses the constructs of coping, self-efficacy and social support. Coping has been defined as the cognitive and behavioral efforts used to manage demands appraised as stressful or exceeding resources (Lazarus & Folkman, 1984). Cancer-specific studies suggest that problem-focused coping is associated with emotional well-being for patients with early stage cancers (Matthews & Cooks, 2009) and emotion-focused coping is associated with improved psychological adjustment (Stanton et al., 2000). Additionally, cancer survivors using a meaning-making coping style experience better emotional and social well-being, less negative affect and higher levels of self esteem and optimism (Park, 2010; Boehmer, Luszczynska & Schwarzer, 2007; Lee, Cohen Edgar, Laizner, & Gagnon, 2006). While coping strategies are what is utilized to protect and improve ones well-being, coping efficacy pertains to beliefs about one's ability to manage the stressors associated with cancer (Merluzzi & Sanchez, 1997; Hoffman, Lent & Raque-Bogdan, 2013). Cancer-specific coping efficacy studies show that higher levels of efficacy are related to increases in quality of life and less negative emotions (Heitzmann et al., 2011).

Additionally, research links having support, especially emotional support, to improved health-related and psychosocial quality of life (Helgeson & Cohen, 1996).

Given the documented benefits of feeling empowered, there has been growing interest in the use of psychosocial interventions over the past 10 years to facilitate the multidimensional empowerment processes. Current research findings support the use of cancer self-help groups as a means of empowering group members (Stang & Mittelmark, 2009). Sharf (1997) observed that an online discussion group, Breast Cancer List, resulted in participants feeling empowered. For instance, online members experienced connectedness, an internal sense of self, improved ability to make informed decisions and a resulting ability to take action. Mok and Martinson (2000) observed empowerment outcomes in Chinese patients with cancer. Specifically, participants in the self-help group reported a sense of interconnectedness, confidence and hope, support and affirmation and a feeling of usefulness. Both studies demonstrate the importance and benefits of informational support and mutual learning. While the literature on the impact of self-help on empowerment is growing, only a few studies have investigated the empowerment processes and empowerment outcomes in cancer intervention groups.

Investigating empowerment and the extent to which it is experienced by patients dealing with cancer is particularly difficult given the loss of control experienced as diagnosis and prognosis change throughout the illness trajectory (Bulsara et al., 2004). This research is further hindered by the lack of validated outcome measures. Despite these limitations, empowerment research is essential in medical care settings that involve power imbalances due to the imbedded hierarchy of physicians providing care to patients

(Stang & Mittelmark, 2010). The development of competence and confidence is regarded as crucial to ensure one's voice heard when interacting with persons more powerful than oneself (Gibson, 1995). Empowerment is especially important given the fact that expert-lay discrepancies naturally occur and lead to a power imbalance towards disadvantaged groups, like the ill who are dependent on others for services and support (Stang & Mittelmark, 2010).

Health Care Service

Patients with cancer often struggle with significant psychosocial problems. Yet, many patients do not receive adequate psychosocial care (Fann, Ell, & Sharpe, 2012; Krebber et al., 2012). The National Comprehensive Cancer Network (2012) reports that less than half of all distressed patients with cancer are identified and referred for psychosocial help. Although several agencies have established screening guidelines for the management of distress (e.g., NCCN; American Society of Clinical Oncology), the current system makes it difficult for health care professionals to deliver these interventions and implement the practice guidelines as recommended (Carlson & Bultz, 2004). These recommendations are difficult to implement as psychosocial oncology departments continue to be understaffed and underfunded and primary care staff are overburdened and often unable to prioritize psychosocial issues (Carlson & Bultz, 2004; Carlson & Bultz, 2003). Funding for psychosocial services in Canada and worldwide remains limited (Holland et al., 2007). This lack of adequate funding limits many patients from accessing adequate psychosocial care (Carlson & Bultz, 2004; Carlson & Bultz, 2003).

Interventions in Psychosocial Oncology

Patients with cancer often experience a sense of vulnerability as a result of their diagnosis and treatment including feelings of uncertainty, anxiety, depression, anger, fear of treatment and loss of control. There have been numerous trials investigating interventions designed to promote better psychological adjustment to cancer. Researchers with the Centre for Reviews and Dissemination (Rodgers et al., 2005) conducted an umbrella review of existing systematic reviews in order to identify the types of psychosocial interventions tested for a cancer population and to evaluate the effects of these interventions on physical and psychological outcomes.

According to Rodgers and colleagues (2005), 16 reviews have been published that evaluated a variety of psychosocial interventions. The interventions evaluated group therapy, individual therapy, family therapy, counselling, psychoanalysis, education, stress management, cognitive behavioural therapy, relaxation, imagery, meditation training, emotional expression, biofeedback, coping skills training, problem solving training, social skills training, cognitive/attentional distraction, hypnosis, desensitization, rehearsal modeling, contingency management, home visits and telephone calls from health care professionals, and various combined approaches (Rodgers et al., 2005). The majority of the reviews focused on adult cancer patients with heterogeneous cancer diagnoses. A variety of psychological outcomes were measured, including anxiety, depression, mood, stress, distress, anger, hostility, confusion, self-esteem, self-concept, locus of control, coping/control skills, emotional adjustment, vocational or domestic adjustment, health beliefs, general affect and quality of life. The umbrella review concluded that most

psychosocial interventions generated beneficial effects on psychological distress or emotional adjustment of patients. Yet, the results suggested that the effects of the interventions on anxiety and depression were ambiguous. The variation and inconsistency in the findings is most likely attributable to the differing inclusion criteria and highly heterogeneous intervention and control groups. As such, it was recommended that further reviews be conducted to derive more specific conclusions.

Following this recommendation, a meta-analysis (Osborn, Demoncada, & Feuerstein, 2006) was conducted in order to explore the effects of cognitive behavioral therapy (CBT) and patient education (PE) on commonly reported problems (i.e., depression, anxiety, pain, physical functioning, and quality of life) in adult cancer survivors. CBT was described as an approach that alters cognitions in order to facilitate behavior change using stress management and problem solving training. PE entailed providing information concerning the illness or symptom, symptom management, and/or discussions of treatment options that may encompass the use of additional materials, such as booklets or videos. While both CBT and PE have been used with cancer patients, the distinguishing effects on certain outcomes are unclear. As such, 15 studies were analyzed, and the results suggest that PE alone was not associated with improved outcomes. However, CBT was associated with short-term positive effects on depression, anxiety and quality of life. Furthermore, CBT interventions delivered in an individual setting were found to be more effective than the group format. The authors conclude that individual CBT is more effective than PE for cancer survivors.

Another systematic review was conducted with a sample of breast cancer patients to explore the clinical efficacy of psychological interventions (Naaman, Radwan, Fergusson, & Johnson, 2009). Anxiety, depression and quality of life were examined. A moderate treatment effect was found for anxiety ($d = -0.40$) and quality of life ($d = 0.74$), and a clinically moderate-to-strong effect was found in trials assessing depression ($d = -1.01$). The authors concluded that short-term treatments with a focus on coping appear to be more suitable for patients with early breast cancer, while patients with advanced stages appear to benefit more from longer-term supportive interventions.

In short, robust knowledge synthesis methods including an umbrella review as well as multiple systematic and meta-analyses support the efficacy of psychosocial interventions for reducing distress and improving psychological adjustment and quality of life among adult patients with cancer.

Stepped Care Model and Minimal Psychosocial Interventions

With a solid research base supporting the efficacy of individual and group psychosocial interventions for cancer patients, it is now essential to focus on finding accessible methods of providing effective services. This need is underscored by the fact that funding for psychosocial oncology services in Canada is severely limited due to ever-diminishing overall healthcare budgets and current resource providers are burdened with heavy patient loads (Holland et al., 2007). Moreover, clinical care teams strive to implement a whole-person approach to their work, i.e., attending to all aspects of an individual diagnosed with cancer (e.g. physical, emotional, social, and spiritual), to relieve suffering and promote healing. Utilizing psychosocial interventions that are not

only effective but also economical helps to treat the emotional and social aspects of individuals living with cancer, as well as provides long-term cost savings to overburdened health-care systems (Carlson & Bultz, 2003).

In order to expand care beyond a biomedical focus on treating an illness and in response to the growing demand of services, the stepped care concept has been introduced, which also attends to the psychosocial needs of patients. Stepped care involves the development of a tiered system of evidence-based services, whereby minimal interventions are offered before more intensive treatments options are implemented (Bower & Gilbody, 2005). In stepped care, usually the more intensive treatments are provided to patients who did not improve with the more minimal first-line treatments (Bower & Gilbody, 2005; Krebber et al., 2012). Treatments being delivered are monitored systematically, and changes to the level of treatment are modified when it is determined that the current treatment is not effective (Bower & Gilbody, 2005; Krebber et al., 2012). Such an approach aims to offer evidence-based interventions to patients in need, as well as reduce the burden on the current public health care system (Bower & Gilbody, 2005; Fann et al., 2012).

The use of stepped care has been promoted for many chronic conditions, including hypertension, diabetes, nicotine dependence, high cholesterol levels, asthma, bulimia, back pain, alcohol dependence and depression (Korff, Glasgow, & Sharpe, 2002). As a result, chronic disease management programs have adopted stepped care in an effort to provide the largest number of patients with the least intrusive and lowest cost care (Mercer, 2011). The chronic disease management stepped-care model aims at

promoting health behavior and better psychological adjustment. This model was established to promote a common hierarchy of services: (1) watchful waiting; (2) psychoeducation; (3) bibliotherapy; (4) computer based interventions/e-health; (5) group therapy; (6) individual therapy; (7) medication; and (8) inpatient services (see Figure 1). Triaging patients is based on the consideration of patient levels of psychological distress; impact of psychosocial and lifestyle factors; motivation; skills and preferences (Mercer, 2011).

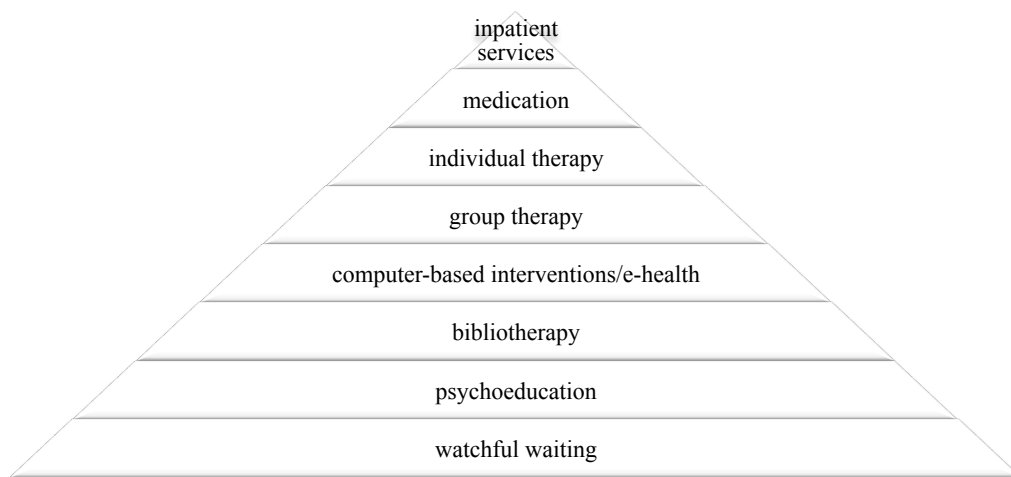


Figure 1. Chronic disease management stepped-care model.

In short, a stepped care framework provides support for chronic illness that strives for cost-effectiveness and is based on patients' needs (Korff et al., 2002; Von Korff & Bea, 2000). Moreover, the tiered model encourages revision of existing services in order to promote strategic levels of specialized care (Hutchison, Steginga, & Dunn, 2006). In order to adapt a stepped care model to psycho-oncology settings, Hutchison and

colleagues (2005) recommend that providers implement a method of assessment or screening; use the assessment and screening results to triage suitable care levels to patients; and make necessary revisions to ensure all levels of care are delivered.

