

Living with a stoma after surgical resection for rectal cancer: An interpretive phenomenological
study to understand how stomas can affect physical activity

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Abstract

The benefits of physical activity for cancer survivors are numerous and well-substantiated. However, it is unclear how to accommodate specific cancer treatments, such as a stoma as part of treatment for rectal cancer, in order to be physically active. To bridge this gap, this study undertook an interpretive phenomenological analysis to explore the experience of 15 rectal cancer survivors' engagement in physical activity with a stoma. Overall, three themes were found: 1) *understanding the drive and the motivation to be physically active*, 2) *despite being motivated to be physically active with a stoma it can be challenging*, and 3) *how to be physically active with a stoma: lessons learned*. The findings suggest rectal cancer survivors with a stoma require motivational support and enhanced competence and self-efficacy in order to engage in greater physical activity. Incorporating these skills into current information and supportive services targeting rectal cancer survivors with a stoma may help promote physical activity in this population.

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Chapter 1: Introduction

An estimated two in five adults living in Canada are diagnosed with cancer each year (Canadian Cancer Society [CCS], 2017a). Of these, approximately 60% are expected to live more than 5 years after completion of acute treatment (CCS, 2017a). Despite this improved prognosis, it is likely that cancer survivors (i.e., from diagnosis onwards; National Cancer Institute, 2017) will experience both short-term side effects of treatment, such as reduced physical and psychosocial functioning (Shapiro & Recht, 2001; Siegel et al., 2012), along with possible late and long-term effects that may continue into their survivorship (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013; Stein, Syrjala, & Andrykowski, 2008). In an effort to offset the negative side effects of treatment, researchers have examined and suggested various supportive care strategies (Howell, Harth, Brown, Bennett, & Boyko, 2017). There is now consistent evidence that engagement in physical activity can help alleviate these negative effects and improve health and quality of life (QoL; Rock et al., 2012; Sabiston & Brunet, 2012; Schmitz et al., 2010; Speck, Courneya, Mâsse, Duval, & Schmitz, 2010).

Nevertheless, most adults are physically inactive or insufficiently active during and after cancer treatment (Littman, Tang, & Rossing, 2010; Neil, Gotay, & Campbell, 2014; Rohan, Townsend, Fairley, & Stewart, 2015). Potential explanations for this may be due to treatment-related concerns, environmental challenges, and psychosocial distress, which may interfere with survivors' ability and/or desire to engage in physical activity (Blaney, Lowe-Strong, Rankin-Watt, Campbell, & Gracey, 2013a; Brunet, Taran, Burke, & Sabiston, 2013; Wurz, St-Aubin, & Brunet, 2015). Accordingly, researchers have developed targeted strategies that can help adults diagnosed with cancer overcome these concerns, helping cancer survivors to engage in physical activity (Mishra et al., 2012; Schmitz et al., 2010). However, these strategies do not always account for the disparate experiences of adults with different types of cancer and therefore

cannot be applied to all cancer survivors (Forbes, Blanchard, Mummery, & Courneya, 2014).

Cancer survivors living with a stoma (i.e., an opening on the abdominal wall for waste product to move out of the body) after surgical resection for rectal cancer may experience additional effects over-and-above typical treatment side effects, creating added concerns to engage in physical activity. For instance, these survivors may experience stoma-specific physical difficulties (e.g., gas, bloating, pain, constipation, diarrhea, ruptures; Cabilan & Hines, 2017; Vonk-Klaassen, de Vocht, den Ouden, Eddes, & Schuurmans, 2016), as well as greater psychosocial distress (e.g., stigma, embarrassment, isolation; Pachler & Wille-Jørgensen, 2012; Phelan et al., 2013). As a result, it is plausible that these added challenges may influence their ability and/or desire to engage in physical activity.

Furthermore, cancer survivors living with a stoma after surgical resection for rectal cancer are under-represented in the psycho-oncology literature exploring engagement in physical activity. In a recent qualitative meta-synthesis review of 40 articles exploring physical activity in cancer survivors, only two studies explored colorectal cancer survivors and among these there were no studies dedicated to exploring the impact of a stoma on physical activity (Burke et al., 2017). This is not surprising as rectal cancer survivors are often reported alongside colon cancer survivors and typically comprise less than 20% of colorectal samples in the literature (Cabilan & Hines, 2017; Cramer, Lauche, Klose, Dobos, & Langhorst, 2014; Wiskemann, Schommer, Jaeger, & Scharhag-Rosenberger, 2016). Moreover, although researchers are beginning to examine the safety and feasibility of physical activity in adults living with a stoma (Russell, 2017; Wiskemann et al., 2016), there is a paucity of published studies describing the in-depth experience of cancer survivors living with a stoma after surgical resection for rectal cancer and how a stoma affects survivors' engagement in physical activity throughout their treatment for rectal cancer.

Given that approximately one-third of colorectal cancer tumours diagnosed in Canada originate within rectal cancer tissue (CCS, 2017a) and that 70% of rectal cancer cases are likely to require a temporary or permanent stoma after surgical resection of their tumour (Porter et al., 2014), it is necessary to gain a better understanding of the impact living with a stoma has on rectal cancer survivors' engagement in physical activity. Therefore, the aim of this thesis was to undertake a qualitative study to describe the experiences of cancer survivors living with a stoma after surgical resection for rectal cancer and to understand the impact of a stoma on survivors' engagement in physical activity. These findings will inform the development of appropriate information and services promoting engagement in physical activity and health among this population.

Chapter 2: Review of the Literature

Physical Activity During Cancer Survivorship

There are over two decades of evidence suggesting engagement in physical activity is beneficial for adults before, during, and after treatment for cancer (McNeely et al., 2006; Rock et al., 2012; Sabiston & Brunet, 2012; Schmitz et al., 2010). Post-diagnosis, engagement in physical activity can improve recovery times after surgical resection of a tumour and reduce acute side effects from adjuvant treatments (i.e., chemotherapy and radiotherapy) such as fatigue, nausea, anxiety, and depression (Carli et al., 2017; Gillis et al., 2014; Sabiston & Brunet, 2012; Schmitz et al., 2010). Furthermore, engagement in physical activity post-treatment (i.e., > 5 years acute treatment completion) has been shown to decrease the risk of mortality, recurrence, and prevent comorbidities such as heart disease, obesity, and type 2 diabetes (Ballard-Barbash, George, Alfano, & Schmitz, 2013; Meyerhardt et al., 2006; Schmitz et al., 2010). For these reasons, physical activity is recognized as an complementary component of cancer care (Carli et al., 2017).

In light of this, various cancer organizations recommend cancer survivors engage in physical activity both during and after their cancer treatments (CCS, 2017b; Cancer Care Ontario [CCO], 2015). Despite these recommendations, in Canada only about 17-25% of cancer survivors are meeting CCS guidelines of engaging in physical activity at a moderate intensity for at least 30 minutes on most days of the week and engaging in resistance training on 2 days of the week (CCS, 2017b; Neil et al., 2014; Peddle, Au, & Courneya, 2008). Furthermore, researchers have recognized that cancer survivors are less physically active both during and after cancer treatment than age-matched healthy controls (Phillips et al., 2015; Rohan et al., 2015; W. Smith, Nolan, Robison, Hudson, & Ness, 2011).

To better understand the reasons for this, a growing body of literature is accumulating on

the contributing influences on engagement in physical activity (Blaney et al., 2013a; Brunet, Taran, et al., 2013; B. Smith & McGannon, 2017; Wurz et al., 2015). Researchers have reported common challenges cancer survivors face to engaging in physical activities, such as, physical restrictions (e.g., pain, fatigue), psychological concerns (e.g., anxiety, depression), and social issues (e.g., isolation; Blaney et al., 2013a; Brunet, Taran, et al., 2013; B. Smith & McGannon, 2017; Wurz et al., 2015). For example, in a qualitative study by Wurz et al. (2015) the authors identified situational factors involving competing roles and responsibilities and issues with the distance of the exercise centre, along with internal factors stemming from cancer-specific limitations, as contributing to poor engagement in physical activity among breast cancer survivors. Brunet, Taran, et al. (2013) found similar challenges in this population, where physical factors as a result of challenges with treatment, psychosocial factors such as lack of motivation and poor confidence, and environmental and organizational factors all played a role in limiting engagement in physical activity. Furthermore, in a needs assessment, Blaney et al. (2013a) identified the top 10 factors that interfered with engagement in physical activity among a mixed sample of cancer survivors. Collectively, these studies look deeper into aspects that may facilitate better physical activity service development. However, most of the evidence on the impact of cancer on adults' physical activity has emerged from studies focusing on breast cancer and prostate cancer (Burke et al., 2017; Schmitz et al., 2010), which may not be representative of the types of treatment challenges those with other cancers face.

Although it is known that living with a stoma may present physical and psychosocial challenges we are unaware of the impact this has on adults' engagement in physical activity. As extrapolating findings from one sample to another is not recommended (Rothwell, 2005), especially given the known differences in the challenges faced by adults with different types of cancer (Forbes et al., 2014), it is imperative to study how the unique side effects associated with

the different treatments for specific types of cancers impact cancer survivors' ability and/or desire to engage in physical activity. Given that over 70% of adults diagnosed with rectal cancer will have a stoma placed after surgical resection (Porter et al., 2014), further research into how adults experience living with a stoma and how this affects their engagement in physical activity is needed in order to develop appropriate information and services for these adults.

