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Empowering survivors after colorectal and lung cancer treatment: Pilot study of a Self-Management Survivorship Care Planning intervention



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ABSTRACT

Purpose: This study evaluates the feasibility and acceptability of a Self-Management Survivorship Care Planning (SM-SCP) intervention in colorectal and lung cancer survivors.

Methods: This is a single-group, pre- and post-mixed methods study of an advance practice nurse-driven survivorship care intervention that integrates a survivorship care plan with self-management skills coaching. Colorectal and lung cancer survivors with stage I-III disease were enrolled at 3–6 months after completing treatments, and the intervention was administered in one in-person or telephone session. Survivor outcome measures included depression, anxiety, self-efficacy, QOL, and satisfaction. Paired *t*-tests were used for exploratory evaluations of pre-to post-intervention score changes. Content analysis was conducted to analyze the qualitative data to describe survivors' experience with the intervention. *Results:* Thirty participants (15 colorectal, 15 lung) enrolled and completed the study (73% retention). It took an average of 40 min to complete the TS/CP and 34.2 min to deliver the intervention. Exploratory analysis revealed significant differences from baseline to post-intervention in depression, anxiety, self-efficacy, physical functioning, role limitations-physical, pain, general health, health transition, physical health summary, and total QOL. Three qualitative themes emerged: 1) Feeling empowered about having a plan; 2) Struggling with psychosocial concerns; and 3) Suggestions for intervention content and delivery.

Conclusions: The SM-SCP intervention was feasible and acceptable for colorectal and lung cancer survivors after treatment completion. Survivorship care interventions have potential to fulfill the unmet needs of colorectal and lung cancer survivors. Their effectiveness might be greater by integrating conceptually-based models of care, such as self-management skills building.

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1. Introduction

The need for evidence-based models of comprehensive survivorship care that address long-term survivorship issues has been

the subject of numerous Institute of Medicine (IOM) reports (Hewitt et al., 2006). Survivorship care planning is considered an essential component of high-quality cancer care (Levit et al., 2013). The American Society of Clinical Oncology (ASCO) has developed and endorsed the use of treatment summary/care plans (TS/CPs) as a vehicle to guide personalized survivorship care planning (McCabe et al., 2013). The American College of Surgeon's Commission on Cancer (CoC) has included requirements related to the provision of TS/CPs into their Cancer Program Standards (American College of Surgeons, 2012).

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Despite the endorsements, guidelines, and standards, there remains a critical paucity in empirical evidence for the value of survivorship care planning on outcomes. This gap in evidence and various barriers associated with delivering TS/CPs has resulted in the slow integration of survivorship care into routine oncology care. Current evidence suggests that the development and preparation of TS/CPs is resource-intensive, lacks evidence-informed integration with technology platforms, and lacks clear reimbursement mechanisms (Parry et al., 2013). The slow uptake of survivorship care planning can be attributed, in part, to the challenges associated with their development and implementation into diverse contexts and settings (Mayer et al., 2015b; Parry et al., 2013; Selove et al., 2016).

Colorectal and lung cancer survivors are underrepresented in the survivorship literature. Colorectal cancer survivors experience bowel dysfunction, pain, fatigue, and sexual dysfunction that negatively affects their quality of life (QOL) (Bours et al., 2016; Gosselin et al., 2016; Sun et al., 2015, 2016; Walling et al., 2015). Among rectal cancer survivors, permanent colostomies represent a major life adjustment (McMullen et al., 2016; Sun et al., 2013; Wright et al., 2015). Colorectal cancer survivors are also less likely to receive appropriate preventive and co-morbid condition care (Hardcastle et al., 2017; Lafata et al., 2015; Sun et al., 2014). Lung cancer survivors have impaired pulmonary functions, and symptoms such as chronic pain, psychological distress, cough, fatigue persisting following treatment (Kenzik et al., 2015; Kim et al., 2016; Oksholm et al., 2015). Large population-based studies have estimated that the rate of smoking among survivors to be at least 20% (Shiels et al., 2014; Yang et al., 2015). Only 45% of survivors were meeting 5-a-day recommendations for fruit and vegetable consumption (Zhang et al., 2015). Survivor adherence to physical activity recommendations ranges from 30% to 52% (Kohler et al., 2016).