Recent studies of e-health interventions demonstrate potential for enhancing psychological well-being for patients with cancer. E-health refers to the use of the internet or technology in health care (Oh, Rizo, Enkin, & Jadad, 2005). Examples of e-health research in psychosocial oncology include the telecare symptom management program (Kroenke et al., 2010); internet coping groups (Owen et al., 2005); computer mediated patient education programs (Shaw, Hawkins, McTavish, Pingree, & Gustafson, 2006), professionally-led online support groups such as Cancer Chat Canada, an internet intervention such as SHUTi-C that addresses insomnia (Ritterband et al., 2011), web-based interventions aimed at providing self-management skills (Duffecy et al., 2012), as well as tailored information and support being delivered to adolescent and young adult patients through the use of telephone, social media, videogames and internet platforms (Zebrack & Isaacson, 2012).

In addition to e-health interventions, the chronic disease management stepped-care model suggests the integration of bibliotherapy as one minimal intervention within the pool of treatment options. However, in comparison to other minimal interventions, the empirical evidence for bibliotherapy in oncology settings is considerably limited and warrants further examination. The following chapter will focus on the empirical evidence regarding the use and effectiveness of bibliotherapy in addressing mental health

issues including the very limited research examining bibliotherapy in the context of mental health concerns related to cancer.

Chapter Two – Use and effectiveness of bibliotherapy to address psychosocial issues in patients with cancer: a literature review

Introduction (Definition and Brief History of Bibliotherapy)

Bibliotherapy, has been known by several names, including bibliocounselling, bibliopsychology, biblioeducation, biblioguidance, and literatherapy (Pardeck, 1998). Bibliotherapy has also been defined in a number of ways, put simply, it means helping people through the use of books (Pardeck, 1998). In current clinical contexts, bibliotherapy generally refers to psychological self-help interventions that utilize treatment books (Bilich, Deane, Phipps, Barisic, & Gould, 2008). Advances in technology have made books readily available on the Internet, as such, the term bibliotherapy is increasingly being used to include the use of books as well as internet-based reading materials.

Samuel Crothers coined the term bibliotherapy in 1916. However, the basic practice of bibliotherapy dates back to ancient times (Pardeck, 1998). The early Greeks had an inscription above their library entrance reading “Place of Healing for the Soul” or “Medicine for the Soul” (Brown, 1975). In the late 18th and 19th century, mental health hospitals in Europe and in North America had their own library for patients. By the 1920s, training programs in bibliotherapy existed. In the 1930s, librarians used literature in a therapeutic context to help people with mental health issues (Pardeck, 1994). Dr. William Menninger used books such as the *Human Mind* (1930) to help individuals deal with mental illness. As a result of Dr. Menninger’s positive endorsements of bibliotherapy, many practitioners began using this emerging approach in treatment. The

1960s and 1970s witnessed an increase in the number of self-help books being published. In the 1980s and early 1990s, bibliotherapy was a valued form of psychotherapy.

Advantages and Disadvantages of Bibliotherapy

The current delivery of psychological services in Canada can be characterized as a silent crisis (Peachey, Hicks & Adams, 2013). The clinical effectiveness of psychosocial interventions for reducing distress has been well established. However, there continues to be a severe gap between the extent of services needed and the rendering of services to patients in need (Peachy, Hicks & Adams, 2013; Bower & Gilbody, 2005; Lovell & Richards, 2000). As such, the current research focus must turn to issues of cost and the efficiency. Attending to these issues will enable more judicious decisions regarding the use of limited psychological therapy resources available in publicly funded or managed healthcare systems (Bower & Gilbody, 2005; Peachey, Hicks, & Adams, 2013).

In the current climate of economic restraint, the integration of bibliotherapy into the medical system has the potential to increase the immediacy and availability of psychosocial services for patients in need. Researchers have noted the usefulness of bibliotherapy within a stepped care model of healthcare provision (Bower & Gilbody, 2005). The concept of 'stepped care' involves the development of a tiered system of services, whereby minimal interventions are offered before more intensive treatments options (i.e., individual therapy). The hope is that the minimal intervention (e.g. bibliotherapy or computer interventions) will be effective at reducing the psychological distress of certain patients to the extent that they do not require additional aid at higher levels of service provision. Such an approach would more readily offer interventions to

patients in need, potentially reducing some of the burden on our current public health care system. Over the past few years this model for the management of chronic diseases, such as diabetes and other medical conditions, has been applied to mental disorders (Bilsker, 2003).

Bibliotherapy's flexible delivery approach makes it appealing for various clinical contexts. For instance, it can be offered as a self-administered treatment, an approach with minimal therapist contact, as well as therapist administered, or therapist directed treatment (Pardeck, 1998). As such, mental health professionals are not always required to deliver or guide the intervention and bibliotherapy can be used to facilitate access to care as needed. Patients do not have to endure long wait lists for treatment, pay for therapy, or incur additional costs associated with travel/parking. Bibliotherapy is a popular and acceptable approach for many individuals, it offers more privacy and is less stigmatizing than traditional psychotherapy. Clients can learn new skills, and always have the material available for reference. Further, even health care providers without specialty training in mental health can introduce an evidence-based book in a manner that retains the fidelity of the treatment model.

Bibliotherapy has been shown to be a helpful self-management tool that improves client access to treatment and provides didactic material that otherwise would not have been available without therapist involvement. Additionally, people can address their own concerns while working at their own pace. Placing the intervention in the hands of the individual has the potential to empower patients and enhance their sense of control over the situation, self-reliance and autonomy (Den Boer, Wiersma, & Van Den Bosch, 2004;

Williams, Niemiec, Patrick, Ryan, & Deci, 2009). Research shows that an empowered individual is a more active participant in their health care and better able to improve their coping strategies and their quality of life (Maunsell et al., 2014).

There are many positive aspects of bibliotherapy that make it an appealing self-help approach; in spite of this it is not suitable or desired by everyone. Without guidance from a professional, consumers of bibliotherapy may not choose books that are suitable for their needs. Additionally, individuals may become discouraged from the lack of immediate progress, and without a professional to provide support some people may disengage (Ellis, 1993). Lastly, it is not recommended for use for people with severe mental health issues, who may be struggling with major depression, suicidality, personality disorders, interpersonal difficulties and comorbid psychological disorders (Ellis, 1993; O'Donohue & Cummings, 2008).

Bibliotherapy for Mental Health Conditions

Bibliotherapy can consist of both fiction and nonfiction self-help books. However, nonfiction self-help books applying behavioral and cognitive based techniques have the greatest empirical support (Pardeck, 1998). The National Institute for Health and Clinical Excellence (NICE) recommends bibliotherapy in their stepped care model for the treatment of mild to moderate anxiety and depression (NICE, 2004, 2009a). NICE also concluded that self-help therapies are highly cost-effective (NICE, 2009b). In Scotland, people can self-refer to receive free copies of a self-help book with phone based support (Williams, 2009). In England, a self-help book and the companion anxiety book are both recommended as minimal cost resources in improving access to

psychological therapies (Williams, 2009). The aforementioned examples highlight several ways in which bibliotherapy can be implemented in clinical settings.

A substantial amount of research now exists on the effectiveness of self-help bibliotherapy for mental health conditions. Meta-analyses and a recent systematic review have confirmed the effectiveness of bibliotherapy, especially for mild to moderate depression and anxiety (Cuijpers, 1997; Fanner & Urquhart, 2008; Gregory, Schwer Canning, Lee, & Wise, 2004; Marrs, 1995). A comprehensive meta-analysis (Marrs, 1995) examining the efficacy of bibliotherapy reviewed 70 studies that compared bibliotherapy with a control group or other therapist-administered treatments for a variety of problems (e.g. anxiety, depression, self concept, weight loss, impulse control). Bibliotherapy treatments included written materials, audio and videotapes and computer-delivered material. The mean estimated effect size of the 70 studies analyzed was 0.56. There was no significant difference between the effects of bibliotherapy and therapist-administered treatments, and the effect sizes were maintained at follow-up. In general, the amount of therapist contact was not associated with improved outcomes. It should be noted, however, that bibliotherapy was more effective for certain problems (e.g., assertion training, anxiety, and sexual dysfunction) than for others (e.g., weight loss and impulse control).

One recent review published findings that used bibliotherapy and information prescription to deliver patient care (Chamberlain, Heaps, & Robert, 2008). The authors examined 57 papers and concluded that there was significant evidence to support the delivery of bibliotherapy in many clinical settings (as information prescriptions, online,

with and without support) for a variety of mental health disorders, especially anxiety and depression. Based on the reviewed results, bibliotherapy is most effective when the client is fully engaged in the process. This finding has important implications for practice as it highlights the potential value of having a professional encourage clients to uptake and then to maintain engagement with bibliotherapy.

Two additional reviews focused on bibliotherapy tailored to persons suffering with depression. Specifically, findings from a meta-analysis reviewing six studies indicated that bibliotherapy was as effective as individual or group therapy for addressing unipolar depression (Cuijpers, 1997). The estimated effect size for treating depression was 0.82. Another meta-analysis reviewed 29 studies using cognitive-behavioral based self-help materials for individuals with depression (Gregory et al., 2004). The overall weighted effect size for the 29 studies was 0.99, representing a large significant effect. The authors conducted an additional analysis including 17 studies with the strongest research designs (i.e. pretest-posttest, waiting list vs. control group), and the resulting effect size was 0.77. There was no significant difference with respect to treatment length and the authors concluded that results were comparable to individual psychotherapy outcomes.

Fanner and Urquhart (2008) conducted a systematic review assessing the evidence for bibliotherapy and confirmed its efficacy for the treatment of mental illness, yet the authors' caution that previous research has its limitations. For instance, researchers are unable to mask the intervention in a randomized control trial. Additionally, the sampling approaches employed can be considered biased because participants choose to engage in

a self-help treatment approach. Studies also tend to use small sample sizes that may make significant effects less likely. Assessing the appropriate duration of the treatment period, the long-term efficacy of bibliotherapy, or what type of bibliotherapy works best is also difficult (i.e., a custom-made treatment manual, a published self-help book, or a computerized training program). Future research examining bibliotherapy would benefit from attempts to address these limitations.

Bibliotherapy to Address Psychosocial Issues in Patients with Cancer

There is a substantial body of research supporting the use of bibliotherapy with a variety of mental health problems. Yet, research investigating the usefulness of bibliotherapy in psychosocial oncology is very limited, which stands in stark contrast to publically available but not scientifically tested cancer self-help books. In March 2015, searching for the word *cancer* at www.amazon.com yielded results for more than 77,000 books. Of these, more than 3,000 were classified as *Self-Help*. The vast amount of self-help material available on this topic suggests a patient-driven demand for cancer-related information in book form. However, the quality of the material published is unknown. Therefore, evaluating the quality of resources available and being able to give an empirically informed recommendation regarding a book's suitability for a patient has the potential to render many benefits for the individual and for psychosocial oncology services at large.

Preliminary findings among patients with cancer suggest that bibliotherapy may be an acceptable therapeutic modality. Patients with head and neck cancer were surveyed about their preferred mode of delivery of a cognitive behavioral intervention. Patients

primarily preferred one-to-one therapy (43%), followed closely by bibliotherapy (36%) with computer administered (14%) and group formats (7%) being the least popular (Semple, Dunwoody, Sullivan, & Kernohan, 2006). Similar findings were noted when preferences were evaluated for a psycho-educational intervention for people with head and neck cancer (Allison et al., 2004). Employing a prospective non-randomized design, patients were offered an intervention program in one of the following three formats: 54% requested individual therapy, 40% preferred material to use at home without a therapist (bibliotherapy), and 6% chose a group format. These findings indicate that there is a sizeable subgroup of patients interested in accessing bibliotherapy.

Angell and colleagues (2003) conducted a randomized controlled trial to evaluate a workbook-journal for rural breast cancer survivors. The workbook-journal, "One in Eight: Women Speaking to Women," contained cancer related education and facts, supportive personal narratives, lists of available resources, as well as a space to journal. Women who received the workbook-journal reported feeling emotionally supported. Women who did not receive the book reported lower levels of fighting spirit, and higher levels of emotional venting and post-traumatic stress symptoms. These findings endorse the usefulness of this workbook-journal in this context.