Surgical and Adjuvant Treatment for Rectal Cancer

Typically, rectal cancer survivors first undergo neoadjuvant chemoradiation therapy (NACRT) prior to surgery in order to control disease spread, shrink tumours, and improve operation success (West et al., 2014). NACRT can lead to increased fatigue, pain, and insomnia, as well as reduced physical and social functioning in these adults (Pucciarelli et al., 2011; West et al., 2014). Following NACRT, rectal cancer survivors typically undergo surgical treatment to remove tumours and cancerous tissues (CCS, 2017c). The three main surgical procedures for rectal cancer are local excision of cancer, lower anterior resection (LAR), and abdominoperineal resection (APR). The medical oncology team decides on the necessary surgical procedure based on the location of the tumour, the stage of the cancer, and compounding factors (e.g., health status, sphincter function), with the goals being prevention of local recurrence and improved survival (Chand, Nash, & Talbot, 2008; Stewart & Dietz, 2007). After surgery, survivors typically undergo adjuvant treatment consisting of chemotherapy and/or radiation, along with long-term follow-up care of regular appointments and check-ups. The stage, grade, and size of the tumour can all impact the different treatments rectal cancer survivors receive, and consequently impact adults' health behaviours differently.

In examining a cross-section sample of colorectal cancer survivors, Lynch, Cerin, Newman, and Owen (2007) found that surgical treatment was a significant predictor of participating in sufficient physical activity. Specifically, having a stoma and undergoing adjuvant

therapy were linked to less time spent in physical activity. As rectal cancer survivors undergo different types of treatments, understanding the unique treatment protocols of rectal cancer is important to appreciate why this group warrants research attention. Therefore, each surgical procedure is described in greater detail below to provide context for understanding the rectal cancer experience and to highlight the additional challenges this population may face.

Local excision of cancer without removal of the surrounding lymph nodes. Local excision is performed on approximately 36% of stage I cases, and among older adults and those not fit for major surgery due to pre-existing health issues (Chand et al., 2008; You, Baxter, Stewart, & Nelson, 2007). The surgeon enters through the anus and removes the cancer along with superficial tissue surrounding the cancer. Since the excision is only in superficial tissue, this surgery does not require the placement of a stoma and leads to a shorter hospital stay. Adults undergoing this procedure experience less pain than other surgical procedures and can often resume regular diet and activity within 24 hours (Althumairi & Gearhart, 2015).

Restorative anterior or low anterior resection (LAR). This type of surgery is performed in some early, but most mid-late stage rectal cancers that are localized in the rectum. The surgeon creates an incision along the abdomen and removes the upper two-thirds of the rectum and in some cases the lower third of the sigmoid colon, depending on the location and stage of the cancer. The surrounding blood vessels and lymph nodes are removed as part of a safety margin to prevent local recurrence. The lower colon is then connected to the remaining rectum to resume bowel continuity. In such cases, a temporary stoma is placed to protect the new bowel connection. Approximately 12 months after the initial stoma placement, the temporary stoma is then reversed (CCS, 2017c). While living with a stoma, a collection bag is placed around the stoma for waste disposal and changed approximately every 2 to 4 days. Hospital stays for LAR are typically 5 to 7 days and adults may experience an adjustment period of 3 to 5

months post-stoma closure before typical body functions can be anticipated (Chand et al., 2008). Overall, approximately 33% of rectal cancer survivors will have a temporary stoma placed following LAR (Porter et al., 2014).

Abdominoperineal (pelvic) resection with a permanent colostomy (APR). APR is used for later stage rectal cancer and cancers found in the rectum, anus, or the surrounding sphincter tissues (Stewart & Dietz, 2007). This procedure consists of the full removal of the rectum, anus, and sphincter tissues along with a safety margin. Since the anus has been removed, the colon is connected to the left side of the abdominal wall to create a permanent stoma. This stoma is connected to an ostomy bag and will permanently function as the exit for bowel movements. Depending on the stoma system in place, the bags may need to be emptied every day or replaced approximately every 2 to 4 days. Hospital stays for APR are typically between 7 to 10 days, and self-care for stomas has been shown to improve over time (Lynch, Owen, Hawkes, & Aitken, 2010), with commonly reported adjustment periods for permanent stomas between 3-5 months (Anderson, Caswell, Wells, Steele, & MacAskill, 2010). In general, approximately 37% of rectal cancer survivors will have a permanent stoma placed (Porter et al., 2014).

As over 70% of rectal cancer survivors will experience a stoma at one point in their treatment trajectory, it is crucial to understand the impact a stoma may have on survivors' engagement in physical activity in order to better aide survivors' adjustment to living beyond cancer.

The Impact of Stomas

Advances in the treatment of rectal cancer, such as the placement of a stoma, have been imperative for improving long-term survival in rectal cancer survivors (Heald & Ryall, 1986; MacFarlane, Ryall, & Heald, 1993). Although lifesaving, these same treatments may lead to

higher psychosocial distress in rectal cancer survivors. Despite the paucity of literature in rectal cancer survivors, other populations who have a stoma placed as treatment for various ailments (e.g., Crohn's disease patients, patients with inflammatory bowel disease) demonstrate higher levels of psychosocial distress than healthy controls (Knowles, Cook, & Tribbick, 2013; McMullen et al., 2008; Pachler & Wille-Jørgensen, 2012). Often this is manifested through increases in depression, anxiety, negative body image, and poor social functioning (Chongpison et al., 2015; Knowles et al., 2013; Pachler & Wille-Jørgensen, 2012; Vonk-Klaassen et al., 2016). Furthermore, as a result of embarrassment over strong odour, leakage, constraints on clothing, concerns with travelling privacy, and social stigma attached to stoma placement adults often experience shame and disgust attached to their disease (Krouse et al., 2009; Mols, Lemmens, Bosscha, Broek, & Thong, 2014; Reynolds, Consedine, Pizarro, & Bissett, 2013; Vonk-Klaassen et al., 2016). Emphasizing the challenging nature of living with a stoma, Phelan et al. (2013) found that over 30% of male colorectal cancer survivors felt at least one stigma associated with their disease (i.e., people avoiding them, awkward and tense around adults with colorectal cancer, others think less of them), while one in four reported self-blame for their cancer. This is concerning, as the presence of stigmas and self-blame are associated with more frequent symptoms of reduced confidence and increased social isolation (Desnoo & Faithfull, 2006; Krouse et al., 2009; Phelan et al., 2013). On account of the social nature of physical activity and the barrier that stigma poses to being physically active in healthy populations (Martin Ginis, Bassett-Gunter, & Conlin, 2012), it is plausible that the negative psychosocial effects from living with a stoma may contribute to the low rates of physical activity engagement in rectal cancer survivors (Forbes et al., 2014; van Putten et al., 2016). Yet, there has been little published research describing the experiences of cancer survivors living with a stoma from rectal cancer and how it affects their engagement in physical activity.

Findings from studies focusing on physical function provide indirect evidence that living with a stoma can interfere with engagement in physical activity (Nichols, 2015). For instance, bowel movement irregularities, leaks, diarrhea, gas, unpredictability, and general bowel and gastrointestinal discomfort create a range of adverse effects on physical capabilities (Anderson et al., 2010; McGrath et al., 2017; McMullen et al., 2008; Mols et al., 2014; Vonk-Klaassen et al., 2016). Further impingements on physical functioning with a stoma involves dealing with stoma care, where bags are often heavy and bindings lead to skin irritations (Mahjoubi, Goodarzi, & Mohammad-Sadeghi, 2010; McMullen et al., 2008). This can be exacerbated by the anatomical location of a stoma and body mass which may restrict movement ability, increase levels of insomnia, increase the number of leaks, and, in some cases, may lead to pain during daily movement (Mahjoubi et al., 2010; McMullen et al., 2008; Schmitz et al., 2010; Skeps et al., 2013). Moreover, due to the invasive nature of stoma surgery, researchers report that long-term health concerns such as poor recovery from the surgery leading to complications, fainting, risks of hernia, and concern over tearing of healing tissues are all challenges to physical function (McGrath et al., 2017; McMullen et al., 2008; Sun et al., 2013; Vonk-Klaassen et al., 2016). In light of these physical limitations resulting from treatment, it is possible that rectal cancer survivors may avoid physical activity to prevent discomfort or future health complications from arising. Therefore, it is important to gain deeper insight to learn how to help cancer survivors living with a stoma after resection for rectal cancer engage in greater physical activity, thus alleviating treatment side effects in this population.

It is also important to consider that the experiences for survivors living with a temporary stoma may not be the same as survivors living with a permanent stoma. Indeed, in a qualitative study by Siassi, Hohenberger, Lösel, and Weiss (2008) participants living with a temporary stoma indicated they increased their amount of time spent in leisure activities after stoma closure

. Neuman, Park, Fuzesi, and Temple (2012) found similar results, whereby the assurance of having a stoma reversed led to feelings of relief in adults diagnosed with rectal cancer and allowed them to feel as though they could move past their cancer to pursue their interests of leisure. However, it is unclear whether the evidence suggests that survivors living with a temporary stoma fare better than those living with a permanent stoma. A Cochrane review of 35 non-randomized trials by Pachler and Wille-Jørgensen (2012) reported no significant differences in overall QoL between adults living with temporary stomas compared to those living with permanent stomas. As physical activity plays an important role in improving QoL in cancer survivors, exploring the effects a temporary versus permanent stoma has on engagement in physical activity will better inform the supportive care needs in cancer survivors living with a stoma after surgical resection for rectal cancer.