A primary goal of comprehensive survivorship care is to inform survivors about the types of treatments received, anticipate late and long-term effects of treatment, and how to maintain health and well-being after treatment (Jacobsen et al., 2016). Although intended to reduce care fragmentation and facilitate care coordination, survivorship care should also enable and empower survivors to participate in their own care. Providing information about ongoing care as part of survivorship care planning could potentially foster confidence in self-management by helping survivors monitor for late and long-term effects, successfully adopt healthy living behaviors, and undergo appropriate surveillance and screening. The primary purpose of this mixed-methods, single group, pre- and post-intervention pilot study was to describe the feasibility and acceptability of an advanced practice nurse (APN)-driven Self-Management Survivorship Care Planning (SM-SCP) intervention in colorectal and lung cancer. Qualitative data were collected to provide contextual information about feasibility and survivors' experience with the intervention. A convergent-parallel mixed methods design was used to gain a better understanding of the intervention so it can be refined for a larger randomized study. Exploratory aims were to examine trends in survivor-specific outcome scores pre- and post-intervention.

2. Methods and materials

2.1. Study design

The study design and outcomes selection were guided by a modified version of Parry et al.'s Conceptual Framework for Survivorship Care Planning Research (Parry et al., 2013). The concentric circles represent key components of the SM-SCP (Fig. 1). At the center of the circle is the TS/CP, which serves as the document that

guides survivorship care and transitions from active treatment to surveillance. The delivery and implementation of TS/CPs involve three key constructs: the process of care, the model of care, and the use of technology platforms. The process of care refers to how key stakeholders (i.e. survivors and providers) interact within a given care system. The quality of these interactions is thought to affect survivor and system level outcomes through the intermediary constructs of care coordination and the quality of patient/provider communication (Parry et al., 2013). For the SM-SCP, APNs served as a vital link for care coordination and communication between survivor and oncologists. The model of care defines the target population, setting, and way the care is organized. Our intervention is disease-specific and follows the principles of integrated survivorship care where post-treatment care is provided in the same clinical setting and location where survivors received their treatments. Preliminary evidence suggests that this model of care is preferred by oncologists and survivors (Klemanski et al., 2016) and facilitates communication and efficient care transitions. The incorporation of technology can facilitate the preparation of TS/CPs, which can be resource-intensive. We used a simple and basic approach for electronic TS/CP development through Adobe PDF templates completed using tablets. Implementation, system and process-specific outcomes include recruitment, retention, time to complete TS/CPs, time to administer the intervention, and measures of resource utilization. Survivor outcome measures include intervention acceptability, depression, anxiety, self-efficacy, and OOL.

2.2. Intervention design

The SM-SCP is based on the Chronic Care Self-Management Model (CCM) in which providers form partnerships with survivors to enable them to assume a more active role in managing their symptoms and achieving their goals of care (McCorkle et al., 2011). Self-management can empower cancer survivors to report and manage potential late and long-term effects of treatment, understand when to seek support, and make lifestyle changes to promote healthy living after treatment (Foster and Fenlon, 2011). The CCM model addresses survivors' goals/preferences and fosters confidence in their ability to perform care activities (Rosenberg et al., 2015). It coaches survivors on key self-management skills such as problem-solving, decision-making, taking action or goal-setting, communication with providers, regular assessment of progress, and resource utilization (Klabunde et al., 2017). Improvements in self-efficacy are likely necessary for improvements to occur in other key outcomes such as QOL and health care resource utilization. The current evidence on CCM models of care supports this concept (McCorkle et al., 2011). Evidence for this mechanism is found in studies with chronic illnesses such as COPD, diabetes, and more recently, cancer patients (Risendal et al., 2014a, 2014b; Salvatore et al., 2015).

The SM-SCP intervention is a multi-component model of survivorship care. It includes the following: 1) preparation of a personalized TS/CP, and 2) provision of the document through one post-treatment review session using self-management principles to support survivor self-efficacy. The APNs reviewed the personalized TS/CP with patients, but also incorporated self-management approaches to engage survivors. Behavioral approaches such as goal setting, problem-solving skills building and self-monitoring skills for late and long-term effects were used. The TS/CP was developed based on IOM recommendations (Hewitt et al., 2006) and existing ASCO templates. Two versions were developed: 1) a shorter TS/CP for providers in response to their preference for a brief, treatmentfocused version; and 2) a TS/CP for survivors that includes additional content to support self-management skills building (i.e.

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