Beatty and colleagues (2010) conducted a randomized controlled trial to evaluate a workbook entitled, "Finding your way: a workbook to help you cope with your breast cancer diagnosis and treatment." The workbook contained cancer-specific information, survivor narratives, strategies for managing side effects, cognitive behaviour therapy coping skills, writing exercises as well as relaxation and meditation audios. The control

group received a book with identical content but it did not include the worksheets and audios. Findings indicated that the self-help workbook was effective for women recently diagnosed with breast cancer. Specifically, the women in the treatment group reported less posttraumatic stress symptoms, cognitive avoidance and feelings of helplessness. The improvements were maintained at the 6-month follow-up. The authors concluded that this self-help workbook was effective in reducing symptoms of distress for women with breast cancer.

A feasibility study examined patients' satisfaction with self-help CBT for insomnia comorbid with cancer (Savard, Villa, Simard, Ivers & Morin, 2010). Eleven patients with breast cancer suffering from insomnia received a 6-week intervention composed of 6 booklets and an animated video that introduced cognitive behavioural techniques to address sleep issues. The booklet and accompanying video addressed sleep and insomnia, coping skills, sleep hygiene and relapse prevention strategies. At post-treatment, significant improvements were reported for most sleep variables and for overall quality of life. The positive findings were maintained at the 3-month follow-up assessment. These results are promising, however the intervention included videos in addition to booklets, therefore it is difficult to attribute the positive outcomes to bibliotherapy alone.

Bibliotherapy has not been extensively researched in the psychosocial oncology literature, however initial results show promise. The above review demonstrates that patients with cancer are interested in and benefit from accessing bibliotherapy as a therapeutic approach. In order to build on current research it is important to examine the

efficacy of pre-existing, published and widely accessible self-help materials utilizing a rigorous research methodology.

The NUCARE Intervention

NUCARE (an acronym derived from NURsing, CAnCER, and REsearch) is a psycho-educational self-help intervention program based on the principles of cognitive behavioral therapy (Edgar, Rosberger, & Collet, 2001; Rosberger et al., 2002). The NUCARE coping intervention delivered by a therapist has been examined extensively and has demonstrated its potential to improve quality of life and reduce symptoms of distress (Allison et al., 2004; Edgar, Rosberger, et al., 2001; Edgar, Rosberger, & Nowlis, 1992; Edgar, Roseberger, & Collet, 2001; Edgar, Roseberger, & Nowlis, 1992; Rosberger et al., 2002; Vilela et al., 2006). The intervention focuses on two major areas: the enhancement of a sense of personal control and the learning of emotional and instrumental coping responses (Edgar, Rosberger, et al., 2001; Rosberger et al., 2002). Given the nature of the program, NUCARE can be offered in a variety of formats (i.e., group setting, individual sessions, completed by one-self via a printed book, or delivered online via a web group chat platform).

The intervention is based on the McGill Model of Nursing, which stresses collaborative, situation-responsive learning about healthy behaviors and coping with medical illness (Edgar et al., 1992). Lazarus and Folkman's (1984) transactional model of coping influenced the development of NUCARE. This model provides a framework for evaluating processes of coping with stressful events (such as being diagnosed with cancer). Coping has been defined as the cognitive and behavioral efforts used to manage

demands appraised as stressful or exceeding resources (Lazarus & Folkman, 1984). In turn, the ability to apply successful coping strategies has the potential for affecting emotional well-being (e.g., depression, anxiety) and subsequent psychological adjustment. Edgar (2001) defined coping as “resourceful, optimistic, practical and flexible.” As such, the specific components of NUCARE address: problem solving techniques, goal setting, cognitive reappraisal, mindfulness, relaxation, the effective use of social support and communication (Edgar, Rosberger, et al., 2001; Rosberger et al., 2002).

Table 1

The 7 Skills of NUCARE

Skill	Description
Mindfulness training	This component of NUCARE focuses on learning mindfulness - being relaxed and aware without judgment. The reader is encouraged to be mindful once every day.
Cognitive reappraisal	This component teaches how thoughts contribute to feelings. Exercises encourage practice for identifying and changing thoughts and feelings in order to achieve a sense of personal control.
Relaxation training	This component introduces relaxation-training exercises and encourages the practice of a chosen technique for three times a week (e.g. deep breathing, progressive muscle relaxation, autogenetics, meditation, tai chi, yoga, and imagery and guided visualization).
Goal setting	This component focuses on how to set appropriate goals in order to

	provide a sense of perceived personal control. The reader learns the guidelines and requirements for goal setting and is encouraged to practice setting an attainable goal daily.
Problem-solving techniques	This component focuses on the steps of problem solving. A neutral example illustrates the steps of problem solving, and then the reader is encouraged to work through a personal problem to achieve a solution.
Communication	This component focuses on and encourages the use of eight communication tools (e.g. the use of “I” statements, assertive communication, knowing how to say ‘no,’ dealing with the health care system, handling anger, disagreeing and active listening, communication with family and journaling or communicating with yourself).
Social support	This component focuses on the benefits of social support, identifying sources of support, the risks of asking for support as well as offering and receiving support. The reader is encouraged to contact a friend for companionship.

There are several studies documenting the benefits of the NUCARE intervention (Allison et al., 2004; Edgar, Rosberger, et al., 2001; Edgar et al., 1992; Rosberger et al., 2002; Vilela et al., 2006). In one study, a heterogeneous group of 205 patients with cancer received the NUCARE intervention either immediately after diagnosis or four months after diagnosis (Edgar et al., 1992). The intervention consisted of five individual sessions lasting approximately 90 minutes each. Results demonstrated that distress among patients with breast cancer ($n = 46$) improved during the year regardless of

whether the NUCARE intervention was delivered immediately after diagnosis or four months after diagnosis. Additionally, patients with any cancer type who received the intervention after waiting 4 months experienced a reduction in depression, anxiety and illness-related worry at the 8 and 12-month follow-up assessments. However, results regarding the benefits of the NUCARE intervention at specific time points in the cancer trajectory differ by cancer type. Patients with breast cancer were the only population that responded positively to the NUCARE intervention

Another study evaluated NUCARE for 225 newly diagnosed patients with breast and colon cancer (Edgar, Rosberger, et al., 2001). Patients were randomized to one of four arms: NUCARE offered on an individual basis by a therapist, NUCARE offered in a group format facilitated by a therapist, a non-directive supportive group facilitated by a therapist, and a no intervention control group. Participants in the intervention arms received five ninety-minute sessions. Results showed that patients with colon cancer did not benefit from the intervention (individual or group). However, patients with breast cancer who received the individual format of NUCARE showed significant improvements in well-being when compared to the other groups. Moreover, these positive findings were maintained at the 12-month follow-up. Breast cancer patients who received NUCARE in a group format did not demonstrate any significant benefits over the control condition.

Rosberger and colleagues (2002) aimed to determine whether positive coping styles could be strengthened with a cost-effective one-day NUCARE workshop. The content of NUCARE was divided into two sections, one workshop focused on problem-

focused coping strategies and the other on emotion-focused coping strategies. One hundred and fifty six women with breast cancer were randomized to either a problem-focused or emotion-focused NUCARE coping workshop or to a wait-list control group. Results showed that if participants in the problem-focused workshop scored high on problem solving at baseline, their problem solving coping scores significantly increased at the post-intervention assessment. There was also a trend found for participants in the emotion-focused workshop; if individuals scored high on emotion-focused coping at baseline, there was a reduction in escape/avoidance coping at the post-intervention assessment. The coping strategy of seeking social support was unchanged by either intervention. The workshops were well accepted and cost-effective (Rosberger et al., 2002).

The feasibility of NUCARE for individuals with head and neck cancer has also been evaluated using a prospective non-randomized design (Allison et al., 2004). Patients were offered the NUCARE program in one of three formats: small group and one-to-one formats with a therapist; and a home format to be completed without a therapist. Fifty-nine participants completed the intervention, 3 patients chose the group, 33 chose the one-to-one setting and 23 chose the home-based format. More men and those with better cognitive functioning chose the home-based format; yet, the authors did not report how cognitive functioning was operationalized for the purpose of their study. When all participant data were combined and analyzed, there were significant improvements in physical functioning, social functioning and global quality of life scores, as well as reduced fatigue, sleep disturbance and depressive symptoms across

each intervention format (i.e. individual, group, home). When the home format participant data were analyzed separately, there was a significant improvement in social functioning. The authors concluded that delivering a psychosocial intervention to head and neck cancer patients is both desired and feasible. However, given the lack of a control sample and inadequate power, the researchers were unable to adequately examine the effectiveness of the intervention.

Another feasibility study for persons with head and neck cancer was conducted by (Vilela et al., 2006). A quasi-experimental design without randomization was used and three different delivery formats of the NUCARE program were offered to the intervention group: (1) small-group format; (2) one-to-one format consisting of two to three sessions with a therapist; or (3) home format without a therapist. At post-assessment, the intervention group indicated improved physical and social functioning, global quality of life, fatigue, sleep disturbance, and depressive symptoms; while the control group demonstrated no changes in quality of life or depressive symptoms. Study outcomes were only reported comparing the intervention to the control group, without comparisons of the various delivery formats. The authors concluded that the overall results demonstrate feasibility of the NUCARE program, as well as the intervention's potential to improve quality of life and to reduce levels of depression among patients with head and neck cancer. Despite these positive trends, a randomized controlled trial with an appropriate sample size is required to corroborate the results of this study.

There is considerable evidence suggesting that NUCARE enhances quality of life and reduces distress for patients with cancer. Previous studies have generally focused on

individual and group formats to deliver the NUCARE intervention, while the self-help/home format has been employed in only two studies. In these studies, there was no control group (Allison et al., 2004), or outcomes were reported as a combined effect of the intervention regardless of delivery format (Vilela et al., 2006). Furthermore, patients self-selected the type of intervention delivery, which may have resulted in patients with certain psychosocial and/or cancer-related characteristics choosing one format over another. Consequently, no conclusions regarding the effectiveness of the NUCARE self-help format for cancer patients or certain subpopulations can be drawn from this initial evidence. More specifically, randomized controlled trials of NUCARE delivered in a bibliotherapy format are needed in order to examine the efficacy of this intervention mode in the cancer context.

Randomized controlled trials examining self-help/bibliotherapy resources are often critiqued as they typically examine unpublished self-help resources (Brewster, Sen, & Cox, 2012; Dysart-Gale, 2008). In order to address this critique, this research project examined the efficacy of NUCARE, a pre-existing, published and widely accessible bibliotherapy tool titled *Mastering the Art of Coping in Good Times and Bad* by Dr. Linda Edgar (2010). This workbook consists of 174 pages, covering 12 chapters on: the body and stress; the importance of practice in learning a new behavior; what is good coping; mindfulness training; cognitive reappraisal; relaxation training; goal setting; problem-solving techniques; communication; social support (see Table 1 for details); a healthy lifestyle; and closing thoughts.

Thesis Objectives

Currently, there are significant gaps in knowledge regarding the efficacy of bibliotherapy for patients with cancer. Empirical studies employing rigorous methodologies are needed to ensure that the offered interventions are feasible and effective at ameliorating psychological distress following the diagnosis and treatment of cancer. While psychosocial interventions provided in group format or in individual one-on-one settings have proven effective in addressing psychological adjustment among cancer patients, there is very limited research on the use of more readily accessible intervention formats such as bibliotherapy.

The literature reviewed above suggests that there is reason to believe that bibliotherapy can be acceptable and effective for patients with cancer. The NUCARE intervention offered in an individual and group format has proven effective in teaching adaptive coping strategies, alleviating distress and enhancing psychological adjustment. However, the self-help format has not been adequately investigated. Although not defined as such in the literature, home-based self-help administrations of the NUCARE intervention are a perfect example of bibliotherapy. Building on the foundational research supporting the group and individual format of the NUCARE interventions and on emerging research-supporting bibliotherapy in the cancer context, the objectives of this thesis are to:

- (1) Determine the acceptability of the NUCARE intervention when delivered in a self-help bibliotherapy format.

(2) Examine the efficacy of the NUCARE intervention, delivered in a self-help bibliotherapy format, to enhance the sense of empowerment and quality of life and to reduce distress among patients with cancer.