Stomas and Physical Activity

To date, there are only two studies exploring physical activity in adults living with a stoma. The first is a single subject case study by Wiskemann et al. (2016) which tested the safety and feasibility of exercising under direct supervision, with the goal of returning to work as a firefighter, after receiving a permanent stoma as treatment for rectal cancer. After 6 months of training, the authors reported an overall improvement in physical fitness parameters (i.e., cardiorespiratory fitness, peak power output), along with an improvement in indicators for QoL, (i.e., fatigue, distress). Further, upon completion of training the participant passed an occupational fitness test and resumed his previous employment. One noteworthy aspect of this study was that despite an aim to attend three to five sessions a week, the participant was only able to attend one to three sessions per week after experiencing fatigue, muscle soreness, and an upper respiratory tract infection. Further, the participant found it meaningful to engage in discussions about his disease with a psychosocial counsellor external to the fitness program,

suggesting psychosocial factors need to be considered when offering a physical activity program. In the second study by Russell (2017), the author delivered an online mixed survey of closed and open-ended questions to 2,631 respondents living with a stoma from various underlying conditions (i.e., ulcerative colitis, colorectal cancer, and Crohn's disease) with the goal of examining the barriers to physical activity after stoma placement. Russell's (2017) main findings included: younger adults engaged in greater levels of physical activity when compared to older adults, higher levels of engagement in physical activity lead to improved perceptions of overall QoL, and that perceived risk of a hernia, concerns over the potential of a leaking bag, and a perceived lack of physical activity guidelines were among the most prevalent limitations to physical activity. Interestingly, Russell (2017) was able to tease apart different physical activity patterns depending on the underlying cause of the stoma, namely that adults who had a stoma placed as part of treatment for cancer were significantly less active than their non-cancer counterparts after stoma placement. Notwithstanding the meaningful contributions of these two studies, it is important to recognize the unique experience of having a stoma placed as a result of resection for rectal cancer since these survivors face additional demands due to the cancer treatment course. Thus, an in-depth exploratory study offers insight into the influence a stoma has on engagement in physical activity in rectal cancer survivors.

The Current Study

There is now consistent evidence that physical activity helps to improve recovery and overall health in cancer survivors (Sabiston & Brunet, 2012; Schmitz et al., 2010). Yet, it is clear that cancer survivors are not sufficiently physically active and, as a result, various strategies have been employed to give more assistance to survivors during and after cancer treatment to help them adjust to treatment-related effects and promote health. However, cancer survivors living with a stoma after surgical resection for rectal cancer may not be adequately represented in this

literature (Burke et al., 2017; Cabilan & Hines, 2017). In addition, a lack of knowledge on the impact of living with a stoma on survivors' experiences of physical activity prevents the development of tailored and appropriate physical activity information and services. As such, there have been multiple calls to develop tailored physical activity information and services for this population (Cabilan & Hines, 2017; Russell, 2017; Wiskemann et al., 2016). To this end the aim of this thesis was to undertake a qualitative study to explore the experiences of cancer survivors living with a stoma after surgical resection for rectal cancer and understand the impact of a stoma on their participation in physical activity.

Study Objectives

We sought to describe the experiences of cancer survivors living with a stoma after surgical resection for rectal cancer and to understand the impact of their stoma on their physical activity engagement in order to inform the development of appropriate information and services promoting physical activity.

Study Design and Approach

The specific approach to inquiry well-aligned to the objectives of our study was an interpretive phenomenological approach (IPA; J. Smith, Flowers, & Larkin, 2009). IPA was chosen as the guiding framework because of the emphasis the framework places on capturing and analyzing personal, intimate, in-depth experiences of a particular phenomenon which is best suited to exploring the experiences of cancer survivors. Further, IPA is largely underpinned by the influence of hermeneutics, the study of interpretation, whereby participants' accounts reflect their attempt to interpret, or make sense of, their experience as they are embedded and immersed in the world around them. These accounts are then further explored through an idiographic analyses, thus conclusions reported from the data are detailed individual cases that create a holistic understanding of the phenomenon. In approaching the study from this perspective, we

were able to provide rich, detailed, and meaningful insight into a particular topic, in this case, the experience of cancer survivors living with a stoma after surgical resection for cancer rectal cancer and to understand the impact of their stoma on their physical activity engagement.

As IPA is a methodology, rather than just a method, we used it as the guiding philosophic framework. Specifically, IPA was the foundation of the epistemological and ontological evaluations of our study, as we pursued a phenomenological focused study (J. Smith & Eatough, 2012; J. Smith et al., 2009; Starks & Trinidad, 2007). In addition, IPA informed our selection of participants, where we chose a homogenous sample of adults living with a stoma after surgical resection for rectal cancer with maximal variation. IPA also served as the basis for our sampling strategy, as we used a purposeful sample technique by recruiting only adults living with a stoma after surgical resection for rectal cancer who could offer rich information about their experiences. The data was collected in line with an IPA framework via qualitative in-depth interviews in which our participants' experiences were explored through broad questions with targeted probes. Last, we used an IPA guided thematic analysis to analyze the data. This was achieved through an idiographic focused thematic analysis, whereby each interview was explored in-depth independently, painting a rich, contextualized, and holistic interpretation of each participants' experience prior to patterning the outcomes across all participants (Braun & Clarke, 2006; J. Smith & Eatough, 2012; J. Smith et al., 2009).

Chapter 3: Article

This chapter presents the manuscript that emanated from the results of this Master's thesis. It has been formatted and submitted to the *Journal of Cancer Survivorship*. We feel this article fits well within the scope of this peer-reviewed journal as the manuscript offers insight into supportive care therapy that complements basic cancer care.

Authors' Contributions

Stephanie Saunders, BA, conceptualized this study, recruited participants, collected data, analyzed the data, and interpreted the results. She also drafted and revised the manuscript.

Jennifer Brunet, PhD, contributed substantially to the study conception and design, supervised the first author and mentored on data analysis, helped interpret the results, reviewed drafts of the manuscript, provided critical feedback, and approved final version to be published.

Title Page

Title: A qualitative study exploring what it takes to be physically active with a stoma after surgery for rectal cancer

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Abstract

Purpose: Rising survival rates suggest adults must increasingly cope with the adverse effects of cancer and its treatments, which may limit their participation in health-enhancing behaviours such as physical activity. Furthermore, the placement of a stoma may cause additional challenges to being physically active. This study aimed to explore the experience of rectal cancer survivors who were living with a stoma and the impact this has on their participation in physical activity.

Methods: This study followed an interpretive phenomenological analysis (IPA) to provide detailed examinations of 15 rectal cancer survivors' personal lived experience. Participants took part in a semi-structured interview post-chemotherapy.

Results: Three themes captured participants' personal lived experience: (1) *understanding the drive and motivation to be physically active*, (2) *despite being motivated to be physically active with a stoma, it can be challenging*, and (3) *how to be physically active: lessons learned*.

Conclusions: Participants' accounts offered insight into the motivating and challenging experiences they faced from cancer and its treatments.

Implications for cancer survivors: Current programs and services offered for cancer survivors to be more physically active may neglect the needs of those who have a stoma from cancer.

Integrating cancer-specific needs with strategies discussed by study participants may better support cancer survivors' choice to be physically active, thus improving their quality of life after cancer.

Keywords: cancer, physical activity, stoma, ostomy,

Introduction

It is estimated that 1 in 2 Canadians will develop cancer within their lifetime (Canadian Cancer Society, 2017a). Although surgery, radiation therapy, and chemotherapy are credited with improving the prognosis of cancer survivors (i.e., from diagnosis onwards; National Cancer Institute, 2017), these common types of cancer treatments can cause adverse physical (e.g., chronic pain, cancer-related fatigue; Shapiro & Recht, 2001; Siegel et al., 2012; Stein et al., 2008) and psychosocial side effects (e.g., isolation, depression, anxiety; Jansen, Koch, Brenner, & Arndt, 2010; Stein et al., 2008). Besides reducing cancer survivors' quality of life, these side effects are associated with an increased risk of chronic comorbidities and mortality (Chan et al., 2015; Miller et al., 2016; National Cancer Institute, 2017).

A lack of physical activity can further increase the risk of chronic comorbidities and mortality among cancer survivors (Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005; Leach et al., 2015; Lynch & Leitzmann, 2017). Low levels of physical activity are associated with an increased risk of poor health, reduced physical and cognitive functioning, negative mood, and impaired quality of life among cancer survivors (Leach et al., 2015; Lynch & Leitzmann, 2017; Zimmer et al., 2016). Moreover, higher levels of physical activity are associated with reduced risk of cancer recurrence, cancer-specific mortality, and all cause-mortality (Meyerhardt et al., 2006). Although there is strong evidence that physical activity can be safely introduced during or after treatment for cancer and that there are many benefits to be gained from being physically active after a cancer diagnosis (Mishra et al., 2012; Sabiston & Brunet, 2012; Schmitz et al., 2010), many cancer survivors spend up to two thirds of their day being sedentary after treatment (Lynch, Dunstan, Vallance, & Owen, 2013). Furthermore, less than 24% meet recommendations

to accumulate 150 minutes of moderate intensity physical activity per week or 75 minutes of vigorous intensity physical activity per week (Lynch et al., 2016).

One potential explanation for the low levels of physical activity among cancer survivors may be that they must overcome a number of general (e.g., lack of social support, cost, and lack of motivation) and treatment-related barriers to physical activity (e.g., cancer-related fatigue, deconditioning from treatment, physical pain from surgery, weakened immune system from treatment; Blaney, Lowe-Strong, Rankin-Watt, Campbell, & Gracey, 2013b; Brunet, Taran, et al., 2013; Wurz et al., 2015). Moreover, because some cancer survivors require either a temporary or permanent stoma (i.e., an opening on the abdominal wall for fecal waste to move out of the body, also called an ostomy; Porter et al., 2014), they may experience additional physical and psychosocial barriers to physical activity (Chongpison et al., 2015; Desnoo & Faithfull, 2006; Krouse et al., 2009; Mols et al., 2014; Neuman et al., 2012; Pachler & Wille-Jørgensen, 2012; Phelan et al., 2013). For example, they may fear adverse physical events (e.g., injury, herniation, gastrointestinal incidents such as fecal incontinence, reduced abdominal stability), have psychosocial problems (e.g., be dissatisfied with their appearance, worry about noises from the stoma), and have uncertainty with regard to the safety of physical activity. However, these potential barriers have not been well-characterized to date among cancer survivors requiring either a temporary or permanent stoma (Russell, 2017; Wiskemann et al., 2016). Understanding the impact of a stoma on cancer survivors is important to inform the development and design of tailored physical activity training programs and services.

The objective of this exploratory qualitative study was to gain insight into the experiences of cancer survivors living with a temporary or permanent stoma and understand the impact of a stoma on their engagement in physical activity. Stomas are relatively frequent in

colorectal cancer survivors, with a rate of up to 35% a year after surgery (Sun et al., 2013; Vonk-Klaassen et al., 2016). Given the lack of understanding of rectal cancer survivors' experiences with physical activity relative to colon cancer survivors (Cabilan & Hines, 2017; Cramer et al., 2014), coupled with data showing that rectal cancer survivors are more likely to have a stoma than other cancer survivors (Porter et al., 2014) and that 76% are not regularly active (Lynch et al., 2016), the current study focused on rectal cancer survivors.

Methods

Participants

Following an interpretive phenomenological analysis (IPA; Smith & Eatough, 2012; Smith, Flowers, & Larking, 2009), a purposive sample of rectal cancer survivors were invited to take part in this study. They were sampled to include a maximum variation of age, sex, and treatment status. Survivors were eligible if they: (1) were at least 18 years of age, (2) were able to read and speak English, (3) had been diagnosed with non-metastatic rectal cancer, (4) had undergone surgery for the placement of a stoma, (5) had completed chemotherapy, and (6) were cleared to participate in physical activity by a member of their circle of care.

The sample was composed of 15 rectal cancer survivors who were between 34 to 71 years of age ($M = 59$, $SD = 8.8$). The majority of participants were male (73%; $n = 11$), White (87%; $n = 12$), had a body mass index (BMI) under 30 kg/m² (67%, $M = 27$; $SD = 5.2$), were married or living with a partner (67%; $n = 10$), had completed post-secondary education (i.e., community college diploma or university degree; 73%; $n = 11$), and had been diagnosed with stage III rectal cancer (67%; $n = 10$). Also, all had undergone chemotherapy and radiation therapy post-surgery, and 53% ($n = 8$) had a temporary stoma.

Procedures

Upon approval from The Ottawa Hospital (TOH) and University of Ottawa research ethics boards, rectal cancer survivors were recruited from January 2017 to September 2017 with the help of staff at TOH and local enterostomal therapists, as well as advertisements distributed at community centres, libraries, stoma support groups, and on social media. After providing written consent, participants were invited to engage in an interview in person or over the phone. Interviews were conducted approximately 6 (20%, $n = 3$), 9 (6%, $n = 1$), or 12 months (40%, $n = 6$) post-stoma placement, or 3 months after stoma closure (33%, $n = 5$).

Semi-structured interviews were conducted in participants' home (6%, $n = 1$), at the university/hospital (60%, $n = 9$), or over the phone (33%, $n = 5$). An interview schedule was developed to explore the impact of a stoma, self-perceptions and physical activity engagement since having a stoma, and how a stoma impacted participants' personal behaviours and beliefs surrounding physical activity. In line with IPA methods (J. Smith & Eatough, 2012; J. Smith et al., 2009), the interview schedule acted as a guide, starting with broad exploratory questions then delving into follow-up probes to have participants expand their thoughts in greater detail, depth, and clarity. Each interview was audio-recorded and transcribed verbatim by the first author and field notes added. Interviews lasted between 45 to 96 minutes. In addition, participants were asked to complete a questionnaire to collect sociodemographic (e.g., sex, age, socioeconomic status) and medical data (e.g., cancer stage, treatments received).

Data analysis

Data were managed and analyzed using Excel version 15.38. Thematic analysis was used to identify emerging themes (Braun & Clarke, 2006). This consisted of first transcribing audio-recorded interviews verbatim. Second, salient initial codes of the raw data in a systematic fashion

were generated for each individual participant, creating a rich, contextualized, and holistic interpretation of each participants' account (i.e., an idiographic focus). Third, similar codes across participants' accounts were grouped together into subthemes. Fourth, subthemes were grouped together, creating patterned meaning across all participants (i.e., analytic focus). The fifth step involved defining and producing an internally cohesive theme. These were discussed and mutually agreed on amongst authors. Last, a narrative description for each theme was created and quotes from participants' transcripts were selected to illustrate the meaning and sentiment of each theme.

The credibility of the analytic claims made in this article has been maintained by applying a relativist approach to enhance rigor (Smith & McGannon, 2017; Sparkes & Smith, 2009). First, a key focus was to maintain a cohesive alignment with the IPA framework, seen through in-depth experiential focused interviews and holistic and ideographic focused analysis. Second, an audit trail was maintained of all notes, interview schedules, recordings, transcripts, and coding analysis in order to maintain transparency.

Results

Participants spoke about the value of physical activity and they believed it was important to be physically active. They explained that being physically active provided a way to rejuvenate their life after experiencing cancer and a stoma. However, participants also felt that it was difficult to be physically activity because of the negative short- and long-term side effects of their cancer treatments and stoma placement. Through the in-depth interviews and using the analytical procedures described above, three overarching themes were identified that illustrated participants' experiences: (1) *understanding the drive and motivation to be physically active*, (2) *despite being motivated to be physically active with a stoma, it can be challenging*, and (3) *how*

to be physically active: lessons learned. These themes are illustrated below through a narrative account along with anonymized quotes from participants' interviews.

Understanding the drive and motivation to be physically active

It was apparent that participants valued being physically active. They recounted how they were motivated to stay physically active because they enjoyed it, it made them feel “energized”, “stress-free”, and it improved their health. For instance, Ahmed stated that the primary reason he went for walks was because he truly enjoyed it. He stated: “I love it, that’s number one. I find I’m really enjoying it. It really reflects back on my happiness and my stress-free [life]. Yeah, you know, I’m enjoying [walking] because you forget all the stresses.” When Karen was asked about her reasons for being physically active, she explained that it helped her re-energize, stating: “I remember distinctly the first time I ran after Angus¹ was reversed and I just felt completely alive. Then, I realized ‘Okay, you’ve got to get back to it’. So, we [my husband and I] walk every day.” Karen also explained that being physically active helped her gain clarity and improve her physical and mental well-being, offering:

It’s your mental health. You feel good about it and physically you feel good. I feel lethargic if I don’t exercise and if I’m not active... You can conquer anything out on a walk. It becomes clearer, allows you to think, stuff just sort of flows in your head. Whereas when you're not exercising and your just in your environment going about your daily activity, you don’t get that extra space in your mind.

¹ Affectionate name for her stoma has been changed to protect participant’s anonymity.

Participants also felt physical activity helped them overcome depression that resulted from their cancer experience. David expressed this and elaborated on how his depression also acted as a barrier to being physically active. He shared:

I realized that I was [depressed]. You kind of just sit there and let the day go by. You know there's things to do, but you don't care... Sometimes if you just force yourself to do [physical activity], it snaps you out of that state and brings you back to the real world.

Participants felt that cancer motivated them to be physically active in order to “keep their ostomy healthy”. For example, Julie offered that: “Being physically active keeps things moving through the intestine and the stoma as well. Quite often, if I'm feeling sluggish I will take my big glass of prune juice and go for a bit of a walk to get things moving. That really helps.” Relatedly, they found that being physically active helped them manage their weight, in turn ensuring their stoma appliance fit their body. Victor shared:

I have lost some weight, not on purpose, but it [walking] actually helped. I was never big, but I was actually a little huffy. So, that's why I said ‘Oh this works, walking works’, and everybody is always telling you that. That's something everybody can do and that's definitely something I can do without any issues.

They also felt motivated to be physically active as a way to return to their “new normal”. For Patrick, he started being physically active right after his stoma surgery by “doing leg lifts in the hospital bed” in order to get back to his normal self. He shared:

Being active and moving around, it's definitely part of me because I want to be active and do the stuff that I would normally be doing. Just trying to have some

semblance of normal, which is the hardest part because everything since cancer has not been normal.

Despite being motivated to be physically active with a stoma, it can be challenging

Although participants were motivated to be physically active, treatments and the placement of a stoma presented various challenges, including experiencing debilitating side effects (e.g., fatigue), having to come to terms with the stoma, and encountering many “unknowns”. In terms of the side effects, they related these to their chemotherapy and radiation therapy, not their stoma. Julie recounted how it was fatigue caused by her chemotherapy and radiation therapy that impacted her ability to be physically active during and immediately post-treatment, offering:

I don't blame the ostomy. I blame more the cancer treatment; the radiation therapy for suffering extreme fatigue, things like that... Well especially right after treatment, if I got really fatigued it was almost like I was on chemo again, that funny, foggy feeling. I don't have that as much now, I have to be really, really, tired to feel that.