Chapter Three - Manuscript 1

Acceptability of bibliotherapy for patients with cancer:

A qualitative descriptive study

Nicole Roberts^{1,5}, PhD Candidate

Virginia Lee⁶, PhD

Annett Körner¹⁻⁵, PhD

¹ Department of Educational and Counselling Psychology, McGill University, Montreal

² Department of Oncology, McGill University, Montreal

³ Louise Granofsky Psychosocial Oncology Program, Segal Cancer Center, Montreal

⁴ Psychosocial Oncology Program, McGill University Health Centre, Montreal

⁵ Psychosocial Oncology Research Training (PORT), McGill University

⁶ Department of Nursing, McGill University Health Centre, Ingram School of Nursing,
McGill University, Montreal

Keywords: bibliotherapy, cancer, qualitative

Abstract

Objective: To determine the acceptability of a self-help workbook, *Mastering the art of coping in good times and bad*, for patients with cancer. **Design:** Descriptive, qualitative. **Methods:** A semi-structured interview guide with open-ended questions was utilized to gather feedback from participants about the workbook. Participants were recruited from the psychosocial support cancer centers of two tertiary care teaching hospitals in Montreal, Canada. **Findings:** Eighteen participants completed the interviews from which the data emerged. Two main categories were identified from the respondent's interviews regarding the acceptability of the book. The first category focuses on content, the other on recommendations. Interviewees specified the following content as most helpful (1) focusing on the positive; (2) mindfulness; (3) relationships; (4) skill reinforcement. Recommendations to improve the intervention focused on having access to additional support while reading the book. **Conclusions:** This study is the first to suggest that patients with cancer consider the book, *Mastering the Art of Coping in Good Times and Bad*, acceptable as a means of helping them manage their stress. **Implications for Nursing:** Bibliotherapy is not only cost effective and easy to administer but can be an acceptable alternative treatment to traditional clinical practices. Offering evidence-based bibliotherapy has the potential to reduce the current strain on resources and enhance psychosocial services offered.

Acceptability of bibliotherapy for patients with cancer: A qualitative descriptive study

Interventions to treat distress and improve quality of life for patients with cancer have been extensively researched and are highly effective (Carlson et al., 2011). The interventions offered typically involve psycho-education, cognitive behavioural training (group or individual), group supportive therapy, and individual therapy (Carlson et al., 2011). However, a significant proportion of patients with cancer who report psychological distress do not take advantage of available psychosocial care (Krebber et al., 2012). Barriers to receiving adequate psychosocial care include a lack of adequate screening for anxiety and depression in oncology settings, reluctance by patients to be referred, lack of trained mental health professionals to complete assessments and deliver interventions, stigma associated with receiving mental health services, inconvenient locations, and traditional models of psychosocial care delivery not meeting current patient demands (Carlson et al., 2012; Hutchison et al., 2006; Krebber et al., 2012; Leykin et al., 2011).

In order to address some of the obstacles faced by those attempting to access psychosocial care, self-help approaches with little or no therapist input are being researched. Self-help interventions that utilize treatment books are referred to as bibliotherapy (Bilich et al., 2008). A substantial amount of research exists on the effectiveness of bibliotherapy for mental health conditions such as mild to moderate depression and anxiety. Meta-analyses and a recent systematic review have confirmed the usefulness of bibliotherapy in this context (Cuijpers, 1997; Fanner & Urquhart, 2008;

Gregory et al., 2004; Marrs, 1995), however such research is scarce in the psycho-oncology domain.

Preliminary evidence suggests that bibliotherapy may be an accepted therapeutic modality for patients in psycho-oncology. Semple, Dunwoody, Sullivan, and Kernohan (2006) surveyed patients with head and neck cancer about their preferred mode of cognitive behavioral intervention. One-to-one therapy (43%), followed closely by bibliotherapy (36%) were the preferred settings; with computer administered (14%) and the group format (7%) being the least popular (Semple et al., 2006). Similar findings were reported when preferences were evaluated during a psycho-educational coping intervention for people with head and neck cancer (Allison et al., 2004). The latter study used a prospective non-randomized design and patients were offered an intervention program (i.e., NUCARE) in one of the following three formats: 54% requested individual therapy, 40% preferred the material to use at home without a therapist, and 6% chose a group format. These preliminary findings suggest that there is a subgroup of patients with cancer interested in accessing bibliotherapy, consequently, it would be important to further examine the evaluation and implementation of bibliotherapy for this population.

Objective

The goal of the current study was to determine the acceptability of a self-help book for patients with cancer. Acceptability refers to “determining how well an intervention will be received by the target population and the extent to which the intervention might meet the needs of the target population” (Ayala & Elder, 2011). Specifically, this study sought feedback on whether *Mastering the Art of Coping in Good*

Times and Bad (Edgar, 2010), is an acceptable self-help book to support patients in their coping with cancer.

Research Approach

This qualitative descriptive study was part of a longitudinal mixed-method randomized control trial. Ethics approval was obtained from the hospital research ethic boards. Consenting, eligible participants completed a socio-demographic questionnaire, baseline measures, and were randomized to the treatment group (i.e. received the workbook) or the control arm (i.e. usual care). The current study focuses on participants from the treatment group who were randomized to receive the NUCARE workbook as well as a recorded 30-minute phone interview 6 weeks after enrollment.

To assess acceptability, a semi-structured interview guide with open-ended questions was utilized. This particular interview type was chosen as it grants the interviewer flexibility to follow-up with relevant questions and probes to gather richer descriptions. Participants were asked their opinions about the book; sample questions included: What was most helpful about the book? What would you recommend we do to improve the book? Would you recommend the book to other patients with cancer?

Participants

Patients were eligible to participate if they were over 18 years of age, had been diagnosed with cancer, and were able to read English. Patients were excluded if they indicated at the time of recruitment that they were participating, or intended to participate, in a workshop offered at one of the participating hospitals that covered the material in the workbook. Creswell (2007) recommends that researchers interview

between 5 to 25 individuals who have all experienced the phenomenon. As such, 21 participants were recruited and interviewed about their experience with the workbook intervention and data was analyzed until saturation was achieved.

Setting

Participants were recruited from the psychosocial support cancer centers of two tertiary care hospitals in Montreal, Canada. Participants were recruited via fliers and handouts posted at both centers. Additionally, emails were sent to patients registered at these centers informing them of the opportunity to be involved in this study. These centers offer free access to programs for cancer patients and their families, such as, one-to-one peer counselling, self-help groups, physical activities (fitness, yoga, tai chi, walking), creative classes and more.

NUCARE workbook intervention

Mastering the Art of Coping in Good Times and Bad (Edgar, 2010) is based on the didactic material of the NUCARE intervention program which embraces two major areas: (i) the enhancement of a sense of personal control; and (ii) the learning of emotional and instrumental coping responses (Edgar, Rosberger, et al., 2001). The approach emphasizes training in 7 skills: mindfulness, cognitive coping skills, relaxation techniques, goal setting, problem solving, communication, and social support. Participants had the workbook for 6 weeks before being interviewed and were advised to read approximately two chapters a week.

Methodological Approach

The research approach chosen was qualitative description, which allows for a straight descriptive summary of the data in everyday language (Sandelowski, 2000) and is recommended for intervention development or refinement (Neergaard, Olesen, Andersen, & Sondergaard, 2009). The interviews were digitally recorded and transcribed verbatim by a trained research assistant. The primary researcher read the transcripts thoroughly to become familiar with the data (Friese, 2012; Pope, Ziebland, & Mays, 2000). Data was coded using content analysis, the most common form of analysis used in qualitative description (Milne & Oberle, 2005; Sandelowski, 2000). Content analysis involves coding data into units and grouping these into main categories based on shared characteristics (Milne & Oberle, 2005). Data coding was performed using the software package ATLAS.ti (Muhr, 1997).

Specific techniques were employed to ensure rigor of the current study (Milne & Oberle, 2005; Whittemore, Chase, & Mandle, 2001). To enhance authenticity, a semi-structured interview guide was utilized to encourage participants to share their opinions, and probes were used to encourage a rich description of the participant's narrative. In order to address credibility, codes were used that emerged from the data rather than being set a priori. Finally, to improve integrity, direct quotations are provided to support interpretations of the data. As such, readers are able to verify the credibility and integrity of the study as a whole.

Findings

Twenty-one patients were invited to partake in the interview. However, one interview failed to record, one participant withdrew from the study, and one participant was unable to commit to the interview time. Consequently, eighteen participants completed the interviews from which the data emerged. Fifteen respondents were female and 3 male. Participants' ages ranged from 18 to 89 years ($M = 53.4$, $SD = 15.4$). The majority of diagnoses were of breast cancer (50%) followed by blood cancers (22.2%) and ovarian cancer (11.1%). Table 1 lists additional demographic information.

Two main categories were identified from the respondent's interviews regarding the acceptability of the book. The first category focuses on content, the other on recommendations. Interviewees specified the following content as most helpful (1) focusing on the positive; (2) mindfulness; (3) relationships; (4) skill reinforcement.

Content

Focusing on the positive. Many respondents reported that the book was most helpful in teaching them how to change their thoughts, gain perspective and think more positively.

“Some of the things that I read... that would have been good to know at the beginning...simply the way it helps you think in the positive... it reminds you to be happy, to laugh.” (Respondent 4)

“... You don't feel hopeless or you don't feel like things are way out of control... you learn to cope ... that's given me a new outlook on things... I identify different

thoughts and how I feel and sort them out and simplify them ... I can deal with them.”

(Respondent 6)

“... It got me to refocus my attention in a more positive, productive way.”

(Respondent 9)

“... I'm able to change my thoughts, I do see how it affects me in a very positive way... it's like I'm able to think better... because I'm changing my thought processes, I'm not wallowing in the dark, I'm actually doing something to be creative, to change whatever it is that I'm going through at that moment.” (Respondent 13)

Relationships. Two categories emerged from the analysis regarding the importance of relationships. First, that the book encouraged respondents to seek new relationships and enhance current relations. Second, that the book addressed the importance of setting boundaries in relationships.

Seeking/enhancing relationships.

“... But I realized the moment that I read that in the book, the moment I decided I was going to forgive that person, I felt better myself! So it was such a relief.”

(Respondent 11)

“...I realized much more that I took intimate friendships and family for granted ... whereas now, I realize how important those relationships are, and how much of a difference they really make... I've learned o really appreciate that... a huge part of coping successfully is having love and close relationships with other people... made me more aware.” (Respondent 13)

Setting boundaries in relationships.

“... I’m not the type of person, usually, to say “I want to do this” or “I don’t want to do this” [in relationships]... But you know, after reading the book, I kind of felt like, “oh you know, maybe I should start doing that, and uh, so I did.” (Respondent 8)

“... I would like to help everybody, I cannot do that anymore... in the book, they say you have to say no sometimes... I never said no, it’s very very hard to say no.” (Respondent 16)

Mindfulness. Interviewees responded positively to the recommendation to being more mindful in order to cope better with stress.

“.. be mindful of the little things...not to take everything for granted, and you know, enjoy doing things that you do every day and kind of focus on it, and be aware of what you do.” (Respondent 6)

“...I don’t remember what it’s called but it takes a moment of your day to just, you know, pay attention to what’s happening around you... it helped me... to be honest, more relaxing than the breathing exercises.” (Respondent 8)

“Mindfulness was very, very helpful. I think it’s just easy to use at times of stress, you know, just to focus on something else, and get your mind off of whatever it is stressing you.” (Respondent 10)

“...Before everything was rushed, now, I slow down.” (Respondent 16)

Skill Reinforcement. Respondents noted that although some of the coping skills were not novel, reading the book still had a positive impact because it reinforced the coping skills they already had.

“I really am lucky because I know this stuff and so I really am not a depressed person at all. So I was thinking in that way, good, thank goodness you know, I am there [not depressed].” (Respondent 1)

“I’ve always considered myself to have good coping skills and I was really impressed – although most of the stuff I already knew. But just the way it’s laid out and some of the exercises and practice suggestions, they really really enforced it a whole lot better.” (Respondent 3)

“...It confirmed some of the things that I already, you know, think and do and act like. But you know, we always need to be reassured.” (Respondent 4)

“I didn’t realize ... I already had a lot of the tools in me, in terms of coping mechanism. I did always look for a silver lining so I just knew “Oh, okay, I could do that again” ... “Okay yeah, I’ve done that before, I could do that again,” I was also working on my strengths, so it was nice.” (Respondent 13)

“...[The book] confirms all the good things I already read, and it made me feel good reading it, it confirmed that I should keep going in that direction ... I need to maintain.” (Respondent 14)

Recommendations. There were two subcategories under recommendations: (1) Recommending the book to others; (2) Recommendations to improve the intervention.