However, Roger had a different perspective than Julie. Rather, he felt that his stoma prevented him from being as physically active as he would have liked. He shared:

Well, one of the things I liked about walking is that I never went for structured walks... I liked to just roam. I'm free-range I guess... Well, [the stoma] does impact that. You can say 'Well, it doesn't need to' but in practice it does, for me anyway... I think being realistic about it, [the stoma] certainly has its impact.

Even when participants felt the stoma itself did not interfere with their ability to be physically active, they still faced the additional concerns about having others see their stoma. For

example, Will avoided physical activity at times because he was concerned about making others uncomfortable, stating: “I'm not too self-conscious about it [my stoma]. That doesn't really bother me too much, but I don't want to cause discomfort to other people.” Similar to Will, others found that feeling self-conscious and embarrassed about their stoma limited their desire to be physically active or at the very least required some adjustments. John illustrated this when he expressed feeling the need to hide his stoma after playing hockey, saying:

How do I change my equipment in the dressing room without everybody seeing?
I'm not too vain, but that's not something I want to advertise either. I can't shower after hockey... Maybe I'll be in that place one day where I can take a shower with 10 other guys and have a bag attached to my stomach. It's not anything I've ever seen so I don't think that's going to happen.

Feelings of self-consciousness and embarrassment seemed to be exacerbated by participants' fear that their stoma could leak or burst, and this impacted participants' desire to engage in physical activity. David expressed how his fear of others seeing his stoma pouch leak made him socially anxious and decrease his participation in physical activity. He said: “My activity went down considerably because of my anxiety of the bag exploding. So, I didn't do a lot.” He further described:

I wouldn't go swimming, I wouldn't go fishing, I wouldn't do the activities because I was afraid of the stoma because I've had a few issues with the stoma at various times. I've had accidents and it's like ‘Oh what a mess’, literally. So, it's embarrassing when that happens especially when you're among people because you've got the odour and all that.... I didn't feel safe to go.

Participants' concerns about the safety of physical activity with a stoma also seemed to limit the types of activities they engaged in. For instance, Ali described that he avoided physical activities that required lifting, bending, or rotating because he was concerned about developing a hernia. He said:

I do a lot of walking, at least, 4000-5000 steps a day. I have no problem. I'm really staying physically fit. Bending there are some restrictions, I cannot do much of bending, I cannot lift anything, I cannot carry my grandkids. Some limitations with that because I don't want to get a hernia.

Patrick also avoided certain activities due to his fear of developing stoma complications. Indeed, his concerns about the safety of physical activity and his lack of knowledge about the types of activities that were safe to do lead him to avoid many physical activities. He stated:

Part of being physical with the ostomy in terms of lifting and stuff like that I'm very cautious. Like okay, what are my weight restrictions? What movements can I do? Can I get away with this stretch and not this stretch? There are a lot of those unknowns and so I'm erring on the side of caution just to protect myself and protect the ostomy as best as I can.

How to be physically active: lessons learned

Although participants had to cope with changes in their motivation to be physically active throughout their cancer experience, the valued outcomes of physical activity encouraged them to keep trying and learn how to be physically active. Participants discussed the significance of finding a strong support network and indicated that receiving encouragement, feedback, information, and insights from others helped motivate them and increase their confidence to be physically active. Participants reported that their friends and family were the main components

of their support network; however, health professionals, others with a stoma, and athletic coaches were consulted. Victor reported feeling supported by his doctor. He stated:

It was encouragement from people more than anything. Really, that was what it was. It was just gentle encouragement. Then when I was in the hospital ... they would say try and walk. There was one doctor, he finally met me on the last day to release me and he said: 'You know, I kept coming to have a talk with you but you were never there' and I said: 'Well, I'm sorry' and he said: 'No, it means you were out walking. That's good.' So, I took that to heart.

In Julie's case, her ties with other runners that she had made prior to her diagnosis were important. She felt supported by them and helped her in getting physically active again, stating: "I had a running community that I ran with and then I got cancer. They were a great force at getting me going again." Participants also explained that seeing others be physically active with a stoma also brought about positive changes in participants' confidence because it allowed them to see that it was possible to be active with a stoma. Ali expressed this when he mentioned the physical activities that he used to enjoy, stating: "I like to run and play sports like tennis or something, like badminton. I used to play it. I like to play it and get back to my normal life. So, if I see somebody is playing with an ostomy then maybe I will have confidence." Patrick also discussed that he found seeing others being physically active with a stoma helpful and saw similar opportunities for himself in the future, sharing: "I've seen like some of the extreme athletes that have an ostomy and stuff like that. So, I'm like it's there, it's doable, and long-term, it's like 'Yeah, I can do this.' It's just the in-between right now that's the hardest part." Some actively sought the help of physical activity professionals who would be able to develop a

program that met their capabilities. By working with an athletic coach, Mary felt supported and that she received advice that would allow her to be physically active with her stoma, offering:

I have a coach who used to be my coach when I did triathlons. I'm still semi-part of the group... but I go to her when I need a training program and she knows my limitations. She knows I can't strain too much here because otherwise my bowel will come through my muscle and stuff like that...So, she tailors them for me.

As a whole, participants experienced a decline in their physical capabilities after undergoing cancer and its treatments. To cope with this, participants indicated that they had to temper their expectations of their ability to be physically active and subsequently set goals to regain their physical capacity. For instance, Julie felt her body was unable to carry the burden of the long-distance running she accomplished prior to her diagnosis and that she would develop complications with her stoma as a result. However, by setting goals and adjusting her expectations she felt she was still able to be physically active to an extent that she enjoys. She offered:

I can't seem to get over 10kms in my physical activity. It just seems my body can't do it anymore. Sometimes [the stoma] causes me problems or a blockage or things like that. Sometimes it's just a physical issue. I'm resigned to 'There's nothing wrong with doing just 10kms.' So, I try to be active every day as best I can. I'm disappointed I can't run as far as I used to. But that's okay. I am trying to do my best.

Similarly, Mary stated: "My expectations of actually being able to perform are quite different than what they were before." Mark also felt that adjusting his expectations of how to be physically active helped him overcome his hesitancy in beginning his activities. He offered:

“You got to be really careful and you have to pace yourself as much as you can. You’ve really got to listen to your body and really work with the stoma because the stoma kind of has a mind of its own.” After readjusting their expectations of what they could physically do, participants spoke about having to set various goals in order to regain their strength. Victor found that setting a daily step goal helped him make walking a priority, stating that “Every day, I set a goal. I’ll walk at least half an hour to an hour everyday outside of everything else.”

However, it was important for participants to mention that despite all the planning and managing there would be unavoidable setbacks that would prevent them from being physically active. For example, when Karen discussed her goal setting strategies to be physically active, she mentioned that despite wanting to achieve her goals, she always had to put accommodate her stoma first. She shared: “Your ostomy totally affects that step-by-step bit [goals] because you could make all the plans you want in the world, but if you're going to have a leak or your bag is bursting, you got to go home. It’s done, you got to go home.”

In addition to setting goals to be physically active, planning specific ways to monitor the output of the stoma helped participants feel more comfortable to be physically active. This involved planning for the inevitability of a leakage, monitoring for a blockage, and coming to terms with how to go swimming. Identifying the signs that the stoma might leak soon was a common first strategy to limit leaks. Victor pointed out that he learned to recognize the signs that a leak might start to happen right away, he stated: “I knew that it was starting to break down a bit because you could start to see [the seal] bubbling. I would, for emergency, tape it up which would get me through the day until I got home to change the bag.” In some cases, sweating could lead to the breakdown of the seal, causing a leak, which posed a problem while being physically active. Victor described this concern saying: “During the hot summer months, when I was

working [on physically demanding tasks], the failure rate went up... For example, when it gets really hot the adhesive starts pulling away. So, then you start getting these leaks” Identified ways to overcome this involved ensuring participants were being physically active with an empty pouch and monitoring fullness, timing eating habits around when they planned to be physically active, ensuring the seal was fully dry before trying to move the appliance, using extra “paste” and heat to seal the appliance, and bringing along extra supplies in the case of a leak. Further, by monitoring the stoma output and preventing a blockage through planning their meals and keeping up their hydration, participants felt able to enjoy their health and physical activity. Julie articulated this when she said:

When you're doing a lot of physical activity with an ostomy you have to be really careful about fluid intake and things like that. There can be times when you're doing a lot of physical activity where it will start to show that you've not had enough fluid intake. You'll get kind of a constipated blockage so you have to be able to learn how to manage that. I sometimes manage it with prune juice and things like that.

Depending on participants' confidence with their stoma system, they felt either able to swim or not swim. Some participants strongly advocated for swimming, provided they undertook proper planning. Mark offered very tangible ways to swim with his stoma system, stating: “Taping it at say about 5 inches going around the bandage itself on the skin so it gave me enough covering. I had longer swim trunks which completely covered it and I would just tie it with the string.” Conversely, others brought up their hesitations and concerns with swimming. Roger said, “I wouldn't have dreamt of going swimming with a stoma, simply because I feel the water contact would have been affecting the integrity of the stoma patch seal.”

An additional component of planning to be physically active with a stoma involved making personal comfort a priority. This meant wearing attire that was conducive to being physically active with a stoma and ensuring proper facilities and amenities were available. Wearing comfortable clothes and exploring the availability of stoma accessories helped participants engage in physical activity. For instance, participants emphasized the importance of wearing a stoma-belt accessory, which served multiple purposes, suggesting that it not only helped with comfort but it also only stopped leaks and reduced the noise. Ben said:

They call it a ‘Stealth Belt’ and it’s basically a bag holder. It’s a belt that fits around your waist and the appliance is inside it. If something happens, like the bag breaks the seal, or the phalange breaks the seal, it’s kind of contained within that belt rather than elsewhere.

Outside of the stoma belt, participants highlighted that clothing needed to be loose around the stoma with a second layer of clothes close underneath to keep the stoma pouch tight to the skin. In layering clothes this way, participants were able to keep the bag from swinging around too much, but also prevented the pouch from digging into the skin. Karen described her clothing choices as enabling her to handle the output of the stoma, while at the same time keep her comfortable in her attire. She said:

I got elastic band shorts and wore those exercising. I remember having to roll Angus² [into my shorts] but then progressively he would empty. So, I would stop, go behind a tree, open up my running pants and then flop him down close to my leg and keep going. I would have to angle him certain ways.

² Affectionate name for stoma

For Roger, he found that he needed to choose very specific types of clothes in order to be comfortable. He described his clothing choices, stating: “Normal pants are going to sit right on top of, or right below, the stoma and interfere with it. I've been coping with by wearing track pants, they happen to have a very high waist line, so I can tie them up above the stoma.” In addition to wearing comfortable clothes, finding a functional facility was deemed difficult and, depending on availability, it changed participants’ ability to be physically active. Roger discussed that poor facilities were a predominant reason he chose not to go out at all, sharing: “I always have to be very cognizant of ‘Is there a washroom I can access in relatively short order if I need to?’. And ‘Is that washroom a practical one for me to use?’... It’s definitely an incentive to stay home more.” Whereas some participants were able to find alternatives to going out, by taking part in yoga at home or, in the case of Carol, she found using home equipment was better than going out, stating: “I felt better using that [treadmill] than going outside, because if I had a leak I was right by the bathroom so it was no big deal.”

Discussion

The purpose of this study was to provide insight into the experiences of adults living with a temporary or permanent stoma after surgical resection for rectal cancer. Three themes were found to be particularly salient within each case and across participants, namely: (1) *understanding the drive and motivation to be physically active*, (2) *despite being motivated to be physically active with a stoma, it can be challenging*, and (3) *how to be physically active: lessons learned*. These first two themes provide insight into rectal cancer survivors’ motivation to engage in physical activity, as well as cancer and stoma-specific barriers that may interfere with their decision or ability to engage in physical activity. The third theme provides insight into what it might take for rectal cancer survivors to be physically active with a stoma.

In general, participants' reports indicated they held positive feelings and attitudes toward physical activity and that these were prominent factors that motivated them to be physically active. This notion aligns with cognitive and motivational models of physical activity. For example, the theory of planned behavior (TPB; Ajzen, 1991) suggests personal attitudes toward physical activity is one of the strongest predictors of people's intention to engage in physical activity. Intentions then either facilitate or constrain behaviour. Indeed, a central premise of TPB is that "people's behavioral intentions are assumed to follow reasonably from their beliefs about performing the behavior" (Ajzen & Fishbein, 2005, p. 193), thereby providing the foundation for behavioural action. Likewise, the transtheoretical model (Prochaska & DiClemente, 1986) postulates that a person will engage in a specific behaviour when the perceived benefits of engaging in that behaviour outweigh the disadvantages. Similarly, self-determination theory (SDT; Deci & Ryan, 1985) posits that the motivation to engage in a behaviour stems from the desire to achieve psychological growth and self-determination, stating that "not only do cognitions affect internal states such as attitudes and motives, but, as this work shows, individuals choose what behaviors to engage in on the basis of their cognitions about the outcomes of those and other behaviours" (p. vi). Our findings are also in line with physical activity dual process models (DPM) that stipulate a combination of both cognitive knowledge and appreciation of the health benefits along with positive affective processes will influence behaviour (Loewenstein, Weber, Hsee, & Welch, 2001). That is, when physical activity is appraised as beneficial and is experienced as pleasant, adults are more likely to perform physical activity. In addition, our findings mirror those of previous qualitative (Brunet, Taran, et al., 2013; Burke et al., 2017; Wurz et al., 2015) and quantitative research with breast, colorectal, and prostate cancer survivors (Forbes et al., 2014; Morielli et al., 2016; Romero-Elias, Gonzalez-

Cutre, Beltran-Carrillo, & Cervello, 2017; Ungar, Wiskemann, & Sieverding, 2016), whereby positive attitudes were associated with physical activity behaviour. Collectively, this suggests that enhancing attitudes toward physical activity and offering opportunities to have pleasant affective responses to physical activity may be crucial to encouraging rectal cancer survivors to consider physical activity as a way to improve their recovery from cancer.

Striving for improved health was another factor motivating participants to engage in physical activity, implying that efforts to alter or strengthen cancer survivors' understanding of the benefits of physical activity through education campaigns, advice, and/or counseling may be effective at improving physical activity, provided that physical activity elicits memories (or anticipation) of enjoyment. This finding is consistent with theorizing by proponents of self-determination theory who suggest that strategies seeking to change people's motivation toward more self-determined and autonomous forms of motivation would be necessary to change their behaviour. As Deci and Ryan (2000) suggest, motivation to perform behaviours exist on a continuum ranging from amotivation (i.e., a lack of motivation), to extrinsic motivation (i.e., where a behaviour is performed to avoid punishments, negative emotions, to gain instrumental value, or align oneself with ones' identity), to intrinsic motivation (i.e., deriving pleasure and satisfaction from the behaviour). Participating in physical activity to improve ones' health is in line with the type of motivation Deci and Ryan (2000) labeled *identified regulation*, wherein a behaviour is performed by choice because the person values the outcome or finds benefit in the activity. Research over the past 20 years has demonstrated that *identified regulation* is a strong correlate and predictor of the amount of physical activity within the general population (Teixeira, Carraça, Markland, Silva, & Ryan, 2012), with similar results being found with breast cancer survivors (Brunet, Burke, & Sabiston, 2013; Milne, Wallman, Gordon, & Courneya, 2008).

Thus, creating a healthcare climate that supports rectal cancer survivors' autonomy by acknowledging their thoughts, encouraging personal choice, and minimizing pressure or demands, may help to increase *identified regulation* to be physically active, and in turn behaviour.

Although participants reiterated that they were motivated to be physically active, they experienced various physical challenges, many of which were similar to side effects previously reported in the literature (Blaney et al., 2016; Brunet, Taran, et al., 2013; Courneya et al., 2005; Fisher et al., 2016; Wurz et al., 2015). These in turn hindered their confidence, desire, and ability to participate in physical activity. For example, having to cope with pain, cancer-related fatigue, being physically ill, and physical limitations caused by surgery had a detrimental impact on their engagement in physical activity. Over and above these physical challenges, participants described psychosocial challenges that stemmed from the visibility of their stoma and their fear of embarrassment. Similar to previous research (Ramirez et al., 2014; Sun et al., 2013), these resulted from their inability to feel control over and maintain “normal” bodily functions. Interestingly, Krouse et al. (2017) reported that engaging in physical activity may help improve perceived bowel function, potentially offering adults a way to regain a sense of autonomy. To this end, stressing the benefits of being physically active in preventing this loss of control, along with providing tangible strategies on how to incorporate physical activity in a safe and supportive environment should be a strategic target for physical activity professionals and researchers.

Practical implications

Despite the many challenges associated with managing their stoma and their cancer diagnosis, participants were proactive in planning and developing the required skills in order to

be physically active. These consisted of maintaining supportive networks, controlling their expectations and physical activity goals, and managing the stoma system through trial and error. These strategies are emphasized by researchers as key to self-managing one's health after being diagnosed with a chronic illness (Howell et al., 2017; McCorkle et al., 2011). Current self-management programs incorporating these skills to help adults manage the physical aspect of a stoma are highly sought after and strongly valued (Dabirian, Yaghmaei, Rassouli, & Tafreshi, 2011; Faury, Koleck, Foucaud, M'Bailara, & Quintard, 2017; Krouse et al., 2016). Furthermore, one critical component of these self-management programs involves enhancing participants' self-efficacy beliefs (i.e., "belief in one's capabilities to organize and execute the courses of action required to produce given attainments" (Bandura, 1997; p. 3). Indeed, previous literature has substantiated the claim that gaining self-efficacy to manage a stoma helps to reduce psychological distress and may enhance perceptions of autonomy and control (Bekkers, Van Knippenberg, Van Den Borne, & Van Berge-Henegouwen, 1996; Knowles et al., 2013; Simmons, Smith, Bobb, & Liles, 2007). Given the profound psychological impact and the strong perceived lack of control a stoma may confer (Ramirez et al., 2014; Sun et al., 2013), learning more about how to provide adults with greater self-efficacy to manage a stoma seems warranted to help them mitigate barriers to engaging in physical activity that are associated with the placement of a stoma.