Recommendations to Others. All participants, except for one who had not read the entire book yet, indicated they would recommend the book to other patients with cancer.

“I would say it was a great book and that I really recommend that they [someone with cancer] read it. Which is why I wish I hadn’t written all over this because I’d love to pass it on.” (Respondent 3)

“I would tell them that it helped me. Changed some of my thought processes and it helped me for the better and I would recommend they read it.” (Respondent 6)

“Even if they feel well, it’s a very good idea to read it, try to manage their stuff with the book because even if it helps only 10%, it helps and it’s positive. So maybe what they read now will not apply right away, if they do it in 6 months, or in a year, it cannot be negative. So it’s only a good thing.” (Respondent 12)

“Yes, we all need skills on coping, you know, I feel very confident generalizing that. I think it is a really great gift for oneself.” (Respondent 13)

“I would suggest them to read the book ... try to do what they say in the book ... and after go see somebody who would be able to help them professionally.” (Respondent 15)

“I think it’s a big help for some, for myself and for other people, to use it as a guide to help cope with life, with family, with the idea of being ill... Looking to the future and not worrying all the time. Coping with worry.” (Respondent 17)

Three participants recommended that the book be offered to everyone – not only patients with cancer.

“It’s terrific. You have to read it even if you don’t have cancer. You have to read it.” (Respondent 5)

“I would highly recommend it... I think it’s really a general coping thing for people, you know, in every day life I think it would really help people out.” (Respondent 10)

“It’s very good, not for just sick people but for a lot of people.” (Respondent 12)

Recommendations to improve the intervention. Respondents had various suggestions on how to improve the self-help workbook. For instance, two respondents recommended the content be available as an audio book. However, most suggestions were related to having access to additional support, i.e., to a coach/therapist, while reading the book.

“...It would be helpful to discuss some things that maybe you weren’t sure about exactly ... just to have a little bit of feedback.” (Respondent 3).

“A directory... with different organizations ... if you’re having trouble maybe call this organization, or try these different tasks.” (Respondent 9).

“I’m speaking to a therapist and I think it helps me very much. But I don’t know if suggesting that ... a possibility of working with someone through the process... discussing it [the book] with someone.” (Respondent 13).

“... Invite you to contact a psychologist, to help you, ... and I thought that was a good idea.” (Respondent 14).

Discussion

The goal of the current study was to obtain feedback regarding the acceptability of the NUCARE self-help book for patients with cancer. The majority of the sample were Caucasian women, diagnosed with breast cancer. Individuals of all ages (range: 18-72), and even patients currently in treatment with more advanced cancers, expressed interest in the self-help book.

Seventeen out of 18 respondents reported that they would recommend *Mastering the Art of Coping in Good Times and Bad* to other patients with cancer. Respondents noted that although some of the coping skills were not novel, reading the book still had a positive impact because it reinforced the coping skills they already had. Additionally, respondents reported that the book was helpful as it addressed ways to think more positively, the skill of mindfulness, and the importance of relationships. These skills have been associated with positive psychological well-being in patients with cancer (Dukes Holland & Holahan, 2003; Piet, Würtzen, & Zachariae, 2012; Shennan, Payne, & Fenlon, 2011).

Although previous research has not explored patients' reactions to and perceptions of the self-help NUCARE intervention at a qualitative level, it is possible to draw parallels with the quantitative studies previously conducted. The NUCARE intervention, when offered in individual and group formats, has been shown to be effective in teaching adaptive coping strategies, alleviating distress and enhancing psychological adjustment (Allison et al., 2004; Edgar et al., 2001; Edgar et al., 1992; Rosberger et al., 2002; Vilela et al., 2006). These findings corroborate the

aforementioned results, which highlight the acceptability and usefulness of the content of this book for this population.

Implications for Nursing

Psychosocial oncology services continue to be understaffed and underfunded to adequately respond to patient needs for professional psychosocial support. Overburdened primary care staff often tends to neglect psychosocial issues (Carlson & Bultz, 2004; Carlson & Bultz, 2003) and is not trained to provide specialized psychosocial services. Consequently, many patients do not have access to adequate psychosocial support (Carlson & Bultz, 2004; Carlson & Bultz, 2003). Bibliotherapy is not only cost effective and easy to administer but appears to be an acceptable form of treatment for some patients. Offering evidence-based bibliotherapy has the potential to reduce the current strain on resources and enhance psychosocial services offered.

Limitations and Future Research

Although the current study goes beyond previous work, it is not without its limitations. The convenience sampling approach employed in this study can be considered biased as only patients interested in participating in a self-help intervention were recruited. Given that participants were recruited from two cancer-care centers in the same large city, findings may not be transferrable to or be representative of all cancer patients.

Despite these limitations, the current findings are promising and provide information to guide future research. For instance, future research might include a replication of the results with a larger and more diverse sample; examination of whether a

book offered with some additional support by a professional or a trained oncology volunteer would be significantly more helpful than a book alone, examining the efficacy of bibliotherapy for patients, researching the implementation of bibliotherapy in current psychosocial departments; and eventually developing and evaluating a stepped care model of service for patients with cancer.

In conclusion, this study is the first to suggest that patients with cancer consider the book, *Mastering the Art of Coping in Good Times and Bad*, acceptable as a means of helping them manage their stress. Because patients are expressing an interest in obtaining a book to help them cope, further investigations of bibliotherapy are warranted for this population.

Table 1

Demographic Characteristics of Respondents (N=18)

Characteristic	<i>n</i>	%
Age Groups (Years)		
18–29	1	5.6
30–39	1	5.6
40–49	5	27.8
50–59	5	27.8
60–69	4	22.2
70+	2	11.1
Gender		
Male	3	16.7
Female	15	83.3
Ethnicity		
Caucasian	15	83.3
Asian	2	11.1

Black	1	5.6
Education (Years)		
11–12 (high school)	3	16.7
13–16 (college/university)	6	33.3
17+ (graduate level)	8	44.4
Job Status		
Full-time	3	16.7
Part-time	2	11.1
On leave	4	22.2
Retired	2	11.1
Unemployed	7	38.9
Marital Status		
Married	6	33.3
Common-law	3	16.7
Single, never married	5	27.8
Divorced, separated	3	16.7

Widowed	1	5.6
Cancer Diagnosis		
Breast	9	50.0
Blood	4	22.2
Ovarian	2	11.1
Prostate	1	5.6
Endometrial	1	5.6
Brain	1	5.6
Cancer Stage		
Early	5	27.8
Advanced	5	27.8
Metastasized	3	16.7
Unknown/Unspecified	5	27.8
Treatment Classification		
Newly diagnosed	1	5.6
In treatment (new diagnosis)	3	16.7

In treatment (recurrent cancer)	2	11.1
Completed treatment	1	5.6
Long-term follow-up	9	50.0
Surveillance	2	11.1

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Connecting Text

Study 1 explored the acceptability of the NUCARE workbook, *Mastering the Art of Coping in Good Times and Bad*. Study 1 was interested in obtaining the participants' opinions regarding the bibliotherapy material. Seventeen out of 18 respondents reported that they would recommend *Mastering the Art of Coping in Good Times and Bad* (2010) to other patients with cancer. Moreover, respondents reported that the book was helpful as it addressed ways to think more positively, practice mindfulness, and the importance of relationships. To further investigate the use of bibliotherapy for patients with cancer, Study 2 examines whether the NUCARE intervention, when offered in the bibliotherapy format, is efficacious in improving empowerment and quality of life and reducing distress for patients with cancer.

Chapter Four – Manuscript 2

Bibliotherapy for patients with cancer: A randomized controlled trial

Nicole Roberts^{1,5}, PhD Candidate

Russell J. Steele⁶, PhD

Zeev Rosberger^{2,3,5}, PhD

Annett Körner¹⁻⁵, PhD

¹ Department of Educational and Counselling Psychology, McGill University

² Departments of Psychology, Oncology and Psychiatry, McGill University

³ Louise Granofsky Psychosocial Oncology Program, Segal Cancer Center

⁴ Psychosocial Oncology Program, McGill University Health Centre

⁵ Lady Davis Institute for Medical Research, Jewish General Hospital

⁶ Department of Mathematics and Statistics, McGill University

Abstract

Background: Bibliotherapy is a form of self-administered treatment using books to improve psychological well-being. Research strongly supports bibliotherapy as a treatment for a variety of mental health problems. Yet to our knowledge, few studies have investigated its use among patients with cancer. The objective of this randomized controlled trial was to examine the efficacy of the NUCARE intervention delivered as bibliotherapy to enhance empowerment and quality of life and to reduce distress in patients with cancer. **Method:** Eighty-nine adult patients with cancer were randomized to receive bibliotherapy treatment for 6 weeks or the control condition. Participants completed questionnaire packages at baseline, 6 weeks post baseline assessment and 10 weeks post baseline assessment. **Results:** The increase of empowerment scores (main outcome) and quality of life and the decrease of distress in the bibliotherapy group from pre-intervention to follow-up assessment differed significantly from the respective difference scores of the control group. **Conclusions:** Bibliotherapy has the potential to be a cost-effective and accessible minimal intervention to address the psychosocial needs of patients with cancer. Evidence-based bibliotherapy can empower patients and has the potential to reduce the burden on resources and enhance the immediacy of psychosocial services offered.

Keywords: bibliotherapy, self-help, cancer, oncology, randomized controlled trial, empowerment

Bibliotherapy for patients with cancer: A randomized controlled trial

Bibliotherapy is a form of self-administered treatment using books to improve psychological well-being (Gregory et al., 2004; McKendree-Smith, Floyd, & Scogin, 2003; McKenna, Hevey, & Martin, 2010). There are many benefits associated with utilizing bibliotherapy to help individuals overcome psychosocial difficulties (Hawker, 2009; Papworth, Marrinan, Martin, Keegan, & Chaddock, 2013). The foremost benefits of bibliotherapy relate to its accessibility and minimal-cost as patients do not have to endure long wait lists for access to this form of psychological treatment, pay the high costs of private therapy, or accrue the additional expenses of travel and parking. It is also a less stigmatizing alternative to traditional psychotherapy, allowing individuals to privately access care while working at their own pace. Researchers have also suggested that engaging in self-management is empowering and enhances a sense of control, self-reliance and autonomy (Den Boer et al., 2004; Williams et al., 2009).

A substantial amount of research exists on the effectiveness of bibliotherapy for mental health conditions, especially for mild to moderate levels of depression and anxiety symptoms. Meta-analyses and a recent systematic review have further supported the usefulness of bibliotherapy for treating symptoms of anxiety and depression in the general population (Cuijpers, 1997; Fanner & Urquhart, 2008; Gregory et al., 2004; Marrs, 1995; McKenna et al., 2010). The accumulation of positive findings have led to the UK's National Institute for Health and Clinical Excellence to recommend bibliotherapy in their stepped care model for the treatment of mild to moderate anxiety

and depression (NICE, 2004; NICE, 2009a). NICE also concluded that self-help therapies are highly cost-effective (NICE, 2009b).

To our knowledge, few studies have investigated the use of bibliotherapy for treating psychosocial concerns among patients with cancer. Available research indicates that there is a subgroup of patients with cancer who are interested in and benefit from accessing bibliotherapy (Allison et al., 2004; Beatty et al., 2010; Beatty, Oxlad, Koczwara, & Wade, 2010; Savard et al., 2010; Semple et al., 2006; Vilela et al., 2006). In order to advance knowledge in this area, a rigorous evaluation of bibliotherapy among patients with cancer is required.

In the psycho-oncology literature, there is considerable evidence demonstrating that the NUCARE intervention enhances quality of life and reduces distress in patients with cancer (Allison et al., 2004; Edgar, Rosberger, et al., 2001; Edgar et al., 1992; Edgar et al., 1992; Rosberger et al., 2002; Vilela et al., 2006). NUCARE is a psycho-educational intervention based on cognitive behavioral principles. The NUCARE intervention focuses on training in two major areas: enhancement of a sense of personal control and emotional and instrumental coping responses (Edgar, Rosberger, et al., 2001; Rosberger et al., 2002). Previous studies have primarily focused on examining NUCARE delivered as an individual or group intervention but initial evidence suggests that the bibliotherapy format also has potential to improve psychological functioning (Allison et al., 2004; Vilela et al., 2006). Given this, the objective of this randomized controlled trial is to examine the efficacy of the NUCARE intervention when delivered in a bibliotherapy format among patients with cancer. It is hypothesized that participants in the

bibliotherapy group will report improvements in empowerment, quality of life and distress when compared to the control group.