Conclusion

Taken together, three themes captured rectal cancer survivors' experiences and demonstrate the considerable impact a diagnosis of rectal cancer and subsequent placement of a stoma may have on them and their participation in physical activity. In addition to providing support to prominent cognitive and motivational theories (e.g., TPB, TTM, DPM, SDT) and prior research, the

findings from the current study highlighting the multiple challenges rectal cancer survivors face upon diagnosis and treatment. Moreover, they offer insight into current strategies rectal cancer survivors can use to overcome various challenges to being physically active and underscore the value of fostering self-efficacy to manage a stoma. Thus, incorporating a blend of motivational and self-efficacy enhancing strategies in future training programs and services may support rectal cancer survivors' endeavours to engage in physical activity.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

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Chapter 4: General Discussion

Discussion

The benefits of engaging in physical activity after a diagnosis of cancer are numerous and well substantiated within the literature (Mishra et al., 2012; Sabiston & Brunet, 2012; Schmitz et al., 2010). Still, few engage in sufficient physical activity needed to achieve health benefits (Littman et al., 2010; Rohan et al., 2015). Common negative side effects cancer survivors experience from treatment and their diagnosis (e.g., pain, fatigue, physical deconditioning) may partly explain these low rates. Moreover, the placement of a temporary or permanent stoma may create additional challenges to being physically active over and above those experienced from more traditional forms of cancer therapy. Although the burdens and challenges cancer survivors face to being physically active are increasingly being investigated (Blaney et al., 2016; Brunet, Taran, et al., 2013; Romero-Elias et al., 2017), research focused on those who have a stoma from cancer is scant. There is a critical need to gain insight into the experiences of these cancer survivors to better understand what additional challenges they may face and learn the ways in which they overcome these challenges. By doing so, this information will lend support to researchers and healthcare providers who offer physical activity information, programs and services to survivors, thereby helping to reduce the burden of cancer and its treatments. Thus, this thesis explored the experiences of 15 adults living with a temporary or permanent stoma after surgical resection for rectal cancer in order to understand the impact of a stoma on adults' engagement in physical activity. Overall, three themes were captured: 1) *understanding the drive and motivation to be physically active*, (2) *despite being motivated to be physically active with a stoma, it can be challenging*, and (3) *how to be physically active: lessons learned*. These themes

detail both cancer and stoma-specific motivations, challenges, and the strategies that may best facilitate being physically active with a stoma.

The notion that survivors are motivated to engage in physical activity but experience several challenges to being physically active has been well documented in the literature (Brunet, Taran, et al., 2013; Burke et al., 2017; Forbes et al., 2014; Morielli et al., 2016; Romero-Elias et al., 2017; Wurz et al., 2015). The identified motives for being physically active discussed by participants in this study align with well-substantiated theories of motivations discussing why individuals continue or discontinue physical activity behaviours (e.g., theory of planned behaviour, dual processing model, self-determination theory (SDT); Ajzen, 1991; Deci & Ryan, 1985; Loewenstein et al., 2001). For instance, the theory of planned behaviour (TPB) indicates that personal attitudes towards a behaviour will dictate future engagement with this behaviour. The dual processing model (DPM) suggests that if individuals experience positive feelings from performing a behaviour, they are more likely to engage in this behaviour in the future. Last, SDT posits that adults are more likely to engage in and sustain a behaviour if they are intrinsically motivated (e.g., if they enjoy the experience, appreciate the health benefits, want to become stronger) rather than if their behaviour is driven by external forces (e.g., feeling pressure from others, enhance their body image). After noticing how being physically active helped participants achieve their health goals and derive positive feelings, participants were even more motivated to manage their cancer diagnosis and stoma in order to be physically active. This gives support to the use of theory-based interventions as a way to improve physical activity in this population. This is significant since being physically active after a cancer diagnosis can help cancer survivors feel empowered to take control of their health. As such, healthcare providers and researchers have the opportunity to draw upon these same motivations to better help cancer

survivors be physically active, and further help cancer survivors view physical activity as a strategy to better cope with the impacts of cancer.

Despite participants being motivated to be physically active, they indicated that they faced various challenges which limited their ability to be physically active. One frequently cited challenge was chronic fatigue – a commonly reported side effect by many cancer survivors. Other challenges included pain and debilitation at the surgical site, being physically ill from treatment, and challenges with neuropathy. These findings support previous evidence suggesting fatigue, along with pain, muscle degeneration, and lasting side effects from treatment were all barriers to physical activity in cancer survivors (Blaney et al., 2016; Brunet, Taran, et al., 2013; Courneya et al., 2005; Fisher et al., 2016; Lynch et al., 2007; Mols et al., 2014; Wurz et al., 2015). For example, in a longitudinal study of 538 colorectal cancer survivors, Lynch et al. (2010) found disease-specific barriers presented the greatest challenges for participants 5 months and 12 months post-diagnosis. These barriers were fatigue, not feeling well-enough for physical activity, and difficulties with incontinence. Similarly, Courneya et al. (2005) found that out of the 353 barriers cited for failing to adhere to an exercise protocol within a randomized controlled trial of 62 colorectal cancer survivors, 54% (190/353) were a result of treatment side effects, such as fatigue, nausea, diarrhea, surgical complications, flu or sore throat, joint pain, and not feeling well. Based on these findings, it is necessary to explain to cancer survivors that all types and intensities of physical activity are beneficial; simply advocating moderate-to-vigorous intensity physical activity guidelines is restrictive and contributes to dropout. As cancer survivors start (re)engaging in physical activity during and post-treatment, it is important to find ways to incorporate enjoyable and feasible physical activities into their daily routines.

In contrast to previous studies exploring physical activity and stomas in adults (Russell, 2017; Wiskemann et al., 2016) where there was no mention of concerns regarding the stoma system malfunction, participants in this study found the visibility of their stoma was a great hindrance in their ability, desire, and commitment to engage in physical activity. The fear of others seeing their stoma or having the stoma system leak has been illustrated clearly in QoL studies in adults with a stoma as well. For instance, Sun et al. (2013) described stoma leaking as affecting QoL in 130 colorectal cancer survivors. Similarly, in a review of 14 cross-sectional studies examining QoL in adults who have a stoma from colorectal cancer, Vonk-Klaassen et al. (2016) found adults' embarrassment of their stoma negatively impacted QoL. Further, in a study seeking to establish research priorities with regards to QoL in 225 individuals with a stoma, the highest-ranking priority was on how to better deal with leakage problems (Hubbard et al., 2017). This seems to cumulate with the findings by McGowan et al. (2013), which suggests colorectal cancer survivors with a stoma were less likely to prefer being physically active in public spaces. As highlighted in this study, reasons for why this is the case may stem from the notion that individuals may be embarrassed or concerned about leakages and stoma visibility. Therefore, it may be necessary to take into consideration the impact of a visible stoma for this population. Determining the physical activity preferences of this population may be one step that would help alleviate some of these challenges.

In addition to visible embarrassment, safety concerns surrounding what participants were physically able to do with a stoma greatly limited their physical activity. In this respect, participants stressed a lack of competence with their ability to be physically active when trying to explain their low participation in physical activity. Several theories, including SDT (Deci & Ryan, 1985; Ryan & Deci, 2000, 2002) and social cognitive theory (SCT; Bandura, 1997)

highlight the importance of competence and self-efficacy beliefs when engaging in physical activity. SDT posits that all individuals have a universal need for autonomy, relatedness, and competence (Ryan & Deci, 2002) and fulfilling these needs can explain the degree to which adults experience enhanced motivation and psychological wellbeing. Similarly, SCT proposes that self-efficacy, defined as the belief in one's ability to achieve an outcome, is a cognitive construct that relies on previous mastery experiences, opportunities for vicarious experiences, verbal persuasion from others, and cognitive affect, to influence behaviour (Brady et al., 2013; Herts, Khaled, & Stanton, 2017). With these theories in mind, several studies stress the importance of enhancing both feelings of competence and self-efficacy to promote physical activity motivation and participation. Indeed, Teixeira et al. (2012) reviewed 66 studies examining associations between SDT-related constructs (including perceptions of competence) and physical activity and reported a positive association between competence and physical activity. In the literature concerning cancer survivors, researchers have reported positive associations between enhanced competence and increased levels of physical activity (Mack, Meldrum, Wilson, & Sabiston, 2013; McDonough & Crocker, 2007; Peddle, Plotnikoff, Wild, Au, & Courneya, 2008). For example, Peddle, Plotnikoff, et al. (2008) investigated competence needs in a cross-sectional sample of adults diagnosed with colorectal cancer and noted a positive association between competence and physical activity behaviours. The importance of self-efficacy also emerges when examining stoma-care behaviours, where those who completed a program aimed at improving stoma self-efficacy (i.e., gaining mastery and vicarious experiences) felt more able cope with the impact of their stoma (Xu et al., 2017). Since the concern over stoma safety during physical activity posed challenges for participants in this study, enhancing stoma self-efficacy by gaining mastery and vicarious experiences may be an important factor to

consider when promoting physical activity. Interestingly, McGowan et al. (2013) found that colorectal cancer survivors with a stoma (14%) were more likely to want physical activity advice from a physiotherapist than those without a stoma. One potential explanation for this may be that they felt the advice would be more tailored toward their specific circumstances, offering better stoma mastery and competence-focused experiences while being physically active. Collectively, these findings suggest that encouraging competence and self-efficacy enhancing skills for this population through autonomy support (Deci & Ryan, 2000) will likely improve their motivation and ability to better self-manage their stoma, potentially leading to greater engagement in physical activity.

The support participants experienced from others was a critical aspect for continuing to overcome the challenges they faced. Previous research, both qualitative and quantitative, has stressed the importance of social support in facilitating physical activity engagement in cancer survivors (McDonough & Crocker, 2007; Milne et al., 2008; Peddle, Plotnikoff, et al., 2008; Sabiston & Brunet, 2012). Moreover, a recent qualitative meta-synthesis of 40 articles exploring physical activity in cancer survivors, the authors reported that engagement in physical activity confers improved social wellbeing (Burke et al., 2017). These claims have been further supported in longitudinal research where Mack et al. (2013) have indicated in their prospective study of breast cancer survivors that social connectedness and relatedness (i.e., how socially engaged individuals are with their surroundings; Ryan & Deci, 2002) was positively associated with physical activity. Beyond experiencing improvements in social wellbeing, social support can have a consequential impact on behaviours by enhancing self-efficacy as indicated in social cognitive perspectives (Bandura, 1997). Verbal persuasion and comparing behaviours amongst similar others, all support-behaviours reported by our participants, can promote greater health

behaviours (Bandura, 1997). For example, in a sample of 20 mixed cancer survivors participating in a cancer-specific yoga program, participants felt that despite facing challenges, seeing other cancer survivors be physically active encouraged them to return to the program in order to reap the health benefits (Mackenzie, Wurz, Yamauchi, Pires, & Culos-Reed, 2016). Thus, having encouragement from others, along with seeing those who have a stoma be physically active, may help to empower cancer survivors living with a stoma after surgical resection for rectal cancer to be physically active themselves. Partnering with community groups and others with a stoma, along with creating a supportive environment may be a valuable way to utilize this effect, in order to offer cancer survivors living with a stoma after surgical resection for rectal cancer the most impactful information, programs and services.

Taken together, participants' accounts demonstrate the significant impact a temporary or permanent stoma has on their motivation, self-efficacy, and participation in physical activity. Understanding the personal experiences of cancer survivors advances the ways in which professionals can help adults with chronic disease to acquire the relevant information, skills, and confidence to take responsibility for their health (Howell et al., 2017; McCorkle et al., 2011). The participants in this study have highlighted the impact a rectal cancer diagnosis has had on their physical activity and the broader implications this has for promoting physical activity for this population. Specifically, participants underlined the importance of gaining positive feelings and improved overall and stoma specific health from physical activity, recognized the psychosocial and physical challenges they faced to being physically active (i.e., embarrassment, safety concerns), and provided critical learned strategies which helped them to be physically active with their stoma. Given that both motivational and chronic disease self-management programs are helpful for adults to engage in physical activity and other health behaviours,

creating environments that motivate individuals to self-manage and offer individuals ways to learn and master specific skill may address the physical activity needs of adults who have a temporary or permanent stoma. Therefore, based on participant reports, offering autonomy supportive environments that provide information, programs, and services that build up survivors' motivation, competence, and learned strategies to cope with their disease may be a starting point for enabling survivors to overcome their challenges to engaging in physical activity.

Theoretical implications

This thesis makes two significant contributions to the literature which may offer potential theoretical implications. First, the motivations and challenges that participants experienced offer additional support to well-known theoretical motivational research, suggesting the importance of using theoretical constructs to promote physical activity among this population. Regarding future research, it is important to consider the constructs which may play the largest role in having cancer survivors living with a stoma after surgical resection for rectal cancer engage in physical activity. Further, keeping in mind the considerable impact a stoma can have, these constructs may differ from previously identified constructs in the cancer survivorship and physical activity literature. Second, this study raises the question of exploring the potential impact of using multiple theoretical concepts within a single intervention. The beginnings of this have been explored by Gourlan et al. (2016); Hagger (2009); Prestwich, Webb, and Conner (2015). Gourlan et al. (2016) compared non-theory-based physical activity interventions in healthy adults to theory-based interventions, finding that the use of a theory positively impacted physical activity behaviour of participants, however, using multiple theories did not yield a higher level of physical activity among participants. Despite these findings, the authors, along with others

(Prestwich et al., 2015) stress the difficulty in evaluating theory-based interventions due to poor application of theories and confounding impacts of comparison groups. These concerns are exacerbated in studies with cancer survivors, as there are greater challenges to implementing physical activity studies to evaluate this. Our findings highlight the possible overlapping of theoretical constructs and perhaps exploring interventions in this style may offer additional insight into how to encourage cancer survivors to be more physically active with a stoma.

Practical implications

Despite the high level of physical activity found in our participants, few adults are active after a cancer diagnosis (Blanchard, Courneya, & Stein, 2008; Ottenbacher et al., 2015; Sabiston, Brunet, Vallance, & Meterissian, 2014). One significant reason for this is because of treatment-related barriers and challenges. Given that rectal cancer survivors face specific challenges, this study provided much needed insight into strategies that could be used to promote cancer survivors' competence and motivation to engage in physical activity with a stoma. Based on participants' accounts, one potential strategy would be to help survivors identify their motivations and encourage physical activities that align with these motivations. For instance, researchers Ladwig, Hartman, and Ekkekakis (2017) have advocated for health professionals to move away from offering strict physical activity guidelines and instead instruct their clients to be physically active in a way that makes them 'feel good' or offers pleasure. As a result, the authors found that participants still selected physical activities which improved cardiorespiratory fitness and health parameters. Another potential strategy is to have survivors undertake trial and error learning and then have survivors reflect on what worked compared to what did not work. By doing so, survivors may learn important stoma self-management strategies which have been

shown to improve QoL and overall wellbeing (Altuntas et al., 2012; Danielsen, Burcharth, & Rosenberg, 2013; Krouse et al., 2016).

Whereas it may be difficult to incorporate these strategies into clinical practice, community-based cancer care programs are often readily available in city centres and discuss different ways to cope with cancer and its treatments. Often, these programs target similar concepts reported in this study (i.e., motivation, self-efficacy) as these concepts are imperative for engaging in successful cancer survivorship. Therefore, incorporating a combination of stoma self-management education along with cancer-care education into these programs may illustrate potential strategies for engaging in physical activity in cancer survivors living with a stoma after surgical resection for rectal cancer, while also shifting the burden of long-term care away from primary health providers.

Limitations

The limitations of this study should be acknowledged when interpreting the findings. First, not all interviews were conducted in person. These differences could lead to small unintentional differences in the data between participants because of the interviewer's mannerisms or potential unintended facial reactions. However, in a study by Sturges and Hanrahan (2004), where the researchers were interested in understanding how correctional officers and visitors viewed their roles at county jails, and looked at interview transcripts collected over the telephone and compared them to transcripts collected in face-to-face interviews. The authors found no discernible differences in the data when using the two different modes of interviews and reported a set of flexible guidelines that researchers may consider when choosing a mode of interviews. Despite these findings, in our case the mode of interview may still have influenced small nuances between participants, which are essential in qualitative

research and could lead to minor influences on the data. Second, interviews were conducted with participants at various stages of their cancer experience. Although this helped to provide maximal variance within our homogenous sample, which is advocated by an IPA methodology, the stark differences emerged between those who had a stoma placed recently, those who had had a stoma for up to a year, and those who had had a stoma reversed. Perhaps exploring these individuals exclusively might generate more detailed insight for adults in their position. In addition, participants within this study were all volunteers and therefore confer a self-selection bias (Creswell, 2013). This may be why many participants were quite active and readily undertook trial and error behaviours. As a result, this study may not have highlighted all the challenges encountered by cancer survivors living with a stoma after surgical resection for rectal cancer who are inactive.

Future considerations

Whereas the findings from this study offer a foundation from which to build future physical activity information, programs, and services regardless of where adults are on the cancer trajectory, there remains several gaps in knowledge. First, physical activity programs that are tailored and address adults' needs have been identified as one way to encourage adults to be physically active (Forbes et al., 2014; Irwin, 2009; McGowan et al., 2013); yet, given the limited research on physical activity in cancer survivors living with a stoma after surgical resection for rectal cancer, it is unclear what types of information, programs, and services these adults would prefer. For instance, in women diagnosed with breast cancer researchers have documented that walking is the preferred form of physical activity (Irwin, 2009). Although walking confers physical benefits, the results in this study highlight the need for appropriate facilitates in adults who have a stoma, and as such walking far distances from these may not be suitable for this

population. Future research identifying the preferred types of information, programs and services can allow for slight tailoring of existing programs in order to encourage cancer survivors living with a stoma after surgical resection for rectal cancer to engage in physical activity.

A second area of future inquiry highlighted by this thesis would be to investigate the potential ways to incorporate healthcare community partnerships in this population. McCorkle et al. (2011) emphasize that communication and partnerships between cancer survivors and community health professionals offer a roadmap to optimal health after cancer through social support and learn self-managements skills. Interestingly, the influence of nursing professionals on encouraging adults to engage in physical activity did not emerge very prominently in these results. Previous researchers have indicated enterostomal nurse therapists (ENT) are pivotal for the successful management of a stoma (Faury et al., 2017; Zhang et al., 2013). In one of the first systematic reviews of patient education in cancer survivors living with a stoma after surgical resection for rectal cancer, Faury et al. (2017) identified 15 studies that ran an educative program, seven of which employed the use of an ENT as the main educator of the program. Faury et al. (2017) indicated that due to ENTs' expertise in dealing with stoma care, they were a valuable component of a successful program. Perhaps, exploring the role of these professionals in encouraging cancer survivors to engage in physical activity will have substantial ramifications for this population.

Conclusion

Overall, the findings from this thesis contribute to the limited literature on physical activity engagement in adults with a stoma from rectal cancer. We have highlighted the reports participants offered on their experience of being physically active with a temporary or permanent stoma, namely: 1) *understanding the drive and the motivation to be physically active*, 2) *despite*

being motivated to be physically active with a stoma, it can be challenging, and 3) how to be physically active with a stoma: lessons learned. Exploring the intersection of these themes brings to light possible ways to promote physical activity in this population. Blending the educative components of current self-management programs with motivational and competence-enhancing programs targeted for those who have a stoma may equip future adults with the tools required to live their optimal lives after receiving a stoma after surgical resection for rectal cancer.

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