Methods

Participants and Setting

Adult cancer patients were recruited from hospital based psychosocial support services in Montreal, Canada. Participants were excluded if they indicated at the time of recruitment that they were currently, or intending to, participate in a workshop that covered the material in the NUCARE book.

Design and Procedures

A mixed method randomized controlled trial was conducted (see Figure 1). Eligible, consenting patients completed a socio-demographic questionnaire, baseline measures and were randomized to the treatment group (i.e. receiving the workbook) or the control arm (i.e. receiving usual care). Participants completed measures at three assessment points: baseline (week 0), post reading the book/post waiting (week 6), and at a 1-month follow-up (week 10).

Randomization. The Consolidated Standards of Reporting Trials statement (Schulz, Altman, & Moher, 2010) guided the randomization procedure. Block random allocation was used and the sequence was produced by www.randomization.com. An independent research assistant ran the sequence and created sequentially numbered, opaque, sealed envelopes containing group allocation for participants. As such, the recruiter was blinded to the allocation until they assigned the intervention to the

participant to ensure they were not biased by that knowledge. Given the nature of this psychosocial intervention, it was not possible to blind the participants or the interviewer.

Bibliotherapy. The NUCARE intervention emphasizes training in 7 skills: mindfulness, cognitive coping skills, relaxation techniques, goal setting, problem solving, communication, and social support. The treatment group received the published version of the workbook, *Mastering the art of coping in good times and bad* (Edgar, 2010). Participants had the workbook for 6 weeks before being interviewed and were advised to read approximately two chapters a week.

Usual care. All study participants had access to a variety of hospital-based as well as community resources. Psychosocial services of oncology volunteer organizations in Montreal include one-to-one peer counselling, self-help groups, physical activities (fitness, yoga, tai chi, walking), creative classes and more. The comprehensive clinical care approach at the hospital comprises Psychosocial Oncology Programs with limited access to professionals in the fields of social work, psychology, psychiatry, nursing and pastoral services.

Measures

Primary outcome. Empowerment was the primary outcome in this RCT. A previously validated set of scales from the Health Education Impact Questionnaire (heiQ; (Osborne, Elsworth & Whitfield, 2007) were used to assess empowerment. The heiQ consists of eight independent scales: (1) health directed behavior; (2) positive and active engagement in life; (3) emotional well-being; (4) self monitoring and insight; (5) constructive attitudes and approaches; (6) skill and technique acquisition; (7) social

integration and support; (8) health service navigation. For our purposes scales 3, 5, 6, 7 and 8 were used, comprising a total of 25 items. Factor loadings of the items on the five scales are moderately high (0.65-0.91), and the Cronbach alphas are as follows:

emotional well-being (.91); constructive attitude (.87); social integration and support (.86); health services navigation (.84); skill and technique acquisition (.76) (Maunsell, Lauzier, Brunet, Campbell, & Osborne, 2011). These scales have been validated as a measure of patient empowerment, a “multi-faceted construct that, in the cancer context, refers to feelings of being able to manage the challenges of the disease and gain a sense of control over the cancer experience” (Maunsell, Lauzier, Brunet, Campbell & Osborne, 2010; Maunsell et al., 2014; Maunsell, Lauzier, Brunet, Campbell & Osborne, 2011).

Secondary outcomes. The Functional Assessment of Cancer Therapy – General (FACT-G; Cella et al., 1993) was used to assess patients’ quality of life. This scale includes 27-items encompassing four primary quality of life domains: physical well-being, social/family well-being, emotional well-being, and functional well-being. The internal consistency of the FACT-G measured by Cronbach’s alpha coefficient is .89.

Distress was defined as symptoms of anxiety and depression and measured using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The HADS is a 14-item self-report measure assessing symptoms of depression (7 items) and anxiety (7 items). The internal consistency of the HADS, measured by the Cronbach’s alpha coefficient, has been found satisfactory for both the anxiety and depression scales; 0.83 and 0.82 (Bjelland, Dahl, Haug, & Neckelmann, 2002).

Sample Size

An a priori power analysis determined that a sample size of 102 participants would be required to detect a moderate degree of power (70%), a conventional level of significance ($\alpha = 0.05$) and a moderate effect size ($d = 0.5$). Time constraints associated with completing this doctoral research project restricted the researchers from fully reaching this ideal sample size goal. Nevertheless, 89 participants were recruited for participation in this study from September 2012 until May 2014.

Statistical Methods

Preliminary analysis. Quantitative analyses were conducted using the Statistical Package for the Social Sciences, version 21. Prior to conducting analyses, mean item substitution was used for missing values as recommended by the instrument developers. Baseline differences between the experimental and control group were assessed using *t*-tests (2-tailed) for continuous variables and chi-square tests for discrete/categorical variables. Inverse probability of missingness models (Seaman & White, 2011) were conducted to assess the sensitivity of the results to loss of follow-up, using baseline covariates in a logistic regression model to estimate the probability of missingness.

Outcome analysis. The main outcome variable (i.e., empowerment) as well as the secondary outcome variables (i.e., quality of life and emotional distress) were analyzed on an intention-to-treat basis. Paired *t*-tests were conducted to evaluate group differences pre intervention, post intervention and at the one month follow-up. Significance was established using a conventional level of probability ($\alpha = .05$).

Results

Eighty-nine participants enrolled in the study. The mean age was 54 years ($SD = 12.21$), the majority of participants were female (77.5%) and heterogeneous cancer diagnoses were represented. Socio-demographic information for participants based on group allocation is presented in Table 1. Thirty-four percent of participants in the control group, and 23% in the bibliotherapy group received emotional support from a psychologist/counsellor/social worker during the study. Additionally, 21% of participants in the control group and 20% in the treatment group reported taking medication for mood/depression/anxiety. No significant differences between the bibliotherapy and control group conditions were found at baseline for sociodemographic, dependent and independent variables.

Post Intervention Outcomes

The change in the levels of empowerment, quality of life and distress from pre intervention to post intervention did not differ significantly between the bibliotherapy group and the control group (see Table 2).

Follow-up

The increase of empowerment scores and quality of life and the decrease of distress in the bibliotherapy group from pre-intervention to follow-up assessment differed significantly from the respective difference scores of the control group (see Table 3).

Inverse probability weighting analyses

In order to investigate whether participant dropout biased the findings, observations were re-weighted by the inverse of the probability of being observed. A logistic regression was conducted with distress, gender, disease stage, and education entered in the model to determine predictors of drop out at post assessment and follow-up. Education at follow-up was the only significant predictor (Odds Ratio = .40; $B = -.93$; $p = .04^*$). Weighted regressions were conducted with the outcome measures entered as the dependent variables and group assignment entered as the independent variable.

Tables 4 and 5 summarize the results of the inverse-probability weighted (IPW) analyses. We noted some small differences in interpretation between the complete case and inverse probability weighted results. At post assessment, levels of distress reduced significantly in the bibliotherapy group, while prior analyses revealed no differences. No other significant differences were noted at post assessment for either group. At follow-up, changes in distress scores remained significant, however quality of life was no longer significant and empowerment showed a trend to improve ($p = .058$). It is possible that the results differ from the completed cases reported because people with lower education levels were more likely to drop out, and when data was re-weighted, participants with lower educational attainment who did not drop out had a higher weight. Note that the direction of the associations and the general conclusions from the IPW analyses remained the same as those in the complete case analyses; the only differences are in the standard errors of the effects and some slight differences in magnitude.

Conclusions

The findings of the present study indicate that bibliotherapy can be effective in improving psychological well-being in patients with cancer. In summary, the hypotheses were confirmed and study completers receiving bibliotherapy treatment experienced an increase in empowerment and quality of life and reductions in distress at the one-month follow-up when compared to the control group. Improvements in outcomes found at follow-up that were not present at post treatment could be explained by additional time that allowed for opportunities to practice and implement the learned coping skills.

To our knowledge this is the first randomized controlled trial to examine the effects of bibliotherapy on empowerment, quality of life, and distress in patients with cancer. Our findings are consistent with those in the psychotherapy literature confirming the effectiveness of bibliotherapy in fostering a sense of empowerment (McKenna et al., 2010) and alleviating symptoms of depression and anxiety (Cuijpers, 1997; Fanner & Urquhart, 2008; Gregory et al., 2004; Marrs, 1995). Our findings are also comparable to the existing evidence-base for bibliotherapy in psycho-oncology demonstrating improvements in psychological adjustment, specifically coping and cognitive functioning (Beatty et al., 2010), sleep and overall quality of life for breast cancer patients (Savard, Villa, Simard, Ivers, & Morin, 2011).

With advancements in cancer care more people are surviving cancer. Psychosocial services have limited resources to meet these growing demands, are overburdened and are lacking trained professionals to provide specialized services (Carlson & Bultz, 2004; Carlson & Bultz, 2003). When resources are limited,

empowering patients is key as research suggests that patients who feel empowered are more likely to play an active role in the management of their physical and mental health (Maunsell et al., 2014; McCorkle et al., 2011). Offering evidence-based bibliotherapy to patients has the potential to empower patients, reduce burden on existing resources, and enhance the availability of psychosocial services being offered.

This study highlights the benefits of bibliotherapy for patients with cancer, however appropriate caution should be taken when interpreting the results. First, the drop out rate in the intervention group was higher than in the control group and analyses revealed that people with lower levels of education were more likely to drop out. Further, the sampling approach limits generalizability as patients self-selected based on their own interest in participating in a self-help intervention. Although findings may not be generalizable to the greater population of patients with cancer, studying this subpopulation remains valuable as they represent the target audience for this treatment approach. More specifically, the target audience for bibliotherapy includes those with a preference for treatment in a self-help format. Lastly, the statistical significance found does not necessarily imply clinical significance. Future research might consider replicating the results and examining longer-term effects of the intervention. It would also be of value to examine bibliotherapy in contrast to existing interventions to compare benefits and cost-effectiveness.

In short, bibliotherapy is a low cost intervention with minimal demand on personnel resources. More importantly, the results of the current study provide initial evidence that bibliotherapy is efficacious in improving feelings of empowerment and

quality of life and reducing symptoms of distress among patients with cancer. With appropriate advancements in our knowledge of this intervention, evidence-based bibliotherapy should be considered for inclusion in a stepped care model of psychosocial services for cancer patients.

Figure 1. CONSORT flow diagram.

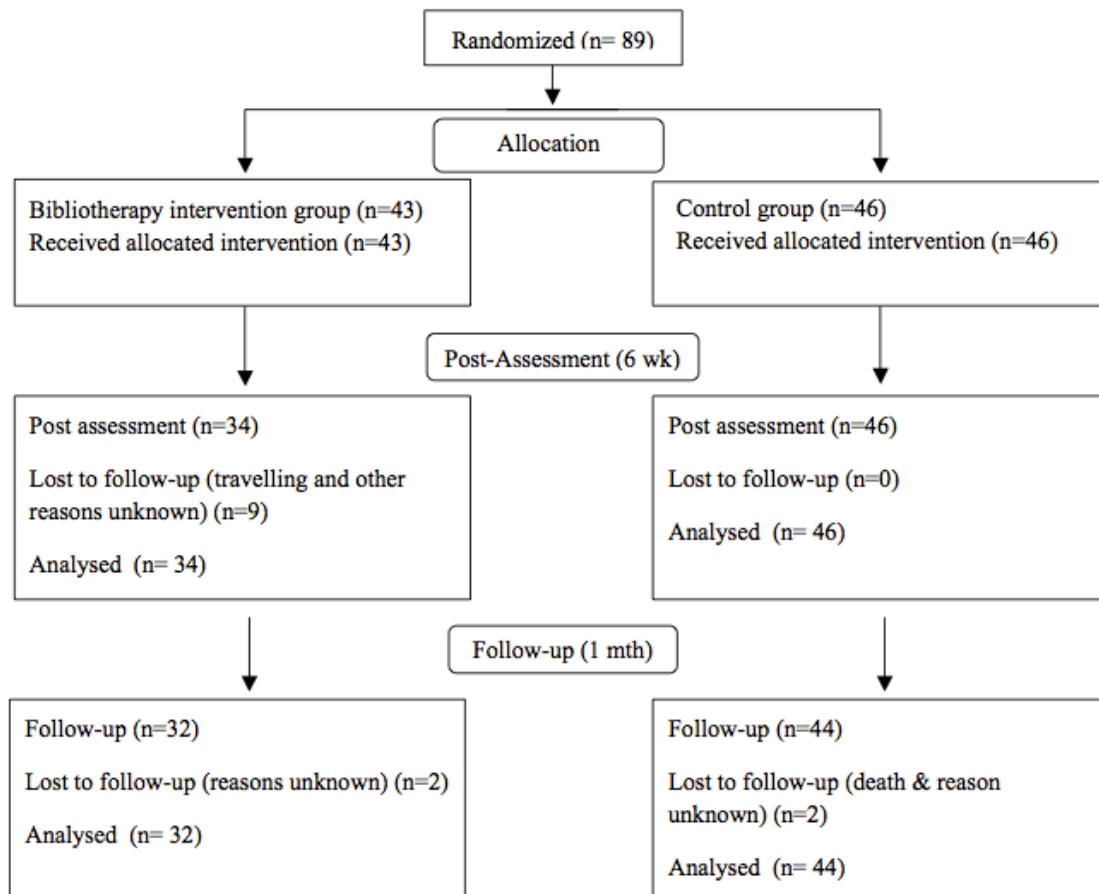


Table 1

Demographic and Medical Characteristics as a Percentage of the Sample

Characteristic	Control (n = 46)	Intervention (n = 43)	χ^2
Age Groups (Years)			.85
18–29	2.2	2.3	
30–39	4.3	11.6	
40–49	21.7	20.9	
50–59	37.0	25.6	
60–69	28.3	30.2	
70+	6.5	9.3	
Gender			.86
Male	21.7	23.3	
Female	78.3	76.7	
Ethnicity			.55
Caucasian	76.1	86	
Asian	10.9	9.3	

Black	2.2	2.3	
Hispanic	4.3	0	
Other	6.5	2.3	
Education (Years)			.73
11–12 (high school)	13	18.6	
13–16 (college/university)	39.1	37.2	
17+ (graduate level)	47.8	41.9	
Job Status			.28
Full-time	8.7	20.9	
Part-time	19.6	9.3	
On leave	30.4	25.6	
Retired	23.9	18.6	
Unemployed	17.4	25.6	
Marital Status			.37
Married	39.1	32.6	
Common-law	2.2	11.6	

Single, never married	26.1	32.6	
Divorced, separated	30.4	20.9	
Widowed	2.2	2.3	
Cancer Diagnosis			.61
Breast	34.8	37.2	
Blood	21.7	14.0	
Ovarian	4.3	9.3	
Prostate	6.5	4.7	
Endometrial	0	4.7	
Brain	4.3	4.7	
Colorectal	2.2	9.3	
Lung	6.5	4.7	
Other	19.6	11.6	
Cancer Stage			.85
Early	38.6	37.2	
Advanced	18.2	18.6	

Metastasized	18.2	11.6	
Unknown/Unspecified	25.0	32.5	
Treatment Classification			.64
Newly diagnosed	2.2	2.3	
In treatment (new diagnosis)	26.7	23.3	
In treatment (recurrent cancer)	8.9	7.0	
Completed treatment	6.7	7.0	
Long-term follow-up	51.1	51.2	
Surveillance	0	7.0	

Table 2

Mean (SD) and mean differences in empowerment, quality of life and distress between baseline and post assessment in the bibliotherapy and control group^a

	Bibliotherapy (<i>n</i> = 34)		<i>d</i> ¹	Control (<i>n</i> = 46)		95% CI for <i>d</i> ² - <i>d</i> ¹	<i>p</i>
	Baseline	Post assessment		Baseline	Post assessment		
Empowerment	3.01 (.34)	3.11 (.28)	.11 (.29)	2.94 (.43)	2.91 (.42)	-.03 to .29	.11
Quality of life	75.63 (15.00)	75.29 (14.95)	-.34 (11.01)	70.73 (15.27)	69.31 (16.27)	-1.42 (13.00)	-4.41 to 6.57 .70
Distress	12.44 (5.26)	10.91 (7.09)	-1.53 (4.91)	13.17 (6.83)	12.93 (7.32)	-.24 (5.54)	-3.66 to 1.09 .29

^a *d*¹ and *d*²=difference between baseline and 6 months in the control and intervention group, respectively; *p* values and 95% CI are for *d*²-*d*¹.

Table 3

Mean (SD) and mean differences in empowerment, quality of life and distress between baseline and the 1-month follow-up in the bibliotherapy and control group^a

	Bibliotherapy (<i>n</i> = 32)		<i>d</i> ¹	Control (<i>n</i> = 44)		<i>d</i> ²	95% CI for <i>d</i> ² - <i>d</i> ¹	<i>p</i>
	Baseline	Follow-up		Baseline	Follow-up			
Empowerment	3.03 (.34)	3.25 (.35)	.22 (-.02)	2.93 (.44)	2.91 (.45)	-.02 (.40)	.06 to .41	.01**
Quality of life	77.17 (13.89)	82.37 (11.86)	5.20 (9.41)	71.21 (15.40)	70.25 (16.35)	-.95 (11.01)	1.34 to 10.98	.01*
Distress	11.97 (4.99)	9.44 (4.68)	-2.53 (3.88)	12.89 (6.82)	12.99 (6.25)	.10 (4.57)	-4.62 to -.64	.01*

^a *d*¹ and *d*²=difference between baseline and the 1-month follow-up in the control and intervention group, respectively; *p* values and 95% CI are for *d*²-*d*¹.

Note: SD = standard deviation

Table 4

Weighted Regression with the Outcome Measures entered as the Dependent Variables and Group Assignment Entered as the Independent Variable at Post Assessment

Dependent Variable	B	SE (B)	β	<i>t</i>	<i>p</i>
Empowerment	-.05	.083	-.077	-.63	.53
Quality of life	-2.12	1.59	-.14	-1.34	.19
Distress	2.60	1.17	.25	2.22	.03*

Table 5

Weighted Regression with the Outcome Measures entered as the Dependent Variables and Group Assignment Entered as the Independent Variable at Follow-up

Dependent Variable	B	SE (B)	β	t	p
Empowerment	-.17	.09	-.23	-1.9	.06
Quality of life	-1.55	1.64	-.10	-.94	.35
Distress	3.17	.96	.36	3.30	.001**

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Chapter Five - General Discussion

There is a strong need for research into feasible, accessible, cost contained psychosocial interventions for patients with cancer. As such, the objectives of this dissertation were two-fold. First, the researcher sought to explore the acceptability of the chosen bibliotherapy material as determined by patients with cancer. Second, the researcher sought to examine the efficacy of bibliotherapy for patients with cancer.

Summary of Findings

The aim of Study 1, Acceptability of bibliotherapy for patients with cancer: A qualitative descriptive study, was to determine the acceptability of the self-help workbook for patients with cancer. This study sought feedback on how *Mastering the Art of Coping in Good Times and Bad* (Edgar, 2010), was perceived by participants. More specifically, the researchers explored patient's perspectives on the usefulness of the workbook for improving areas of psychosocial functioning. For example participants were asked, what was helpful about this workbook and how could this intervention be improved?

The findings suggested that participants found the book helpful and 17 out of 18 of the respondents reported that they would recommend *Mastering the Art of Coping in Good Times and Bad* to other patients with cancer. Respondents noted that the most helpful aspects of the book were (a) skills that focused on thinking more positively, (b) instructions on how to practice mindfulness, and (c) an emphasis on the importance of relationships. Several participants shared that although this information and these skills were not new, reading the book was beneficial as it reinforced the importance of practicing and implementing the coping skills they possessed. To improve the intervention, participant's recommendations centered on making additional support

available while reading the book, such as having access to a book club or a professional to discuss the book with. Although participant's suggested additional interactions with peers or professionals be available while engaging in bibliotherapy, they still engaged with the book on its own in a helpful manner as documented by the findings of the RCT. As such, we know that the intervention was successful even without the addition of these higher levels of service. In short, this study is the first to suggest that patients with cancer consider the book, *Mastering the Art of Coping in Good Times and Bad*, useful as a means of helping them cope with stressors associated with cancer and life in general.

The aim of Study 2, Bibliotherapy for patients with cancer: A randomized controlled trial, was to examine the efficacy of the self-help NUCARE workbook in enhancing empowerment and quality of life and reducing distress for patients with cancer. Participants in the bibliotherapy group reported improvements in empowerment, quality of life and distress when compared to the control group at follow-up. There were no significant differences between the changes in the intervention group and the control group from pre to post assessment. The significant differences found in multiple areas of psychosocial functioning at the one-month follow-up could potentially be due to participants benefiting from continued engagement in the bibliotherapy intervention. Post-hoc analyses were conducted to confirm the robustness of the statically significant findings regarding within group differences at the pre, post and follow-up assessment points, as well as between the intervention and control group (see Appendix A).

To our knowledge, the findings from this study are the first to suggest that bibliotherapy material, specifically, *Mastering the Art of Coping in Good Times and Bad* (Edgar, 2010), can be efficacious in enhancing empowerment and quality of life and reducing symptoms of

psychological distress for patients with cancer. These findings are consistent with previous research on the efficacy of bibliotherapy, outside the oncology domain, for improving quality of life, symptoms of anxiety and depression (Cuijpers, 1997; Gregory et al., 2004; Marrs, 1995).

Taken together, findings from this dissertation suggest that there is a subgroup of patients with cancer who are interested in bibliotherapy, that the administered coping workbook alone is efficacious in enhancing empowerment and quality of life and reducing symptoms of distress. As well, patients find the content acceptable and would recommend it to others.

Limitations

This research built substantially on what is currently available regarding bibliotherapy within and beyond the field of psycho-oncology. Further, the researcher was able to provide empirical evidence derived from the rigorous design of a randomized controlled trial that employed quantitative and qualitative methodology, a substantial sample size, randomized assignment and included a control group. Despite these strengths and the original contributions of these studies, several limitations should be taken into consideration. The manuscripts of the dissertation each contain a section discussing study limitations. These limitations are summarized and expanded upon below.

The generalizability of these findings is limited by the sample characteristics. The sample consisted primarily of well-educated, middle aged, Caucasian, women. Although this sample is representative of populations in psycho-oncology research (Steginga et al., 2008), their experiences may not necessarily reflect the larger population.

The sampling procedure used in the present study also limits the generalizability of findings. Participants were recruited through psychosocial support services, therefore,

individuals not registered or not pro-actively seeking support from the hospital service were not exposed to the study advertisement (such as patients in oncology clinics). Additionally, results in part may be due to a self-selection bias, whereby only individuals motivated to participate in a study on bibliotherapy participated in this dissertation project. Further, this study was unable to blind participants to the treatment, i.e., participants were aware if they were randomized to the treatment group or to the control group. As such, it is possible that some of the improvements noted in the bibliotherapy group may be the result of a placebo effect.

Directions for Future Research

Future research should consider replicating the results with several but each in themselves more homogenous samples. It is possible that more restrictive inclusion and exclusion criteria regarding diagnosis, stage, treatment status and levels of distress enable results with more clearly defined clinical significance. Notably, patients with heterogeneous cancer diagnoses, stages, distress levels and individuals across all ages of adulthood (range: 18-89 years), at various points in their treatment trajectory were interested in utilizing bibliotherapy. The here presented study serves as an important first stepping-stone for subsequent research that can build on the assumption that this self-help workbook is effective for patients with cancer. After establishing the optimal recipient group, research is also needed into the implementation of this minimal intervention in clinical practice and a larger framework of stepped care.

Additionally, a subsequent study would benefit from having a third condition that introduces an alternative intervention in addition to the bibliotherapy condition and the waitlist control group. Also, researching the efficacy and cost-effectiveness of different delivery modes

is worthwhile, e.g. book only, book plus peer support/club, book plus limited contact with professional.

It is also recommended that the longer-term efficacy of the intervention be examined. Participants in this study demonstrated psychosocial improvements not only immediately post-intervention, but also at the 1-month follow-up. As such it would be of interest to determine if positive gains are maintained and increased over time as patients implement changes (e.g., relaxation and communication skills in everyday life and interactions with others).

The majority of the research thus far has focused on examining the effectiveness and efficacy of bibliotherapy (in individuals with mental health issues), while the mediating and moderating variables have been neglected. Future research is warranted in order to better understand what are the active ingredients of change. Compliance with treatment, client characteristics (e.g. motivation), diagnostic variables (e.g. severity of symptoms), and bibliotherapy content (e.g. psychoeducation) are likely related to treatment outcomes in bibliotherapy similarly to traditional therapy (Ellis, 1993; O'Donohue & Cummings, 2008), however research is needed to confirm the significance of these variables in the bibliotherapy context. Larger intervention effects might be achieved when this self-help intervention is administered to the most appropriate group of recipients. Further research is needed to identify the characteristics of patients most susceptible to what this intervention approach has to offer. This may be patients with neither too little nor too much psychological distress and sufficient motivation/determination/capability for self-structuring and openness to experience.

Given the current financial strain on psychosocial oncology services, it is imperative to examine the cost-effectiveness of bibliotherapy. For instance, future research could investigate

the most clinically relevant and cost-effective bibliotherapy delivery methods (i.e., a book with access to a professional, a book with an online support group, audio book, etc.). With research trends focusing on e-health and e-technology it was surprising that no participant made mention of having the book content available online, especially since internet interventions have the added benefit of being a customizable interactive tool. It is possible that patients did not consider this option or that some patients prefer reading books, may not be computer literate or have internet access. These speculations highlight the importance of continued research to determine what format of delivery of bibliotherapy is optimal for which subgroups of individuals.

Clinical and Training Implications

Despite the above-mentioned limitations and suggestions for subsequent research, this study has important clinical implications for health professionals, patients with cancer and training programs. Bibliotherapy may be attractive in many contexts because it is a flexible and convenient therapeutic approach. For instance, bibliotherapy can be offered as a self-administered treatment, with minimal professional contact, therapist administered, or therapist directed. Any professional can recommend the self-help book to patients, as there is no requirement for access to a specialized mental health professional. Alternatively, clinicians working with patients with cancer may be interested in encouraging their patients to engage in bibliotherapy as an adjunct to therapy. Having access to bibliotherapy provides more immediate support for patients. Offering evidence-based self-help material can be considerably helpful to patients who are unable to access available therapy and support, perhaps due to rural habitation, diminished mobility due to illness or treatment side effects, cost or desire for anonymity

(Pardeck, 1998). Bibliotherapy gives patients access to knowledge to help them cope and engage in their own self-management, which is empowering.

Given the efficacy of bibliotherapy for a host of mental health issues, it could be of interest for mental health professionals to be formally trained in the use of bibliotherapy (O'Donohue & Cummings, 2008). Numerous professionals report using bibliotherapy in their practice but lack formal training on how to best incorporate and implement it (O'Donohue & Cummings, 2008). Professionals and trainees in graduate training programs could benefit from being familiarized with empirically supported bibliotherapy and learn how and when to match bibliotherapy material to a client's presenting problem and individual characteristics.

The use of bibliotherapy in psychosocial oncology departments can be expanded if integrated into a stepped care approach. Offering bibliotherapy as an initial treatment has the potential to benefit the burdened psychosocial services. It is possible that providing immediate support to patients through bibliotherapy may meet the needs of some and reduce the number that required additional services. For others who require higher-level treatments, having bibliotherapy precede professional intervention may serve as a catalyst for readiness and change. Further, given the positive impact on empowerment found in the bibliotherapy intervention tested here, accessing bibliotherapy has the potential to empower clients to take further responsibility for therapeutic outcomes, improve client motivation and reduce the amount of time needed in treatment.

Conclusion

In conclusion, this dissertation suggests that evidence-based bibliotherapy can empower patients, improve their quality of life and reduce feelings of distress. Moreover, patients with

cancer found the bibliotherapy intervention, *Mastering the art of coping in good times and bad* (2010), acceptable and would recommend it to others while our patient sample noted as most helpful aspects of the self-help intervention: (a) skills that focused on thinking more positively, (b) instructions on how to practice mindfulness, and (c) an emphasis on the importance of relationships. Future research examining this bibliotherapy material and its integration into oncology services has the potential to improve the psychosocial support that is made available to patients and families touched by cancer.

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Appendices

Appendix A – Supplementary Quantitative Statistical Analyses

Between Group Analyses

Wilcoxon Rank Sum analyses were conducted to further evaluate between group differences at the pre, post and follow-up assessment points. The non-parametric Wilcoxon rank sum analyses (see Tables A1-A3) confirmed the robustness of the statically significant differences reported in Study 2 between the intervention and control group.

Table A1

Between Group Analyses Showed that the Treatment and Control Group are Comparable, and Not Statistically Different at Baseline

	<i>W</i>	<i>Z</i>	Sig.	<i>Mdn</i>	
				Bibliotherapy Group	Control Group
Overall					
empowerment	1582.00	-1.18	.24	2.98	2.92
Quality of life	1534.00	-1.68	.09	77.38	69.50
Overall distress	1191.50	-.43	.67	13.00	14.00
Anxiety	1216.50	-.16	.87	7.00	7.00
Depression	1191.00	-.44	.66	5.00	4.00

Note. *Mdn* = medium score; *W* = Wilcoxon W

Table A2

Between Group Analyses Showed that Empowerment, at Post-assessment, is Statistically Different Between the Treatment and Control Group

	<i>W</i>	<i>Z</i>	Sig.	<i>Mdn</i>	
				Bibliotherapy Group	Control Group
Empowerment	1620.50	-2.36	.018*	3.13	2.96
Quality of life	1693.50	-1.65	.099	76.00	71.00
Overall distress	1257.50	-1.17	.24	11.50	12.00
Anxiety	1297.50	-.78	.44	6.00	7.00
Depression	1214.50	-1.59	.11	3.00	4.34

Note. *Mdn* = medium score; *W* = Wilcoxon *W*

* $p < .05$. ** $p < .01$.

Table A3

Between Group Analyses Showed that at the Follow-up, the Treatment Group Differs From the Control Group on All Outcome Measures

	<i>W</i>	<i>Z</i>	Sig.	<i>Mdn</i>	
				Bibliotherapy Group	Control Group
Empowerment	1405.00	-3.05	.002**	3.10	2.98
Quality of life	1398.50	-3.11	.002**	83.00	69.50
Overall distress	994.00	-2.38	.017*	8.00	12.50
Anxiety	956.00	-2.80	.005**	4.00	7.00
Depression	1013.50	-2.31	.02*	3.00	6.00

Note. *Mdn* = medium score; *W* = Wilcoxon W

* $p < .05$. ** $p < .01$.

Within Group Analyses

T-test analyses were conducted to evaluate within group differences at the pre, post and follow-up assessment points. The analyses confirmed statically significant differences in empowerment in the bibliotherapy group at post assessment (see Table A4). Also, empowerment, quality of life and distress were statistically different at follow-up in the bibliotherapy group (see Table A5). No statistical differences were noted in the control group.

Table A4

Within Group Analysis for Outcome Measures at the Pre-Post-Assessment in Both Groups

Variable	Bibliotherapy group (N=34)			Control group (N=46)			Effect Size (Cohen's D)
	Pre Mean (SD)	Post Mean (SD)	t value	Pre Mean (SD)	Post Mean (SD)	t value	
Empowerment	3.00 (.31)	3.13 (.26)	-2.71*	2.92 (.42)	2.91 (.42)	.26	.63
Quality of life	75.62 (15.00)	75.25 (14.95)	.20	70.73 (15.27)	69.33 (16.26)	.74	.38
Overall distress	12.44 (5.26)	10.91 (7.09)	1.82	13.17 (6.83)	12.93 (7.32)	.30	-.28

Note. SD = standard deviation* $p < .05$

Table A5

Within Group Analysis for Outcome Measures at the Pre- 1-Month Follow-up in Both Groups

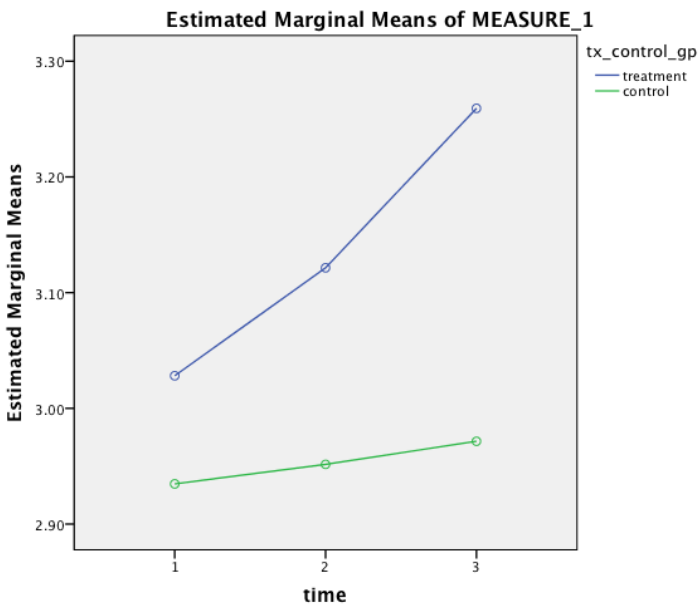
Variable	Bibliotherapy group (N = 32)			Control group (N = 44)			Effect Size (Cohen's D)
	Pre Mean (SD)	Follow- up Mean (SD)	t value	Pre Mean (SD)	Follow- up Mean (SD)	t value	
Empowerment	3.03 (.34)	3.25 (.35)	-3.63**	2.93 (.44)	2.91 (.45)	.33	.84
Quality of life	77.14 (12.87)	82.31 (11.88)	-3.13**	71.21 (15.40)	70.25 (16.35)	.57	.84
Overall distress	11.97 (4.99)	9.44 (4.68)	3.69**	12.89 (6.82)	12.99 (6.25)	-.15	-.64
Anxiety	7.37 (3.63)	5.00 (3.01)	6.24***	7.77 (4.09)	7.64 (4.10)	.32	-.73
Depression	4.59 (2.96)	3.50 (2.58)	2.26*	5.11 (3.76)	5.58 (3.88)	-1.17	-.63

Note. SD = standard deviation* $p < .05$. ** $p < .01$. *** $p < .001$.

Repeated Measures ANOVA

A repeated measures analysis of variance (ANOVA) was conducted to corroborate the findings reported in Study 2. The results of the repeated measures ANOVA showed that a main effect for time was significant, Wilks Lambda = .85, $F(2, 62) = 5.51$, $p = .006$. This indicates there was a change in empowerment scores across the three time points. The effect size for this result, reported as partial eta square, is .15 (large effect). Additionally, statistically significant between subject effects were found [$F = 4.91$, $p = 0.03$], which suggests that the groups are statically different, i.e. empowerment scores were different according to group assignment. The partial eta squared was .72 a large effect size. Lastly, levels of empowerment were significantly different between pre assessment to follow-up in the intervention group ($p = .01$).

Profile Plots for Empowerment Score



Appendix B - Interview guide

Thank you for agreeing to take part in this interview. I will be asking you questions about your experience taking part in this study, and there are no right or wrong answers... all information you share is helpful.

Is it okay if I tape this interview so I can listen to what you say instead of having to take notes?

To begin, can you please share...

How did you decide to participate in this study?

How did you proceed with reading the book?

Why did you choose to do it that way?

How did it feel while you were doing it?

How has the intervention/reading the workbook impacted your life?

Probe for impact on:

level of stress

ability to handle/cope with stress

feeling more in control/ empowered

over-all quality of life

What was the most helpful about the intervention?

What was the least helpful about the intervention?

What would you suggest we do to improve the intervention?

Did you complete the homework exercises?

if YES - How did you find the practice/homework exercises?

probe: easy/hard - prefer more/less

if NO – Can you tell me, what prevented you from doing the homework exercises?

If someone else with cancer asked about your opinion on this book, what would you tell them?

Is there anything about your experience with the intervention that you think is important that I have not asked about?

Thank you for your time!